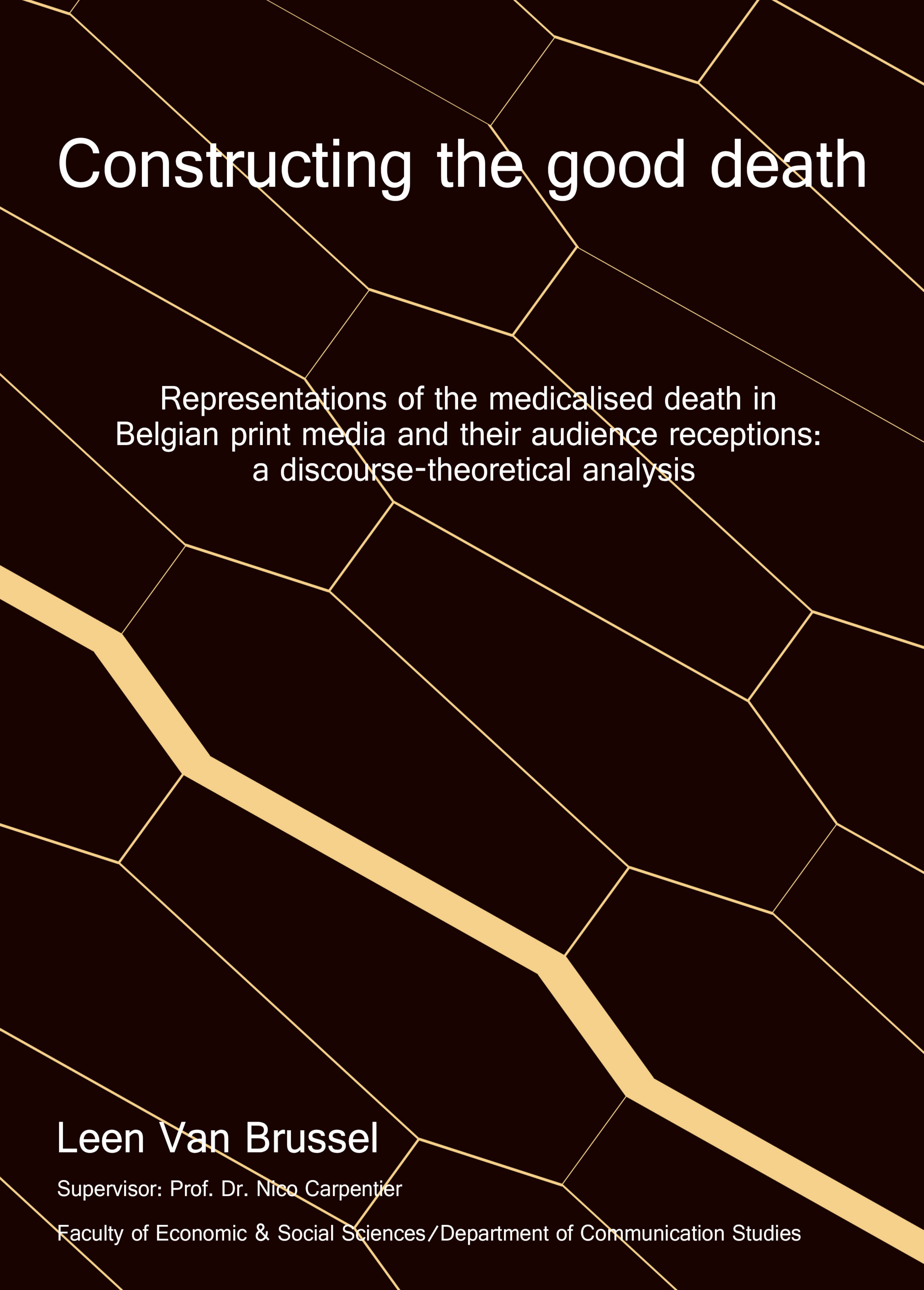

Constructing the good death

Representations of the medicalised death in Belgian print media and their audience receptions: a discourse-theoretical analysis

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INTRODUCTION

> “[…] it has simply become too difficult not to be a constructivist. Regardless of the field of social science one focuses on, the most noticeable thing is change, and changes often touch upon and challenge fundamental values, raising questions about the constituent character of what we see” (Andersen, 2003: ix)

> “I already chose the music for my farewell. I have already chosen the text of my obituary as well. I left one open line at the bottom. I hope I can put there: ‘Thanks to the Belgian parliament’” (Mario Verstraete in the Belgian Parliament, 2001)

This is a statement of Mario Verstraete, a 39-year old man suffering from the incurable neurological disease Multiple Scleroses. Verstraete was an activist for the right to die, and he was the first and only person who was ever heard as a patient in the discussions about the legalisation of euthanasia in the Belgian Parliament. He was the first man who made use of the euthanasia law, established in Belgium in 2002.

The quote above nicely captures three important shifts or changing patterns of death and dying: medicalisation – referring to dying today often taking place in a medical(ised) setting and following after a (number of) medical end-of-life decisions, politicisation – referring to the way death and dying are more and more regulated in and by legal-political frameworks as well as surrounded by political struggle and activism, and individualisation – referring to the way the dying process increasingly becomes a feature of self-identity, subjected to the individual’s urge to bring death under autonomous control. It is within a context of medicalisation, politicisation and individualisation that the concept of the good death - which is at the very core of this dissertation - should be situated.

1. The good death and changing patterns of death and dying

The processes of medicalisation, politicisation and individualisation are crucial to this dissertation, for they fundamentally impact on *what it means to die well*. They form a demographical, medical, technological and social breeding ground for the concept of ‘the good death’ that is becoming increasingly prominent. This dissertation intents to grasp the meaning of the good death (in a medical(ised) setting) in its contemporary (Western) appearance and does so by focusing on its discursive/ideological dimension and its construction in the meaning-making circuit of mass media representations and their audience receptions. Before turning our attention to the questions of what it means to focus on the discursive/ideological dimension of the good death and how media studies are brought into the research field of death studies, it is deemed necessary to draw attention to a more general contextualisation of the good death by looking further into the processes of the medicalisation, politicisation and individualisation of death.

- Medicalisation

In the West, life expectance has been increasing ever since the mid-twentieth century; in Belgium, life expectance rose from 65.8 in 1950 to 78.7 in 2002, and several other Western countries have undergone a similar shift (Cohen, 2007: 6). Reductions in infant mortality and in early childhood deaths are responsible for this rise for a great deal (Seale, 2000: 918). But there is another shift contributing to increasing life expectancies; the end of the great epoch of infectious disease – also referred to as the 'epidemiological transition'. With improvements in housing, water supply, food and education (Turner, 2003: 19), people today more often die from chronic diseases like cancer and heart diseases instead of from pneumonia, bronchitis and tuberculosis (Cohen, 2007, 6; Seale, 2000: 191). Alongside increasing life expectancies, which also resulted in a lengthening of dying trajectories, death and dying increasingly came under the influence of the medical system where, ever since the 18th century, technological developments made it possible to sustain life. The medical approach towards death and dying became, according to Illich's (1976) well-known analysis, a highly instrumentalist and impersonal one; one where the dying process became a technical matter, *"bereaved of its existential and personal significance"* (Cohen, 2007: 6). According to Illich, the medicalisation of death resulted in a loss of the capacity to accept death and suffering as meaningful and significant aspects of life, in a devaluation of traditional rituals surrounding death and dying and in a crippling of personal and family care (Clark, 2002). Death, moreover, became something to be resisted, postponed and avoided (Cohen, 2007: 5); with medicalisation, a *"sense of being in a state of 'total war' against death"* emerged (Clark, 2002). Trends of individualisation (see further), however, triggered a certain turnaround; the individual was put back in play (Cohen, 2007: 5). Gradually, too, the downsides of a modern medical approach to death and dying became visible and the idea that curative treatment is always the right (and the only possible) option became increasingly challenged (Cohen, 2007: 7). The late modern approach to death and dying, then, encourages medical professionals to be milder and gentler in dealing with death and the dying. The development of palliative care, demanding for a humane and dignified approach to death and dying, but also the passing of the euthanasia laws in a number of countries should be seen in the light of this new approach to death and dying (Cohen, 2007: 5). Death and dying are still very much medical(ised) affairs, as several large-scale studies have indicated that death in many European countries is indeed often preceded by medical end-of-life decisions with possible life-shorting effects (Van Den Block, 2008: 23; van der Heide et al. 2003). At the same time, concepts that emerged as a form of resistance against the medicalisation of death, like 'quality of life' and the 'wellbeing of the patient' - increasingly steer medical decision-making at the end of life. This decision-making, it should finally be noted, encompasses a variety of possible decisions. The following groups of medical end-of-life decisions can be distinguished (Bilsen, 2005: 11):

- Non-treatment decisions: decisions to withhold or withdraw potentially life-prolonging treatments.
- Alleviation of pain and symptoms: decisions to administer potentially life-shorting drugs.
- Euthanasia: decisions to administer life-shortening drugs at the explicit request of the patient, with the explicit intention to hasten his death.

    - Physician-assisted suicide: decisions to prescribe or supply potentially life-shortening drugs to be taken by the patient and at the explicit request of the patient, with the explicit intention to accelerate his death.
    - Life-ending drug use without the patient's explicit request: decisions to administer life-shortening drugs without the patient's explicit request, with the explicit intention to accelerate his death.

- Politicisation

As a concept, the 'end of life' today has both a medical and a political dimension, and both are fundamentally intertwined. Indeed, death and dying are increasingly becoming subject to political intervention, and the end of life is thus no longer the exclusive domain of medicine and medical ethics. The politicisation of death should be seen against the background of an increasing politicisation of a variety of issues that were considered private for a long time; including for instance sexuality, parenting and the organisation of the family. These are, in the words of Giddens (1991: 214), issues of 'life politics'; political issues flowing *"from processes of self-actualization in post-traditional contexts"*. Embedded within this broader politicisation, and triggered by concerns over the patient's wellbeing, the rights of the (terminally ill) patient became increasingly regulated in legal-political frameworks[1]. In many countries (including many European countries, but also non-European countries like India), the individual's right to refuse treatment (often captured in laws on patients rights) and the right to palliative care have for instance become legally enforceable rights. The right to proper care at the end of life increasingly becomes a human right, and is also defined as such. The right to palliative care indeed falls under the international human rights law. In some countries, laws exist that legally insure the patient's

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[1] Death and dying, of course, have always been surrounded a wealth of political and ethical frameworks. 'Thou shall not kill' is indeed one of the oldest and most universal ethical guidelines, illustrating that death and dying have always had a public (and ethico-political) dimension.

right to euthanasia or assisted suicide (when meeting certain criteria), but in most countries active euthanasia and physician-assisted suicide are forbidden. Very often, existing laws on the end of life continue to struggle with questions about the permissibility of human control over the timing and manner of death. Unsurprisingly, they often are also difficult to interpret, of which the many end of life cases brought to court bear witness.

It should be noted at this point that the politicisation of death does not exclusively refer to institutionalised politics, but also to struggle and conflict at a variety of levels that indeed transcend the level of institutionalised politics. This more broad approach towards politicisation – as a broader sphere of struggle and conflict that runs throughout the entire social sphere - also brings political protest and activism of individuals into the picture (and the case of Mario Verstraete is an example here). And also activism organised in and expressed by social movements - like the right to die movement – is to be seen as part of the politicisation of death and dying. Very often, activism and protest of individuals and movements constitutes the breeding ground for the establishment and development of legal-political frameworks.

- Individualisation

Changing patterns of death and dying cannot be isolated from broader trends of individualisation and de-traditionalisation, where people increasingly want to have control over their own life. According to authors like Beck (1994) and Giddens (1991), a result of the de-traditionalisation of late modern societies is the way individuals become planning agents of their own life and gain more and more autonomy and responsibility over their own life. According to Seale (2000: 925), the tendency to plan and control important life events is a feature of self-identity in late modern societies. Gradually, he goes on to argue, dying too becomes subject to this urge to control life events. More and more, then, people are concerned with *how* they die; they want the way they die to be in accord with

> the way they lived; dying in this way becomes a crucial feature of self-identity. Hospice and palliative care workers provide a relevant expertise to assist this urge to control the circumstances of death and dying, and also the increasing support for euthanasia in many Western countries is symptomatic for the concern with suffering and dependency in the last phase of life, and euthanasia can indeed be a means to control the manner and timing of death (Seale, 2000: 925). It comes a no surprise, then, that discussion about the end of life increasingly build on notions of autonomy and self-determination; they reflect the need of individuals to be the planning agents of their own life *and* death.

Illustrative for changing patterns of death and dying is the concept of 'the good death', which is becoming increasingly prominent against the background of the three processes sketched above. The concept underlies medical-decision making at the end of life, where the aim is to provide a painless, comfortable death; a good death as an aspect of quality of life, one might say (Cohen, 2007: 7), but it also underlies processes of politicisation, where the aim is to make a good death a human right, and processes of individualisation, where a good death becomes a key feature of self-identity. This research picks up on the concept of the good death, and does so in a specific way. Concretely, the dissertation focuses on the meaning of the good death, and thereby defines meaning in terms of discourse, representation and ideology[2], which entails a research interest not so much in what a good death means in a specific context (e.g. for cancer patients or patients with dementia) but in the culturally shared, taken for granted and hegemonic assumptions that underlie the meaning of the good death. The interest in studying the meaning of the good death is motivated by the conviction that these assumptions function in an ideological way; under hegemonic meanings of the

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[2] The notion of ideology refers here to the way Ernesto Laclau defines it as "the 'will' to totality of any totalising discourse" (1990: 92).

good death some ways of dealing with and encountering death and dying are considered acceptable, desirable and normal, while others are considered non-acceptable, non-desirable and/or not normal.

2. Situating the dissertation in the field of thanatology and end-of-life care research

This dissertation, with its research interest in the meaning of the good death, is to be situated in the field of thanatology; a research area where death and dying are studied by means of scientific methods. The field of thanatology also encompasses (bio-) medical and forensic research, but increasingly refers to the social study of death and dying – a number of 'classic works' include amongst others: "Endings: A Sociology of Death and Dying" (Kearl, 1989), "Constructing death. The Sociology of Dying and Bereavement" (Seale, 1998), "Death and Dying. A Sociological Introduction" (Howarth, 2007) and "A Social History of Death and Dying" (Kellehear, 2007). This dissertation, then, contributes to the already extensive field of social and cultural thanatology. A wide variety of themes are dealt with by thanantologists who engage with the social-scientific research into death and dying; (cultural) attitudes towards death and dying, care for the dying, the medicalisation of death and dying and the medical death, death education, grief and mourning, ethical and legal aspects of death and dying, and spirituality and religion in death and dying – to name only a few. This dissertation primarily adds to existing research on the medical(ised) death[3], where the

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[3] Given its focus on a discursive (and discourse-as-ideology) dimension of the good death, this thesis reaches beyond the main theme of the medical end of life. In (historically) sketching the evolving systems of meaning surrounding death and dying and in studying the meaning of the good death, this dissertation also contributes to the body of knowledge on other thanatological topics, like cultural approaches to death and dying and cultural histories of death and dying. Moreover, the dissertation also stretches beyond the field of thanatology. Engaging with topics like illness, ageing and the body, the thesis also contributes to the fields of social gerontology and social health studies – which are, of course, closely related to thanatology.

latter refers to dying processes taking place in a medical(ised) setting, involving medical care (which excludes sudden death caused by, for instance, a car accident from the scope of this dissertation).

The topic of the medicalised death, and more specifically the issue of medical decision-making at the end of life, has sparked much academic attention. Triggered by changing practices of decision-making (e.g. the growing number of deaths being the direct outcome of decisions like stopping or withholding treatment, administering pain relief etc.), changing medical ethics at the end of life (e.g. the tendency not to withhold 'bad news' from the patient), evolving medical technologies (e.g. technologies to sustain and prolong the patient's life), research about medical decision-making at the end of life has indeed grown increasingly over the last decades (Van Den Block, 2008: 16). This dissertation adds to existing research on medical end-of-life decision-making, but does so in a specific way; by respectfully distinguishing itself from the dominant research agendas of medical sociology and medical philosophy.

As a research discipline, medical sociology is at the forefront of research on the medical death and end of life care. Medical sociological studies focus on topics like palliative care, (national) patterns of end-of-life decision-making, the place of death, attitudes towards euthanasia and so forth. In looking into these topics, both quantitative and qualitative studies are conducted[4] with the (often explicit) purpose to improve patient care (Cohen, 2014) (see for instance Barbera et al., 2005; Finlay, 2002;

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[4] In Belgium, medical sociological research about the medical end of life is especially conducted by the End-of-Life Care Research Group. In an international context, examples of medical sociological research are the Support study (US) and the Regional Study for Care of the Dying (UK), both highlighting the importance of palliative care and pinpointing problems and issues in the quality of care for the dying. Philosophy (and more specifically the domain of medical ethics) is another discipline where research about the medical end of life and end-of-life decision-making booms.

Grande et al. 2004; Mezey et al. 2002). Given this explicit and certainly very noble objective to answer to voids in existing patient care, this type of research is often very much aligned with the dominant biomedical model. Taking too much distance from this dominant model indeed hampers scholars' chances to actually impact on existing medical end-of-life practices and policies. In order to achieve the goal of improving patient care and of answering to voids in existing patient care, death and dying are often approached from a caregiving or health-policy orientation (Cohen, 2014). Whilst medical sociological research and its aim to contribute to the quality of patient care is very valuable and necessary, it is at the same time important that this type of research is complemented with research that allows to contextualise and simply better understand the culturally and socially embedded nature of the meaning of 'dying well'. This dissertation aims at engaging in second-order observations; it envisages to deconstruct and de-essentialise the meanings of a series of concepts (with the good death as a master concept) that often remain unquestioned (also in existing end-of-life care research). That is not to say that concerns with the improvement of patient care are absent from this research. Concerns with the quality of patient care motivate this research, as it is indeed the conviction that the meaning of the good death impacts on expectations towards the terminally ill and the way they encounter the dying process (which in turn affects end-of-life care practices) that underlies this research. More applied studies may turn to this research, as well as to other studies embedded within a social constructionist research tradition, to contextualise and better understand their research findings. In this way, as Cohen (2014: 266) rightfully argues, research focussing on meaning serves "*the purpose of suggesting the possibility of alternative explanations".* Research focussing on meaning and its socially and culturally embedded nature may for instance interpret results of a medical sociological study linking negative attitudes of doctors towards the performance of euthanasia to medical paternalism by drawing attention to dominant medical ideologies (e.g. a scarcity of life ideology and a 'medicine as curing' ideology) - rather than to a paternalistic culture per se – as an explanatory factor.

The medical end of life has also sparked attention of medical philosophy, where research about the topic indeed booms. Medical philosophy above all engages with themes like patient autonomy, ethics of care and euthanasia (e.g. Munthe et al. 2012; Palm, 2014; Sandman, 2002, Secker, 1999 and Somerville, 2001). Research in the field of medical philosophy often critically scrutinises existing end of life care practices by looking into their underlying ethics. This type of research is again very valuable, and changing patterns in death and dying and the way they impact on medical ethics indeed demand philosophical reflection. Often, medical philosophical accounts subscribe to a particular normative ethical framework to suggest (alternative) ways of organising and practicing end of life care. In her study about the concept of patient autonomy in bioethics, for instance, Secker (1999) deplores the dominance of a Kantian autonomy concept in bioethics and pleas for a *"more promising concept of autonomy for patients"*(p.43) by drawing on a communitarian philosophy that emphasises human relations and interconnectedness. Also Somerville (2001) denounces the contemporary dominant focus on autonomy in her 'case against euthanasia' and argues for an approach that centralises care. Another example is the study of Sandman (2002), who questions the use of the concept of human dignity in palliative care contexts, arguing that it blurs rather than enhances an understanding of good palliative care.

This dissertation has close ties with the tradition of medical philosophy and extensively draws on its literature. At the same time, this dissertation (respectfully) distinguishes itself from medial philosophical research as it incorporates the critical moment in a later stage. This means, more concretely, that the dissertation does not a priori subscribe to a particular ethical framework (e.g. a communitarian framework, a liberal (right to die) framework). Instead, it takes a certain distance from all ethical frameworks. In adopting a social constructionist and more specifically a discourse-theoretical approach (see further), the dissertation uncovers the ideological/discursive dimension of all these frameworks, which allows identifying disciplining mechanisms inherent to all of them, including 'progressive' discourses.

In order to identify and study the meaning of the good death and its discursive dimension, this dissertation turns its attention to mass media, approached here as social arenas where meaning circulates and where dominant ideologies are reproduced, but also negotiated and contested. *"Drawing on existing ways of making sense of the world"*(McKee, 2003: 46), media contents provide important cultural resources that teach us something about the society in which they operate. Rather than (always) being the origins of meaning and discourse, which then become further distributed throughout the social, media are inseparable parts of the social. The discursive dimension of the good death can be analysed in a variety of other ways, for instance by looking into end of life practices, legal frameworks, institutions of care and so on. Mass media thus provide only one entry point to study the discursive and ideological dimension of the good death. The capital earned by mass media from bringing meaning into wide circulation, i.e. to be constituted by a broader social reality but equally to be constitutive of that reality, legitimises the choice to analyse media material. At the same time, it is crucial to note that media are not just any platform where the meaning of the good death circulates. Media indeed operate in specific ways, following specific mechanisms. It is important to be well aware of the fact that the meanings of the good death circulating in mass media do not entirely and/or necessarily overlap with the meanings of the good death circulating in other social fields and arenas. At the same time, it is a key objective of the thesis to embed media representations of the good death in a broader social context, and to produce claims on a level that transcends the specificity of mass media representations. This is why, first of all, this research not only looks into media *representations*, but also into audiences' *receptions* of these representations. Audience resistance against particular ways of representing the medical death in the media generates insight in and understanding of other views on the good death that are not necessarily visible in media contents. Second, an extensive literature review is conducted that facilitates and supports the contextualisation and deconstruction of the research findings. This literature review, more concretely, identifies discourses of death and the good death as well as other relevant systems of meaning that impact on the meaning of the good death, like those on medicine and medical ethics. This relates also to another strategy not to loose sight of the broader context in which media are embedded, achieved by the general approach adopted in this dissertation that allows bridging media representations and receptions to more encompassing discourses that surround the concept of the good death. This general approach consists of a social constructionist, discourse-theoretical perspective and will be discussed later in this introduction.

In the remainder of this introduction, I will go on to position the dissertation, and I will do so, more concretely, in a threefold way. First, I situate the research in the field of media studies, which - as a discipline – is brought into the field of thanatology. Second, I explain how a social constructionist perspective is adopted, and how it impacts both on our understanding of the concept of the good death and on our understanding of (the role of) mass media (in society). Third, I discuss the discourse theory of Laclau and Mouffe as a theoretical perspective that introduces a specific way of understanding the social construction of the good death. The specific and contribution of this dissertation to the field of thanatology is located at each level of this threefold positioning. Elaborating on each of these levels not only allows to further emphasise the innovative value of this research, but also – and even more importantly – to formulate the research questions of this dissertation. In each phase of positioning the dissertation, the research questions will be (re-)formulated and refined. The final research questions will be formulated after having introduced the discourse theory of Laclau and Mouffe as the main theoretical approach, because it allows us to fine-tune the research questions using the specific vocabulary discourse theory provides us with.

3. Bringing media studies into thanatology

It was mentioned earlier that thanatology encompasses research about a wide scale of topics. This is connected to thanatology's interdisciplinariness, which is a direct result of the omnipresence of death and dying in the social. Indeed, a variety of disciplines engage with the study of death and dying, amongst which sociology, legal studies, political sciences and philosophy[5]. This dissertation brings another discipline into the field of thanatology, one that to date has shown only very little interest in the study of death and dying: media studies. Only a few media scholars, indeed, have focussed their attention in a substantial way on the role of mass media in representing death and dying[6]. Folker Hanush's "Representing death in the news" (2010) and Daniel Ashton's work about the representation of the illness and death of Jade Goody (2014) are some recent examples of media scholars studying death in the media. Thanatology, from its part, has often positioned research on the mediations of death and dying in the background. Existing research is presented in discrete chapters in publications intended for a wider audience (see for instance the work of Kearl (1989), Bryant (2003) and Howarth (2007)). An important innovate value of this dissertation, consequentially, is the way it brings media studies into the field of thanatology and in so doing contributes to the enrichment of both media studies and thanatology.

The dissertation brings media into the scope of thanatology by looking into the representation of the good death in media contents and audiences' receptions of these media contents, and their relation to existing meanings of the good death circulating in the social. This dissertation focuses on two places and moments of meaning-making: media contents as places where the meaning of the good death is constructed

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[5] It was noted that above all medical sociology and medical philosophy engage with the topic of the *medicalised* death

[6] Chapter IX of this dissertation provides an overview

and the moment of media reception, where audiences interpret these media contents[7]. In more concrete terms, this dissertation looks into Belgian print media coverage of the medical death and their receptions by members of the general public, medical professionals, and relatives of deceased persons.

At this point, then, the main research questions can be formulated as follows:

- How, and following what media-specific logics of representation, do Belgian print media contents about the medicalised death represent (the meaning of) the good death? (RQ1)
- How do audiences (including members of the general public, medical professionals and relatives of deceased persons) receive these contents? (RQ2).

The analysis that is conducted in the light of these research questions (iteratively) triggers a research interest in the notion of 'good journalism' and more specifically draws attention to the way audiences and media contents evaluate 'quality' coverage of the medical death[8]. A second set of research questions can thus be formulated:

- How do media representations of the medical death define 'good journalism' in relation to coverage of the medicalised death? (RQ3)
- How do audiences define 'good journalism' in relation to coverage of the medicalised death? (RQ4)

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[7] That is not to say that the moment of production is neglected in the dissertation. While the research focus goes to media contents and their receptions, the production of media contents about the end of life is taken along in contextual terms.

[8] It should be noted at this point that this research question was formulated retrospectively; the reception analysis drew attention to how media representations of the good death not only triggers audiences' reflection about the meaning of the good death, but also about the meaning of good journalism.

To answer these two sets of research questions, a theoretical framework is needed that supports the empirical analysis. The development of a theoretical framework is guided by a theoretical research question that can, at this point, be formulated as follows: "What is the contemporary meaning of the good death and how is this meaning socially and culturally embedded?" (TRQ).

The research questions formulated above build on a series of premises and principles that can be linked to, or that are inspired by, specific approaches and streams in the field of media studies. A first premise concerns the centrality of the notion 'meaning' and - inspired by the British Cultural Studies - its relation to the concepts of representation and reception. The approach taken to media representation in this dissertation regards media contents as platforms of meaning-making. Media contents produce, but often reproduce and distribute, and sometimes contest, systems of meaning and belief systems in interaction with other fields and systems of meaning.

This dissertation thereby subscribes to a 'ritual' model of mass media, according to which media - including not only news media but also a variety of other genres including (popular) fiction – represent shared values and beliefs (Carey, 1975) rather than to a transmission model, which defines mass media above all in terms of the transmission of information and news. The approach taken to media reception is very much inspired by the notion of the active audience and more specifically by the work of Stuart Hall on encoding and decoding. The concept of the active audience locates the attribution of meaning mainly with the receiver and his capacity to 'decode' the media message differently then indented by the communicators who *"encode messages for ideological and institutional purposes"* (McQuail, 2001: 73).

A second premise regards the significance of 'popular media', which is again inspired by a cultural studies approach. This dissertation not only looks at so called 'quality press', but also at popular press and more specifically at human-interest genres. The reason to include popular and human-interest genres precisely builds on the assumption that these genres, by covering individual and personal cases rather than political and ethical discussion, provide interesting insights in shared beliefs about the good death as well as accessible material for audiences' to identify with and relate to.

A third premise is related to the critical nature of this research. The focus on meaning in this dissertation is in essence a critical one, as this research is indeed - as mentioned earlier – interested in the discursive dimension of the good death. In media studies, critical approaches can be found in the traditions of both political economy and cultural studies. The critical approach adopted in this research finds its origins with the Marxist School of Applied Social Research in Frankfurt, with Max Horkheimer and Theodor Adorno as most important members of the group. The group was above all concerned with ideological domination, and while critical research on media and communication today extends well beyond this early concern, it still often in one way or another centralises issues of ideology and inequality (McQuail, 2001). Critical research often focuses, amongst others, on media representations and media experiences of specific groups, including women, the working class and ethnic minorities, where the main interest goes to the (re-)production of social inequality in relation to gender, ethnicity and class. This dissertation brings death and dying into the scope of critical media studies and does so by focussing on the (potentially) disciplining nature of media representations of the good death. The research is interested in the way media coverage of the medical death normalises certain ways of encountering death and dying while problematising others. Another related point of critical scrutiny is the representation of the dying individual and the way certain expectations towards the dying individual and stereotypes of the ill and ageing are anchored in the coverage of the medical death.

4. A Social constructionist Perspective

Thanatological research in the social sciences and humanities generally acknowledges and accepts the idea that death is culturally and socially embedded, entailing a rich variety of ways in which groups and individuals deal with death and dying. While (recent) publications in the field of social thanatology tend to take on board the general idea of the social construction of death, they simultaneously often shy away from explicit reflections on the underlying ontologies of the paradigm. One of the contributions of this dissertation, then, is to strengthen the paradigmatic reflection in the field of social thanatology and to contribute to a theoretical reinforcement of the field. Another contribution is exactly the inverse of the former, as it also aims at putting death and dying more explicitly on the agenda of social constructionism[9]. It is important to briefly note, at this point, that I use the notion of construct*ionism* here, instead of that of construct*ivism*. Generally speaking, indeed, we can distinguish a more micro-oriented social constructivism from a more macro-oriented social constructionism; the former focussing on the agency of groups and individuals in generating meaning and the latter on collective and cultural structures of meaning (Andrews, 2012).

In the field of media studies, as well as in a variety of disciplines in the social sciences and humanities, the idea of the social construction of gender, nationality, class etc. is well established (see e.g. Lupton & Barcklay, 1997; Perry & Turner, 1992; Weber, 2010; Wodak, 1997; Wodak et al. 2009). Talking about death as a social construction might make eyebrows rise, however - as death is indeed one of the most pervasive phenomena of the social and is sometimes described as 'the only certainty in life'. A biomedical approach to death is very much dominant in Western thought, but its constructed nature is revealed when we set aside our (late-)modern Western gaze and take a look at alternative ways of defining death and dying in, for instance, the Hindu culture where dying is defined as a process where the soul ritually detaches from the body (Robben, 2004). Then again, while the definition of death is culturally embedded, the changes the dying body goes through seem to put certain restrictions to the way death is or can be thought of as a social construction. It is thus impossible (and undesirable) to deny the fact that death has a clear materialist dimension in the sense that it is an event/process/moment that exists and occurs independently from

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[9] This has also been argued in Van Brussel & Carpentier (2014)

human will, though and interpretation. At the same time, death only becomes meaningful because humans interpret it, both in micro settings of interaction as in macro cultural settings where dominant belief systems attribute meaning to death and dying. A key premise of this dissertation is that studying death, and more particularly the good death, through the lens of social constructionism allows to de-essentialise and deconstruct taken for granted concepts and arguments that structure the way we deal with death and dying[10].

The concept of the *good* death brings in a normative dimension, which makes the choice for a social constructionist perspective more evident. Death, indeed, only becomes 'good' because it is interpreted as such in a specific cultural and historical context. The good death, and this is a main premise of this dissertation, is the outcome of continuous processes of meaning-making, rather than a fixed reality. Arguably, the dissertation is deeply influenced by post-structuralism and its argumentation that meaning is generated through signifying relations that are not fixed in a structure but that are ambiguous and contingent. Such a post-structuralist presumption comes with a non-essentialist and non-foundationalist position, rejecting the existence of universal meanings with underlying systematic structures and foundations. These positions also imply the rejection of a rigorous realism where social reality is seen as having an underlying objective and essential structure determining social relations and identities. Rather, constructionist traditions assume that there is no pre-given and determining essence capable of ultimately structuring and fixing identities. At the same time, it is important to note that a post-structuralist rejection of essential social fundaments does not suggest a total impossibility of social structure, which would basically make any meaning impossible[11]

The post-structuralist constructionist ontology described above means that 'the good death' derives its meaning through contingent signifying relations. While its meaning consists of a series of generally taken-for-granted elements that construct dominant

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[10] This has also been argued in Van Brussel & Carpentier (2014)

[11] See Van Brussel & Carpentier (2014)

structures of meaning, these elements at the same time open up a range of gasps, complexities and unfixities.

The constructionist and post-structuralist perspective outlined above is also adopted as a general approach to mass media, which boils down to what has been explained above as a critical interest in the meanings that are inscribed in mass media contents and the way these contents are interpreted and received by mass media audiences. The underlying assumption is that media play a role in the social construction of reality in the sense that they (re-)produce, negotiate, and sometimes contest and resist dominant meanings, ideologies, value systems and so on. Mass media do not 'create' meaning in the sense of their being the 'origins' of meaning, but they are important social spheres or arenas where meaning-making takes place and where signifying relations are established, reproduced and negotiated. A social constructionist perspective on mass media also refers to audiences' meaning-making activities in interpreting media contents and to their capacities to be creative with the meanings offered to them through the media text. Focussing on audiences' agency in making meaning of the good death allows us to bring a constructivist element into a broader constructionist approach.

On the basis of the discussion above, the research questions can be reformulated in a way that emphasises the perspective on the good death as being embedded in processes of social construction – taking place in, amongst others, the sphere of mass media. The first (and main) set of research questions thus becomes:

- How, and following what media-specific logics of representation, is the meaning of the good death constructed (through contingent signifying relations) in the Belgian print media coverage of the medicalised death?
- How do audiences construct the meaning of the good death in interpreting the Belgian print media coverage of the medicalised death?

The second set of research questions can be formulated as follows:

- How is the notion of 'good journalism' constructed in media coverage of the medicalised death?
- How is the notion of 'good journalism' constructed in audiences receptions of media representations of the medicalised death?

The theoretical research question, answered by means of a literature review, is formulated as follows: "What are the different constructions of (the medical) death and the good death circulating in society?".

Choosing for a discourse-theoretical approach, embedded within a social constructionist and post-structuralist ontology, allows us to bring in a particular vocabulary to further fine-tune and deepen the focus on the *meaning* of the good death and its discursive construction. Below, a discourse-theoretical perspective on the good death (and its construction in mass media) will be introduced and justified, leading to a final formulation of the research questions.

5. A Discourse-theoretical perspective- and analysis

This dissertation uses the post-structuralist discourse theory of Erneso Laclau and Chantal Mouffe (1985) as the backbone for the study of media constructions of the good death and their audiences' receptions, and the way both moments of meaning-making are linked to more encompassing discourses on death and the good death. While discourse theory has above all been deployed in the study of political-social reality, death plays a too significant role in the social to be excluded from the theoretical and analytical gaze of discourse theory[12]. Adopting a discourse-theoretical perspective to study the medical death, and more specifically the concept of the good death, provides an innovative approach – precisely because discourse theory has largely remained within the confines of political theory and has mainly been adopted in the study of nationality, ethnicity and social movements. One of the challenges

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[12] This argument was also made in Carpentier & Van Brussel, 2012, and Van Brussel, 2014.

post-structuralist discourse theory faces today, according to Torfing (2004: 25), is indeed the necessity to move beyond the traditional research interests, and to focus on a variety of core topics and areas within social and political sciences. Death is an uncharted territory where discourse theory has the potential of demonstrating its analytical value – on the condition that it avoids lapsing into a self-indulgent theoreticism and that it produces new insights.

Drawing on the discourse theory of Laclau and Mouffe brings a specific definition of discourse. Rather than regarding discourse *"merely as a linguistic region within a wider social realm"*, Laclau and Mouffe offer a broader conceptualisation of discourse that *"insists on the interweaving of semantic aspects of language with the pragmatic aspects of actions, movements and objects"* (Torfing, 1999: 94). This broad definition of discourse can be described as discourse-as-representation or discourse-as-ideology, in contrast to approaches that use the discourse-as-language definition of discourse (Carpentier and De Cleen, 2007: 277). Laclau and Mouffe's discourse theory corresponds to the notion of the big-D Discourse, which unlike the little-d discourse or a language-in-use definition of discourse, refers to *"different ways of thinking, acting, interacting, valuing, feeling, believing, and using symbols, tools, and objects in the right places and at the right times"* (Gee, 1999: 13). At the same time, Laclau and Mouffe's discourse theory is specific, given its use of a particular vocabulary and particular concepts to describe the mechanics of discourse.

A particularly important concept for this dissertation is the concept of **articulation**, which is defined as *"any practice establishing a relation among elements such that their identity is modified as a result of the articulatory practice."* (Laclau and Mouffe, 1985: 105) For discursive elements relating to the subject, Laclau and Mouffe use a specific notion: **the subject position**, which refers to the way subjects are positioned within a discursive structure (Laclau and Mouffe, 1985: 115). Crucial to Laclau and Mouffe's discourse theory is that discourses have to be partially fixed, since the profusion of meaning would otherwise make any (temporal fixation of) meaning impossible (Laclau and Mouffe, 1985: 112). The articulation of elements produces discourses that obtain a certain (and very necessary) degree of stability, enhanced by the role of privileged signifiers or **nodal points**. Torfing (1999: 88–89) points out that these nodal points *"sustain the identity of a certain discourse by constructing a knot of definite meanings"*. At the same time, the field of discursivity has an infinite number of elements that are not connected to a specific discourse. Due to the infinitude of the field of discursivity and the inability of a discourse to permanently fix its meaning, then, discourses are always liable to disintegration and re-articulation, which produces contingency. Through the **discursive struggle** for meaning *"in a field crisscrossed by antagonisms"* (Laclau and Mouffe, 1985: 135–136), and through the attempts to create discursive alliances (Howarth, 1998: 279; Howarth and Stavrakakis, 2000: 14), discourses can be dislocated and altered.

The question may now rise as to how a discourse-theoretical perspective adds value to the study of the medical death. It is not claimed that discourse theory provides the only suitable framework to study all aspects of death and dying, nor to achieve all research purposes. Research that has a first-line purpose of contributing and adding to the quality of patient care, for instance, probably benefits better from less abstract and (meta-)theoretical frameworks. But a discourse-theoretical perspective does seems to be well suited for analysing the construction of the master-signifier of the good death and how the subject position of the dying person becomes articulated within this construction. Adopting a discourse-theoretical perspective on the good death (in mass media), more concretely, adds a specific value to the study of the medical death in a fivefold way. To discuss this added value, I draw on arguments formulated by Torfing (2005), who emphasises the added value of discourse theory to the study of politics. Torfing's arguments also apply (albeit in a slightly different way) to the study of death and dying, which demonstrates that discourse theory extends beyond the study of politics and provides a post-structuralist perspective that is not exclusively tied to one specific field or area of the social.

A first response to the question as to what discourse theory adds to the study of the medical death is that is poses different type of research questions (Torfing, 2005: 22).

Adopting a discourse-theoretical approach to the medical death does not come with the intention to develop a general theory of, for instance, attitudes towards euthanasia or physician-assisted suicide. Rather, discourse theory is problem driven and seeks to shed new light on the issue of the medical end of life and the debates about the permissibility of human (medical) intervention in dying it entails.

A second argument in favour of the added value of a discourse-theoretical perspective on the medical death relates to the way it draws attention to the contingent nature of particular discursive structures and formations. Discourse theory, as Torfing argues (2005: 22), refuses to privilege certain structures, frameworks or interests as starting point of analysis. Torfing illustrates this with the example of globalisation: a discourse-theoretical political analysis looks into the way a discourse on globalisation constructs different accounts of globalisation rather then taking a globalised capitalist economy as the starting point of the analysis of political responses. In similar vein, a discourse-theoretical study of the good death does not start from or subscribes to, for instance, a right to die framework. Rather it analysis how this framework, as well as other frameworks, construct the good death (bearing in mind that these constructions impact on concrete end of life practices). A discourse-theoretical perspective allows us to look at the wealth of ethical frameworks that normatively evaluate medical decision-making at the end of life *as* discourses, without (directly) subscribing to one of them.

A third distinctive feature of discourse theory that adds to the study of the medical death is the acknowledgement of the importance of language as a carrier of discourse. Although discourse in Laclau and Mouffe's theory does not solely encompass language but rather refers to a togetherness that includes aspects of language and actions, moments and objects (Torfing, 1999: 94), discourse theory sees language and rhetorics as important carriers of discourse, which can be constitutive of social structures and identities. This motivates and justifies the choice to analyse the circuit of mass media, where primarily language and its semantic aspects operationalise discourses in a way that contributes to their partial and temporal fixation.

A fourth argument in favour of a discourse-theoretical study of the good death is that it allows shedding light on (the dynamics between) continuity and discontinuity. Discursive formations - including those surrounding death and dying - are continuously challenged by alternative discourses, which causes discontinuity. Sometimes, discursive frameworks are dislocated, and new social orders are created. Often however, only the surface of existing orders is scratched and affected, and challenging discourses do not succeed in achieving enough credibility to establish new social orders (Torfing, 2005: 23). This dissertation, then, pays attention to the way discourses surrounding death and the good death are dislocated and challenged by new discourses as well as to the way 'old' discursive regimes continue to exist and impact on the contemporary meaning of the good death.

A last asset of a discourse-theoretical perspective relates to the focus on power and power struggles, where power is not defined *"in terms of a resource or capacity one can possess, store, or retrieve, or as a relation of domination"* (Torfing, 2005: 23), but in terms of acts of meaning-making of inclusion and exclusion. Applied to the issue of the good death, this boils down to an interest in the way discourses categorise and construct particular ways of dying as 'good' and other as 'bad', in this way normalising or alternatively problematising particular ways of encountering death and dying – which contributes not only to the construction the 'good death' but also to the normalisation of certain subject positions of the dying individual/patient.

It has now become clear how a discourse-theoretical perspective sheds a potentially interesting and innovate light on the good death. Given this dissertation's research focus on the representation of the good death in media contents and their audiences' receptions, it is also crucial to theorise the relationship between discourse and media. The general assumption here is that mass media are important social arenas where discourses circulate and where different discourses engage in a struggle over meaning, while audiences possess of capacities to be creative with the meanings and discourses offered to them through media representations. Introducing two concepts allows us to further theorise the relationship between discourses and media. These concepts are ‘operationalisation’ and ‘identification’. While both concepts are extensively discussed later in the body of this dissertation, it is crucial at this point to briefly explain them – for they indeed occupy a central place in the final formulation of the research questions. The concept of **operationalisation**, first, basically refers to the way discourses are imported in mass media contents, where they are deployed in specific ways and where their operationalisation contributes to a specific construction of the good death. The operationalisation of discourses in and by media is specific, as for instance intimisation, personification and dramatisation can be thought of in terms of media-specific politics of representation that encourage the importation of certain discourses in a specific way. The concept of **identification**, second, basically refers to the way audiences – in allocating meaning to media contents – relate to and identify with more encompassing discourses. The concept of identification should be seen in relation to the notion of interpretation, which was introduced earlier and refers to the way audiences read and give meaning to media representations of the medical death and the constructions of the good death that are inscribed in them. Identification – as will be explained later in this dissertation - often goes via the media text, but can also occur to a more or lesser degree independently from the media text, when audiences are for instance in the first place triggered by the media text but then move further and further away from it.

The following visualisation demonstrates the way the notions of operationalisation and identification link the circuit of media representations- and receptions to the concept of discourse. As a theoretical- and analytical model, it thereby illustrates the way the dissertation aims at bridging media representations and receptions to a more encompassing discursive reality.

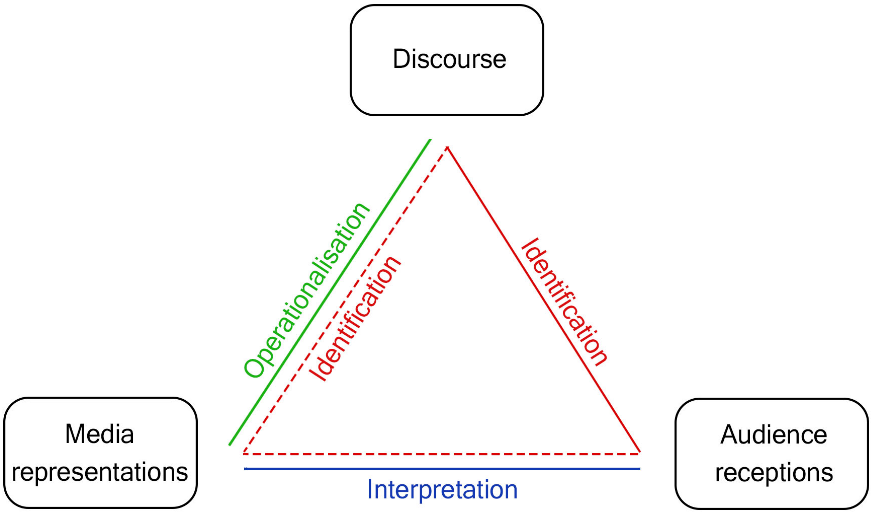

Figure 1: The meaning-making circuit of mass media: a DT interpretation

A discourse-theoretical perceptive, with its distinctive concepts, added with the concepts of operationalisation and identification, allows us to formulate the final version of the research questions. A theoretical research question requires a theoretical inquiry and goes: **"What are the discourses on (the medical) death and the good death, what are their constitutive nodal points and how are they engaged in a discursive struggle over the meaning of what it means to die well?" (TRQ)** This theoretical research question is answered by means of a literature review, where existing literature is read in a discourse-theoretical way, allowing us to identify discourses on (the medical) death and the good death (with their respective nodal points and articulations of subject positions) and other discourses impacting on the meaning of the good death, like discourses on medicine and medical ethics[13].

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[13] It is important to note that this dissertation identifies Western discourses on death and the good death. Whenever claims are made about the hegemony of certain discourses throughout this text, we are always talking about the Western world (or parts of it).

A discursive-theoretical injection is also given to the empirical questions. A first set of research questions thus becomes:

- **How, and following what media-specific logics of representation, does the Belgian print media coverage of the medicalised death construct the good death, through operationalising particular discourses on death and the good death (with their respective nodal points)? (RQ1)**

- **How do audiences interpret the Belgian print media coverage of the medicalised death and in so doing identify with more encompassing discourses on death and the good death? (RQ2)**

The second set of research questions becomes:

- **What discourses on 'good journalism' are operationalised in the Belgian print media coverage of the medicalised death? (RQ3)**

- **What discourses on 'good journalism' are inscribed in the audiences' interpretations of the media coverage of the medicalised death, i.e. with which discourses on good journalism do they identify? (RQ4)**

In order to answer the empirical research questions, discourse theory is translated into discourse-theoretical analysis. Discourse-theoretical analysis uses the general concepts of discourse theory (discourse, articulation, nodal point, subject position, discursive struggle) as well as the concepts constitutive of discourses on death and the good death (which are identified through a discourse-theoretical re-interpretation of existing (thanatological) literature) as sensitizing concepts to structure and support the textual analysis of media representations and receptions. A discourse-theoretical analysis can be defined as a qualitative research method building on the theoretical premises of discourse theory, with which it shares a focus on and interest in the fixation, contestation and reproduction of meaning. Looking into media representations and their receptions by means of a discourse-theoretical analysis leads to a number of concrete research foci, which can be translated into sub-research questions:

Discourse-theoretical representation analysis

- How is the representation of the good death in Belgian print media coverage of the medicalised death embedded and produced in discursive struggle over the nodal points of the late modern discourse of the good death?
- How are the subject positions (inherent to discourses of the good death) constructed and articulated in Belgian print media coverage of the medicalised death?

Discourse-theoretical reception analysis

- How do audiences, in interpreting Belgian print media coverage of the medicalised death, subscribe to competing articulations of the nodal points constitutive of discourses engaged in a struggle over the meaning of the good death?
- How do audiences, in interpreting Belgian print media coverage of the medicalised death, identify with subject positions inherent to (competing) discourses of the good death?

6. Outline of the dissertation

This dissertation is divided in five parts, each encompassing a number of chapters[14]. Part A grounds the dissertation and does so, more specifically, in a threefold way. Chapter I sets the epistemological foundations of the dissertation by discussing the approach it holds towards knowledge and the production of knowledge, which impacts on the research strategy this dissertation follows. Chapter II discusses the

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[14] Note that some parts and chapters are significantly longer than others. The dissertation is divided in parts and chapters based on the way they are to be seen as meaningful entities, which is why – for instance – the empirical chapters (XIII and XV) are the longest.

discourse theory of Laclau and Mouffe as the theoretical backbone for the entire research. Chapter III furthers this theoretical backbone by bringing media studies into the realm of discourse theory.

Part B of the dissertation, the theoretical framework, identifies the discourses on death and the good death that circulate in the social and thereby draws attention to their contingent nature. It does so by re-interpreting and reading existing (thanatological) literature through the lens of discourse theory. The theoretical framework sets out to formulate answers to the theoretical research questions: "What are the discourses on (the medical) death and the good death, what are their constitutive nodal points and how are they engaged in a discursive struggle over the meaning of what it means to die well?" Chapter IV, first, identifies the Western discourse of death. Chapter V grasps the discursive shift from a medical-rational discourse to a medical-revivalist discourse and introduces the late modern discourse of the good death. Chapters VI and VII zoom in on the nodal points of a late modern articulation of the good death: autonomy and dignity. Chapter VIII discusses the political struggle over the meaning of the good death between two social movements (with their respective discursive/political project) that have been at the forefront of debates about end-of-life decision-making and the permissibility of human intervention at the end of life: the hospice movement and the right to die movement. In chapter IX, finally, we shift focus from discourses on death and the good death to discourses on death in the media. Part C (Chapters X and XI) of the dissertation puts down the methodological framework. Discourse theory is translated into discourse-theoretical analysis in a way that allows us to look into Belgian print media representations of the good death and their audiences' receptions. Part D and E present the analyses of Belgian print media representations of the medicalised death (Part D) and their audiences' receptions (Part E). They respectively deal with the research questions: "How, and following what media-specific logics of representation, does the Belgian print media coverage of the medicalised end of life construct the good death, through operationalising particular discourses on death and the good death (with their respective nodal points)?" (RQ1) and "What discourses on 'good journalism' are operationalised in the Belgian print media coverage of the medicalised death?" (RQ2) (Part D) and "How do audiences interpret the Belgian print media coverage of the medicalised death and in so doing identify with more encompassing discourses on death and the good death?" (RQ3) and "What discourses on 'good journalism' are inscribed in the audiences' interpretations of the media coverage of the medicalised death, i.e. with which discourses on good journalism do they identify?" (RQ4) (Part E).

Part D encompasses chapter XII, in which the corpus is both constructed and mapped by means of a basic quantitative analysis, and chapter XIII, which provides a detailed reporting of the discourse-theoretical representation analysis. The subsections of chapter XIII correspond to the main discursive dimensions identified in part B: 'constructing the basics of revivalism', 'the construction of dying autonomously', 'the construction of dying with dignity'- where an answer is formulated to the research question as to how the selected media items construct the good death - and 'the construction of 'good journalism', where the reportage formulates an answer to the research question inquiring the way media reflect about the 'quality' of their own covering of the medical death. The last section of chapter XII discusses the results reported throughout the chapter and formulates a conclusion. In part E, a first chapter (XIV) elaborates on the process of constructing the corpus. The findings revealed in the discourse-theoretical reception analysis are reported in chapter XV, where the different subsections correspond to the main categories of interpretation and identification the analysis revealed: 'patient autonomy and the right to die', 'autonomy and the social network', 'independence of care', and 'hedonism' – which should be seen in the light of the main research question studying the interpretation of media constructions of the good death - and finally 'good journalism', where the reportage focuses on the additional research question of how particular constructions of 'good journalism' are inscribed in the audiences' receptions. Again, a last section formulates a conclusion and provides a discussion.

The visualisation below (figure 2) connects the theoretical- and analytical model presented earlier to the different parts of the dissertation. Part A brings a meta-theoretical elaboration of the relation between the concept of discourse and the circuit of mass-media representations and their audience receptions by building on a discourse-theoretical approach Part A, in other words, explains the discourse - media representation - media reception triangle as such. Part B formulates answers to the theoretical research question and identifies discourses and discursive shifts in the field of the medical(ised) death and the good death, as well as discourses on death in the media. Part D zooms in on the operationalisation of these discourses in Belgian media representations of the end of life and formulates answers to RQ1 and RQ2. Part E looks into audiences' receptions of these media representation and hence formulates answers to RQ3 and RQ4.

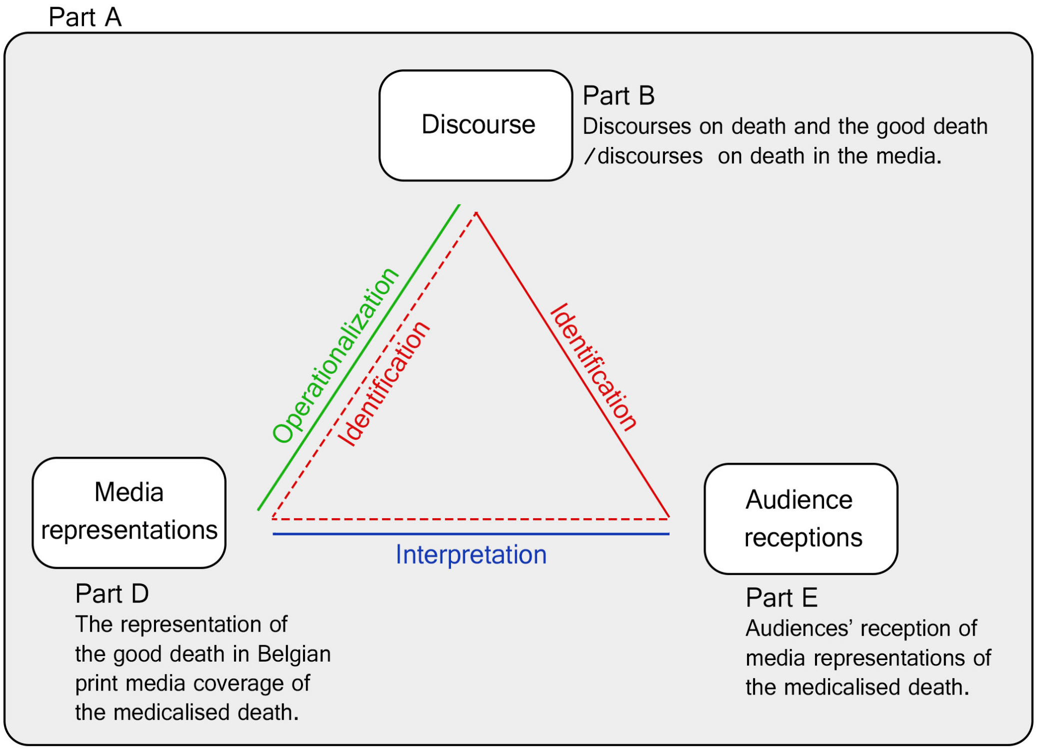

Figure 2: The different parts of the dissertation in relation to the meaning-making circuit of mass media.

It should finally be noted that the dissertation, with its distinctive parts and chapters, is structured on the basis of the 'basic components' of an academic study, including a theoretical framework, a methodological framework, and an empirical analysis. This structure does not 'reflect' the research practice and process, which indeed occurred iteratively – including a constant moving back and forth between theoretical concepts and textual analysis. The issue of iteration is further elaborated on in chapter I of the dissertation.

PART A: EPISTEMOLOGICAL AND ONTOLOGICAL FOUNDATIONS OF THE RESEARCH

> "Discourse is what makes us human" (Graesser et al. 1997: 165)

A first part of the dissertation lays the foundations of the research in terms of epistemology and ontology. The first chapter is dedicated to the construction of a general research approach. Here, attention is drawn to the question of epistemology, which relates to the nature of 'knowledge'. In setting the epistemological foundations of the research, the thesis is situated in the qualitative-interpretative tradition and arguments are formulated to support the theory-supported nature of this research. The research process is also elaborated in more concrete terms, providing the reader with a clear view on how a theory-supported research is combined with the basic principle of iteration. Chapters II and III ground the research in an overall theoretical approach, which implies a twofold elaboration. In chapter II, the term of discourse - which indeed plays a crucial role throughout this dissertation - is discussed by building on the discourse theory of Ernesto Laclau and Chantal Mouffe. This discourse-theoretical approach will be deployed as the main framework underlying every stage of the research – including the development of a theoretical framework, the construction of a methodological framework, and the analysis of textual material. Given the research focus of this dissertation on media representations and media receptions, it is finally crucial to bring media studies into the realm of discourse-theory, and precisely this is done in chapter III.

Chapter I: The construction of a theory-supported qualitative research methodology

At the very basis of every scientific research lay a set of assumptions about the nature of the knowledge it produces, which it turn impacts on the entire research process and subsequent methodological decisions. These assumptions, which often remain implicit, relate to the question of 'knowledge'. What counts as knowledge and counts not as knowledge? What is the relation between the researcher and what is known? In which way is knowledge best acquired and obtained? How do we have access to knowledge? This chapter opens with discussing the two main epistemological stances that mark the field of (social) scientific research, positivism and subjectivism, and goes on to situate this research within the qualitative-interpretative tradition. A research strategy of theory-supported qualitative-interpretative research is presented and legitimised by building on epistemological reflections. In formulating an argument in favour of a theory-supported approach, abduction and retroduction are put forwards as the most suitable research strategies, as they allow for an iterative moving back and forth between the theoretical concept and the texts under analysis. After illustrating how the iterative research process works in practice, I finally turn to the question of quality in qualitative-interpretative research. It is deemed crucial indeed to move beyond a 'pure' epistemological discussion and to formulate a number of quality criteria. Even - or especially - within a constructionist-interpretative framework where scientific knowledge could be seen as just one among many other interpretations of social reality, it is important to strive for scientific quality.

1. Positivism, subjectivism and the question of epistemology

Positivism finds its origins in the natural sciences, and at its core it the belief that there is a knowable reality that exists independent of both the researcher and the research process. Reality, so the argument goes, can be discovered using quantitative methodologies (Hesse-Biber & Leavy, 2010: 8; Cohen, Manion & Morrison, 2000). Until well into the 20th century, positivism was the scientific ideal underlying the social sciences as well. With the concept of 'social physics', August Comte aimed at creating a 'unity of sciences', and he believed that every field of science (including the social sciences) could reach a positive scientific status. Positivist social scientists hold that, just like the physical worlds, the social world is predictable because it is patterned. Under positivism, it is believed that the social world can be observed and known through the use of objective (quantitative) instruments of measurement operated by a rational and neutral researcher (Hesse-Biber & Leavy, 2010).

According to Howarth and Glynos (2008), the tendency to hypostatise prediction reflects the urge among social scientists to conform to the ideals of positivist natural sciences. Research that holds a positivist epistemology often adopts a deductive research practice (Howarth and Glynos, 2008: 21). Following a deductive methodology, theories are either corroborated or falsified by deducting empirical statements or predictions, which are then tested these against observational evidence. Howarth (2005: 322) refers to deduction as 'theoreticism', "*which either logically derives the explanations of concrete phenomena from abstract concepts of a general theory, or subsumes particular events and processes under empirically verified laws*". Contemporary social scientists who rely on deductive reasoning are probably best described as post-positivists who recognise that researchers cannot be absolutely positive about the claims about the social world they produce, but acknowledge that they can only approximate reality (Hesse-Biber & Leavy, 2010; Guba, 1990; Muijs, 2011: 5). Post-positivism is most congruent with quantitative analysis, but some qualitative researchers also work from this kind of epistemological framework. Examples of the kind of questions (post-)positivist qualitative researchers might ask are given by Hesse-Bibber and Leavy (2010: 17). One of these examples they give is the following question: "what evidence is there to support hypothesis that small class sizes in elementary school increase student learning?"

Generally, however, qualitative researchers adopt a subjectivist or interpretative epistemology. Subjectivism finds its roots in critiques against the use of a (post-)positivist deductive approach in the social sciences. These critiques have been increasingly dominant in the social sciences, especially since the 'interpretative turn' of 1980's and early 1990's that introduced the study of cultures, meanings and symbolic practices (Lindlof & Taylor, 2002: xi). A subjectivist or interpretative epistemology is generally embedded within a constructivist paradigm, where it is believed that humans construct knowledge in interaction with the social and physical world rather than the latter existing in an objective state waiting for discovery, and that no such thing as an extra-social point of view is possibly (Denzin & Lincoln, 2011; Gordon, 2009; Guba, 1990).

This research is in line with subjectivism and its critiques on positivism in the social sciences, and more concretely builds on Glynos and Howarth's (2007: 29) argument that the social sciences are fundamentally different from natural sciences, as the former are open systems, *"not amenable to natural science's familiar 'closed' experimental set-ups that can be controlled for potentially spurious factors*". According to Taylor (1981), the positivist empirical testing applied to study rudimental data, i.e. decontextualised and 'meaningless' objects, cannot merely be transferred to and applied in the human- and social sciences - where the main object of interest in the study of self-interpreting subjects. The study of self-interpreting beings, rather, requires subjectivist or interpretative approaches, which oppose the causal law model with their urge to understand the meanings of human actions and practices in particular contexts. According to Glynos and Howarth (2008), interpretative approaches aim at making meanings and social practices intelligible 'from within', which stands in sharp contrast with the positivist approach that adopts an 'outside' position in explaining the social phenomena it studies. The focus on making social phenomena intelligible from within is central to the hermeneutical (philosophical) tradition, where hermeneutics basically refers to subjective understanding or, as Habermas (1972) puts it, *'verstehen'* (Prasad, 2015: 30-31). The hermeneutical critique on positivism, according to Howarth (2005), comes from the acknowledgement that human interpretations of (social) reality cannot be regarded as merely a view on reality that can be isolated from its meaningful context. Hermeneutics, then, assign a privileged role to both context and meaning – it is, according to Hesse-Biber and Leavy (2010: 17) about *"seeking deep understanding by interpreting the meaning that interactions, actions and objects have for people".*

2. Qualitative-interpretative research and induction

This study, like many others situated in the interpretative and hermeneutic tradition that subscribe to a subjectivist epistemological stance, conducts qualitative research. This implies a research focus on meaning rather than behaviour or frequency, and on the contextual conditions in which meaning is produced and practices take place (Hammersley, 1992: 160-172; Yin, 2011: 7-8; van Maanen, 1983: 9). The aim of qualitative research, according Lindlof and Taylor (2002: 18), is to "*perverse and analyze the situated form, content, and experience of social action, rather than subject it to mathematical or other formal transformations*". In essence, qualitative research is about gaining profound understanding of social phenomena (Silverman, 2001). Qualitative research aims at interpreting meanings; meanings embedded into texts and other objects, meanings people attribute to experiences, circumstances, situations and so on (Hesse- Biber & Leavy, 2010). In terms of research strategy, qualitative research is associated with inductive inference, where theory is generated out of the data or in other words where data mould theory. Induction works in an upward way; starting from observations and eventually arriving at theories. Induction is, in other words, a 'bottom-up' approach through which theories are built from observations. Typical to inductive inference is its aim to have data mould theory rather than the other way around (Creswell, 2012; Matthews & Kostelis, 2011; Yin, 2011, van den Hoonaard, 1997).

It is widely acknowledged (Blaikie, 2007; Ritchie et al. 2013) that there is no such thing as ‘pure’ induction; inductive researchers always have in the back of their minds the assumptions deductively arrived at in previous research when approaching their data. Indeed induction and deduction are best seen as two ends of a continuum, still it remains true that the main aim of qualitative research is often inductively inspired and theories and concepts are often build out of the data under analysis (Ritchie et al. 2013: 6).

3. Towards a theory-supported qualitative research strategy

The research conducted here subscribes to the principle of iteration, which allows for the flexible application of theoretical concepts and analytical procedures (Jensen, 2013). Unlike most qualitative studies, however, this research can be described as theory-supported, as it uses a theoretical framework with the aim of rendering the data intelligible and analysing them. This defining characteristic of theory-supported qualitative research has been met with fierce resistance, where the main critique is that data are filtered through a theoretical lens, the result of which the researcher would not be able to identify those features of empirical data that are not in line with the theories imposed on them (Meyer and Lunnay, 2012). A theory-supported approach does not necessarily come with a deductive research strategy, however. An argument in favour of theory-supported qualitative research can be formulated, one that challenges the interpretative conviction that the only way to understand social reality is (only) from the perspective of those experiencing it.

3.1. The socially and culturally embedded nature of theory and scientific knowledge

Before further turning our attention to the nature of theory-supported research and the way it works in practice, it is necessary to dwell upon the nature of theory itself. Reflecting upon the nature of theory might start with the question as to what it is that constitutes the value of theoretical knowledge, knowing that theories can be seen as one construction of reality among many others? Scientific theories, indeed, are socially and culturally embedded forms of knowledge; they produce knowledge in particular ways on the basis of particular rules (Jorgensen & Phillips, 2002: 206). Theories are not neutral or objective; they do not escape the logics of social construction, as they are themselves socially, culturally and historically embedded. At the basis of theory development always lay certain assumptions about what is valid to study and to 'know', and the culturally and socially situated nature of theory 'governs' what can or cannot be studied or theorised.

The above does not imply, however, that theories are useless, because – at least from a relativist position – they would merely be another version, another narrative about the culture it studies (Jensen, 2013; Van maanen, 1988). Theories, indeed, provide lenses through which a particular social phenomenon can be rendered intelligible. Theories are, like all other types of knowledge, contingent constructions "*submitted to discursive regulation*" (Jorgensen & Phillips, 2002: 206), but at the same time useful forms of knowledge to which a researcher, who is part of an academic sphere and culture, can appeal in order to explain and support the social phenomena that are observed and analysed. The latter is related to the specific status of scientific knowledge, where knowledge is produced according to rules and following specific criteria. Scientific knowledge is measured according to other standards than everyday knowledge, and therefore has another authority (Jorgensen & Phillips, 2002: 199). Having a specific status that, at least in the academic community, gives it legitimacy and hierarchy over other types of knowledge, theories allow the researcher to understand the world in a particular way; they provide lenses through which social phenomena can be rendered intelligible. The use of theories in the production and analysis of knowledge, as Jorgensen and Phillips (2002) also believe, enables researchers to engage in second-order observations, i.e. to distance themselves from their everyday understanding of the material.

3.2. Abduction and retroduction

Having explained the socially and culturally embedded nature of theory, we can return to the issue of theory-supported research. Conducting a theory-supported approach in qualitative research is often criticised because it would come with a 'theoretical interference' that hampers an open understanding of that what is observed. Theoretical frameworks, following these critiques, would merely be imposed on the observed meanings and interpretations, which would be subjected to a theoretical 'gaze'. While these critiques rightfully warn against a violent imposing of theoretical codes, other authors have formulated a case in favour of theory-guide qualitative research. Here, I draw on the argumentation of David Howarth (2005) who states that qualitative research adopting an inductive research strategy often tacitly assumes an unmediated access to the 'real-concrete' and tends to shy away from locating meanings and interpretations in a broader perspective or context. Howarth argues that theoretical concepts, that are not readily available to social actors themselves, may be helpful in doing precisely this. In order to engage in second-order observations, Howarth (2005: 320) goes on to argue, we need theory and theoretical concepts. Especially when a researcher is interested in the ideologies anchored and inscribed in texts that are part of the culture in which he/she operates, theoretical concepts - even though they are of course to be seen as culturally and discursively shaped knowledge - are very useful if not necessary because there is no such thing as a 'natural' position from which an underlying ideology can directly be 'read', unmediated by theoretical concepts (see also Wester, 2006). It should be noted at this point, however, that the use of sensitizing concepts (see part C) protects us from muting the data through an imposing of theoretical codes upon them. The role of sensitizing concepts, indeed, is to provide the researcher with theoretical background ideas that provide him with a general sense of guidance and that inform and enhance the analysis (Carpentier, 2010; Charmaz, 2003: 259) rather than eluding or evading it (Blumer, 1967; Chamaz, 2003).

Relying on theory and theoretical concepts should thus not result in a deductive interference, and a theoretical framework can be adjustable and should not be static. A flexible approach to theory allows the researcher to move between theory and what is empirically observed. Abduction and retroduction are two (closely related) research strategies that allow for precisely this: expanding initial theoretical assumptions and extending the research beyond deductive analysis. In abduction and retroduction, data that are not in line with the initial theoretical framework are considered significant to the analysis. Abduction has been identified as the basis of scientific inquiry by Charles Pierce, but only several decades later did social scientists begin to pick up the notion and adopt abduction as a means of inferencing (Reichertz, 2010). Abduction occurs when research findings are 'surprising'; i.e. when there is no proper explanation for what is observed in the existing depot of knowledge (Meyer and Lunnay, 2013; Reichertz, 2010). When facing these surprising findings, abductions urges the researcher to look for theories that help in rendering the findings intelligible (Reichertz, 2010). Abduction, then, is a means of forming associations that enable a researcher to juggle and craft with theories and theoretical concepts and to formulating new and innovative ideas that allow the researcher to see alternative explanations (Danermark et al. 1997). Similar to abduction, retroduction moves the analysis of data beyond the original research premise and facilitates the emergence of knowledge that cannot be gained through deductive inference. Retroduction, according to Meyer and Lunnay (2013), builds on the premise that we must go beyond as well as question the a priori theoretical frameworks we draw on. For Danermark et al. (1997) retroduction involves asking questions about the conditions of existence of a certain social phenomena; when being interested in a specific phenomena (x), a researcher needs to ask what the conditions are under which x occurs or exists and what it is that makes x possible. In asking these questions, the researcher moves between theory and data, involving in a dialogue between theoretical ideas and empirical evidence (Meyer and Lunnay, 2013). In retroductively explaining a certain social phenomena and its conditions of existence, researchers try to 'fit' different theories and theoretical models (Glynos & Howarth, 2007). For Glynos and Howarth (2007), a retroductive approach is problem-oriented. It starts from a problematised phenomenon that demands for thought and (further) theorisation and involves the process of assembling an explanation that makes the phenomenon under analysis intelligible. The retroductive process, in the words of Glynos and Howarth (2007: 34), "*involves a to-and fro movement between the phenomena investigated and the various explanations that are proffered*".

4. The theory-supported iterative research strategy in practice: the method of articulation

The research reported in this dissertation involves a continuous movement back and forth between the different concepts of the theoretical framework and the analysis of the media representations and audiences' receptions of these representations. While the narrative logic and structure of this text might suggest otherwise, iteration is inherently part of the research process – and it is therefore necessary to be transparent about how the research process actually takes place. The iterative practice inherent to the research process assures that the epistemology, the ontology, the research questions, the theoretical concepts, the analysis and the conclusion form a "*complete package*" (Jørgensen & Phillips 2002: 3-4). The research strategy followed in order to arrive at such a complete package can be described in terms of a "method of articulation" (Glynos & Howarth, 2007: 201-208) that articulates all the elements of the research named above into a coherent whole. How this is done in practical and concrete terms is explained below.

The iterative research strategy consists of different rounds of literature review and theory development and analysis, and can best be described in terms of retroduction/ abduction. A good way of visualising the iterative research process is in the form of a spiral, where different rounds of analysis and theory-development inform one another. This way of visualising allows grasping the way we passed via the same point during the different research phases with new or adjusted information that was iteratively arrived at.

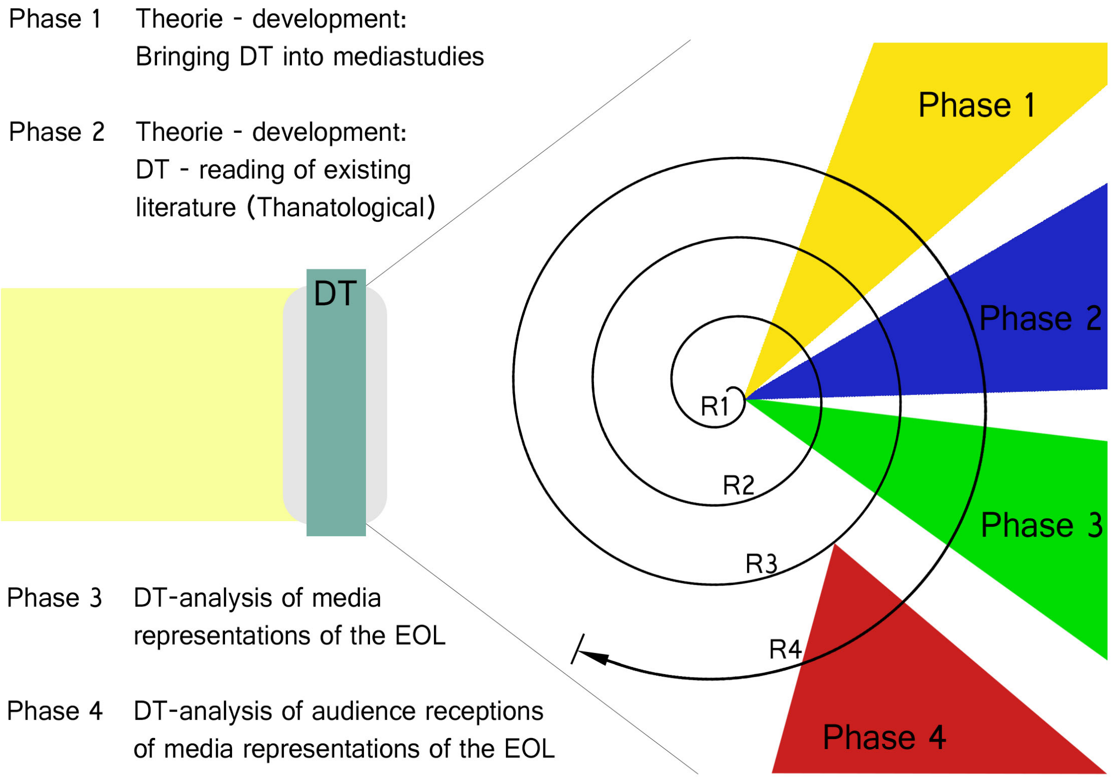

Figure 3: The iterative research process.

As mentioned earlier, this entire research is conducted through the lens of discourse theory. The discourse theory of Laclau and Mouffe operates as the theoretical framework underlying the entire research (see chapter II of this part) – a choice that is informed by the basic interests of this research; i.e. to study the social construction of death and of the master signifier of the good death within a sphere of an ongoing struggle for (hegemonic) meaning, embedded within dynamics of fixity and fluidity. The discourse-theoretical framework is relatively 'stable', in the sense that it provides a lens through which the phenomenon under study, i.e. media representations of the end-of-life and audiences' receptions of these representations, is approached. The discourse theory of Laclau and Mouffe is not entirely part of the iteration as it operates in fact as a *meta*-theoretical approach. At the same time, it is true that bringing media studies into discourse theory urges us to theorise media representation and media reception from a discourse-theoretical point of view, which is done through the notions of operationalisation and identification. These notions, in turn, are brought to the surface during the discourse-theoretical analysis of both media representations of the end of life and audiences receptions of these representations. Bringing media studies into discourse theory also adds to discourse theory itself and contributes to the development of discourse-theoretical analysis. In this way, then, discourse theory *is* part of the iteration. The visualisation given above indeed makes clear that the iterative research process consists of a four research phases that iteratively inform one another, and that a first phase consists of the theoretical development of the notions of operationalisation and identification and should be seen in the context of bringing discourse theory into media studies.

A second phase of which the iterative research process consists is the development of a theoretical framework, which comes about through a discourse-theoretical re-interpretation of existing literature produced mainly (although not exclusively) in the domain of thanatology. The aim of this theoretical framework is to make that what is empirically observed in the analysed texts intelligible. In dialogue with and informed by what is observed in the empirical material (phases three and four), the theoretical framework is adjusted throughout the research process. How theory (phase two) and data (phases three and four) inform another is explained below.

The theoretical starting point of the analysis is found in the 'death-denial' thesis, echoed by several authors amongst which the historian Phillipe Ariès. Before becoming potentially useful for the discourse-theoretical analysis, the death-denial concept, and this goes for all the theoretical concepts used in this thesis, is thus interpreted in a DT way or, it other words, interpreted from a discourse-theoretical perspective. After translating the death-denial thesis into DT terms, i.e. by approaching it as a discourse with a series of nodal points, it can be adopted as a lens to look at the selected media items about end-of-life decision-making. What is found, however, cannot – or at least not entirely – be rendered intelligible with reference to the death-denial concept. A careful reading of the data draws attention to the way many of the articles on end-of-life decision making draw on implicit assumptions about what it means to die well (e.g. the importance quality of life, of participating in the organisation of the own dying process, the importance of enjoyment), which in turn points in the direction of the theoretical notion of the 'good death'. This concept serves as a master signifier throughout the entire thesis. With this master signifier in mind, the media articles are further analysed, looking for other key signifiers in the articulation of the good death. Theoretically, then, these concepts, including autonomy and dignity (and a number of lower-level abstraction concepts) are developed in discourse-theoretical terms, where they are defined as nodal points of a late modern articulation of the good death. In similar vein, an iteration between theory-development and empirical analysis draws attention to competing visions on the good death – which results in a discourse-theoretical identification of an hospice articulation and a right to die articulation of the good death. A discourse-theoretical perspective sheds light on the discursive struggle in which both political projects are engaged as well as on the way this struggle is actualised in the analysed media articles.

Also the DT-reception analysis (part four) is part of the iterative research strategy. It makes its entrance at a later point in time, however, because a research of audience receptions of media representations can only be launched once it is clear what these representations are. The majority of the audiences' responses fit the existing theoretical framework and can thus be linked to the theoretical concepts of autonomy and dignity. At the same time, it is shown that in talking about the end of life and media representations of the end of life, audiences not only identify with discourses on the good death (developed in the theoretical framework), but also with particular normative stances about the visibility and representation of death in the media. This demands for an extension of the theoretical framework through a DT-reading of existing literature about death in the media, and also informs a final round of analysing the selected media articles; looking for reflections about the role of media in representing the end of life in media representations themselves. In short, the reception analysis demands for another round of theory development and representation analysis.

5. Quality in qualitative research

In the elaboration above, I have made explicit the epistemological foundations of the dissertation and I have explained how the (epistemological) principle of a theory-supported interpretative research is put into practice in the case at hand. One of the reasons I have done these things is to enhance the transparency of the research process, which is an important aspect that adds to the quality of the research. On the pages below, I will further elaborate on quality in qualitative research with its different dimensions. A number of quality criteria can be linked to the epistemological discussion above, but at the same time transcend this discussion, as indeed *"a retreat into epistemology or in other words the tendency to reduce disagreements over the value of arguments to philosophical disagreements and positional conflicts"* (Barker, 2003: 333) needs to be avoided.

The traditional notions in assessing quality, reliability and validity, originate in the positivist paradigm. It goes without saying that they cannot merely be transferred to the qualitative-interpretative paradigm. Indeed, unlike quantitative research, qualitative research does not envisage showing (statistical) associations of cause and effect, but instead focuses on meaning and aims at describing or illuminating social phenomena and human experiences (Fade, 2003: 140). While without quantification, reliability and validity cannot actually be measured, they can nevertheless, with the aid of *"a new language"* (Fade, 2003), be translated into sets of more suitable criteria for the evaluation of the quality of qualitative research (Barker, 2003; Seale, 1999).

Traditionally, reliability refers to "*the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions*" (Silverman, 2001: 225). Given the interpretative nature of qualitative research, observations of two or more observers might be different. Moreover, considering the iterative nature of qualitative research, stability of categories and categorisation throughout the research process is impossible and undesirable. In qualitative research, striving for reliability is above all a matter of credibility, which refers to a number of criteria: scientificity, reflexivity and transparency.

In order to meet the criterion of scientificity, first, the research needs to be methodological. This implies that systematic analytical procedures need to become integrated into the methodological frame of qualitative-interpretative research of which openness and iteration are so typical. In this context, Jorgensen and Phillips (2002) point to the obligation of the researcher to follow a certain set of rules as systematically as possible. This adds to the scientific quality of the research as it allows producing knowledge that is normally not produced within other forms of discursive practice (like everyday knowledge). In other words, it is by working in a methodological systematic way that scientific knowledge distinguishes itself from other types of knowledge. Working in a systematic way allows the researcher to cope with the observation that they are producing knowledge and representations of the culture they are themselves part of and with which they share many understandings. Moreover, it counterbalances the possibility of a pessimistic reading of qualitative-interpretative research stating that this type of research provides *"just one among many* *other possible stories about reality"* (Jorgensen & Phillips, 2002: 176). To the end of meeting the criterion of scientificity, this research is conducted in a methodologically systematic way, which above all applies to the empirical research – where the DTA follows the principles of qualitative content analysis.

Second, being reflexive about the research and the own role as a researcher in the research process further enhances credibility. This reflexivity is situated at every level of the research, beginning with the elaborations presented here about the epistemological foundations of the research. These reflections will be complemented later on in the dissertation (see part C) and are shared with the reader, which is evidently crucial in the light of transparency. Transparency also applies to decisions regarding the sampling process and the development of the categories that guide the analysis, which is why the sampling process of the DT content analysis and the DT reception analysis are discussed in detail in parts D and E of the dissertation. Transparency also implies access to the data that have been analysed, which is why all data (media articles, spss data files, interviews, transcriptions but also informed consents, information letters etc.) can be obtained from the researcher and can be found on the attached usb-stick.

Validity refers to the *"extent to which an account accurately represents the social phenomena to which it refers"* (Krippendorff, 2004: 313; Lindlof, 1995: 237). Within the framework of qualitative-interpretative research, the concept of validity above all relates to the extent to which a research actually formulates answers to its research question. Two main criteria for validity within qualitative-interpretative research can be determined. First, the research has to be fruitful, which means that it needs to further and deepen insights into (Howarth, 2000: 141; Silverman, 2001: 222), and generate new scientific explanations about, the phenomenon under study (Jorgensen & Phillips, 2002: 172-173). A discourse-theoretical approach to death and dying, as became clear in the introduction, is rather innovative. In order to ascertain that this discourse-theoretical approach can provide insights that would not have been possible without this framework, the analysis needs to be based on a clearly developed theoretical framework (see part B) and a well thought-out methodology (see part C). Both the theoretical framework and the methodological framework, indeed, allow for the analysis to surpass a *"kind of retelling of the materials themselves"* (Barker, 2003: 331). This brings us to another criterion of validity; the research has to be coherent. This means that the epistemology, ontology, the research questions, the theoretical concepts, the methods, the analysis and the conclusions are not dis-connected from one another. In has been explained earlier in this chapter how a research strategy of articulation needs to ascertain the connection between the different elements of the research named above.

In addition to these two main dimensions of validity, there are a number of other criteria that enhance validity on the level of the analysis of empirical material; these include solidity, comprehensiveness, and integrity. To these criteria, saturation can be added as a technique that furthers the validity of the analysis (see parts D and E).

Chapter II: Discourse theory

The previous chapter revealed the *epistemological premises* that underlie the iterative and theory-supported logic inherent to the research process (which was also discussed in concrete and practical terms, shedding light on how the research process actually occurred). In this chapter, I set fort the *ontological foundations* of the thesis by presenting the discourse theory of Laclau and Mouffe as the theoretical perspective adopted throughout this entire research. As mentioned earlier, the discourse theory of Laclau and Mouffe is deployed to construct a theoretical framework shedding light on discourses on death and the good death and to conduct an empirical analysis of media representations of the end of life and audiences' receptions of these representations. It is therefore absolutely crucial to make very clear what exactly a 'discourse-theoretical perspective' implies; i.e. on what (ontological) premises it builds and how it is to be distinguished from other discursive approaches.

1. Defining 'discourse'

The notion of discourse takes up a variety of meanings and is deployed in a wide array of theoretical and analytical disciplines – amongst which linguistics, literature, and political theory. Often, the term is left undefined or is defined in very vague terms as it is used. It comes as no surprise that the concept is therefore often accused of being noting but an empty rhetoric. It indeed often seems that "*anything at any level can be discourse*" (Jorgensen & Phillips, 2002: 143). The reason for this vagueness relates to the very complexness of discourse as a concept that spans a rich variety of possible definitions:

> "Samples of spoken dialogue, in contrast with written text', 'spoken and written language', 'situational context of language usage, 'interaction between reader, writer and text, 'notion of genre'" (Fairclough, 1992: 3).

The way the concept of discourse is used in a research project depends on the social reality the researcher wishes to examine; the social problem under investigation. In this sense, 'discourse' is above all an analytic concept that helps the researcher comprehend and interpret that part of reality under investigation, rather than something that merely exists 'out there'. In other words, 'discourse' shapes the lens through which the researcher looks at social reality. The purpose of this research to study the meaning of the good death and its articulation in media representations and audiences' receptions of these representations entails a privileging of a certain approach to discourse; one that is different from a discourse-analytical and socio-linguistic engagements with the often detailed linguistic analysis of written or spoken language. The discourse-analytical and socio-linguistic approaches to discourse are close to what Jorgensen and Phillips (2002: 62) call 'discourse-as-language'. A more fruitful approach to discourse in light of this research' interest in deep-rooted structures of meaning underlying the concept of the 'good death' can be found in the discourse theory of Laclau and Mouffe (1985), which indeed brings in a specific definition of discourse. Rather than regarding discourse *"merely as a linguistic region within a wider social realm",* Laclau and Mouffe offer a broader conceptualisation of discourse that *"insists on the interweaving of semantic aspects of language with the pragmatic aspects of actions, movements and objects"* (Torfing, 1999: 94). This broad definition of discourse can be described as discourse-as-representation or discourse-as-ideology (Carpentier & De Cleen, 2007: 277). The notion of the "big-D Discourse" offers another way to position Laclau and Mouffe's approach; in contrast to the little-d discourse or a language-in-use definition of discourse, it refers to *"different ways of thinking, acting, interacting, valuing, feeling, believing, and using symbols, tools, and objects in the right places and at the right times*" (Gee, 1999: 13). At the same time, Laclau and Mouffe's discourse theory is specific, given its post-structuralist ontology and its use of particular concepts to describe the mechanisms of discourse.

2. The discourse theory of Laclau and Mouffe

On the pages that follow, I will set out Laclau and Mouffe's discourse theory in more detail. I will do so by elaborating on the notion of discourse at two different levels of abstraction – distinguishing between 'the discursive' as an ontological category, and 'discourses' as contingent and relational systems of meaning. Discourse as an ontological category refers to the discursive totality in which different discourses give meaning to reality. At this more abstract level, discourse (the discursive) refers to an approach to social reality *as* a discursive practice. Second, and at a more concrete level, discourses refers to historically specific systems of meaning. Discourses on death and dying should be understood at this more concrete level of abstraction because they "*gather around an object, person, social group or event of interest providing a means of 'making sense' of that person, object, and so on*"(Lupton, 2010: 2).

2.1. The discursive

The basic (ontological) starting point of Laclau and Mouffe's discourse theory is the assumption that all social phenomena are made meaningful within a 'discursive' reality in which all objects, subjects, practices, organisation and so forth derive their identity through socially constructed and contingent relationships of meaning (Howarth, 2000:8-9, Howarth & Stavrakakis, 2000: 2-3). To understand discourse at this highest level of abstraction, it is crucial to elaborate on the poststructuralist ontology in which Laclau and Mouffe's discourse theory is grounded. The ontology of Laclau and Mouffe's discourse theory indeed has close ties with the work of Michel Foucault and Jacques Derrida, who are generally considered founding fathers of post-structuralism.

2.1.1 The post-structuralism of Foucault and Derrida

Foucault's discourse theory offers a response to two closely intertwined approaches to discourse: the foundational approach and the essentialist approach. A foundational approach argues that social phenomena have ultimate foundations - such as the desire to survive or the will of God - whilst an essentialist approach claims that social phenomena have tightly fixed characteristics. Unlike both foundational and essentialist approaches, the work of Foucault is directed towards the de-essentialisation of both taken-for-granted practices and their origins. It is concerned, more specifically, with the discursive conditions and the conditions of their realisation, posing questions as to what can be said, how it can be said, by who and from what position (Dreyfus & Rabinow, 1983: 47, 123; Torfing, 2005: 158). Foucault is more specifically interested in the 'archives' or roots of particular (groups of) statements (1992: 129), the latter referring to the smallest or 'basic' units of discourse. Archives - the *"body of formulated statements"* (Andersen, 2003: 8), function as discursive frameworks or formations that set the remits within which meaning can be negotiated (Mills, 2004: 16) and through which statements become dispersed (Andersen, 2003: 8). With his archaeological method, Foucault (L'Archéology du savoir, 1969) tries to expose the archives that organise the taken for granted in a particular society (McHoul & Grace, 1993: 40; Howarth, 1998: 286). Archaeology aims at discovering and describing the discursive roles that produce objects, subjects and so forth, and in the end at developing a general theory of such production (Dreyfus & Rabinow, 1983: 98). The, perhaps rather utopian, aim of archaeological discourse analysis is to "*read everything, study everything*", until having *"at one's disposal the general archive of a period at a given moment"* (Foucault, 1998: 263). As the archaeological method has been criticised for its merely descriptive nature, for *"avoiding a claim to truth or seriousness"* (Dreyfus & Rabinos, 1983: 98), and for its lack of critical interpretation (Howarth, 1998: 286), Foucault developed a second, more critical and interpretative method: the genealogical method. With his genealogical writings, Foucault concentrates on the political en historical construction of objectivity (Torfing, 2005: 7). An archaeological analysis has an explicit political goal: to disrupt the taken-for-grandness of the present and to show how things could be different (Buntun & Petersen: 4). It is thus not the aim of Foucault to confirm an existing reality, but rather to – after having shown the eventuality of reality - criticise and contest this reality

(McHoul & Grace, 1993: 40; Howarth, 1998: 286).

Similar to Foucault's focus on objectivity as politically and historically constructed, Jacques Derrida rejects the existence of essentialist entities when he opposes the 'metaphysics of presence'. Derrida radically opposes the idea of universal meanings that pre-exist human thought whilst equally rejecting the assumption of fixed and non-contingent entities. More concretely, Derrida (1978) delegitimises the idea of a transcendental centre that is given by itself, structuring the entire structure while itself escaping the logics of structuration. In the absence of a transcendental centre, accourding to Derrida (1978: 280), *"everything becomes discourse"*, which he defines as a system of differences where *"the play of signification extends infinitely due to the absence of a transcendental signified"* (Torfing, 2005: 40). Discarding the idea of a determining centre, Derrida concludes that social identities are no longer fixed, but that their meanings depend on a multitude of limited and provisional centres (Torfing, 2005: 8). By means of his well-known deconstructivism, Derrida aims at showing the impossibility of essential entities. It is the aim of deconstructionism "*to take apart, to undo, in order to seek out and display the assumptions of a text*". More concretely, "*it involves the dismantling of hierarchical binary oppositions such as speech/writing, reality/appearance, nature/culture, reason/madness etc. that are said to guarantee truth trough excluding and devaluing the 'inferior' part of the binary"* (Barker & Galasinski, 2001: 10). Derrida has above all focussed on the binary oppositions within Western philosophy. For this reason, his attention was mainly drawn to metaphysical texts. Using deconstruction, Derrida demonstrated the way entities derive their meaning in relation to the other pillar of the binary opposition they are part of. Briefly, the identity of both pillars of the opposition is deconstructed in a mutual relation of exclusion[15].

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[15] Derrida's deconstructivism has been severely criticised for being merely formalistic. More importantly, it is often argued that Derrida lapses into a nihilistic way of thinking in which all meaning would be arbitrary (Barker & Galasinki, 2001: 11-12)

2.1.2 The ontology of Laclau and Mouffe's discourse theory

Having close ties with the ontologies of both Foucault and Derrida, the discourse-theory of Laclau and Mouffe can be labelled 'poststructuralist' in the sense that it holds that meaning can never be totally fixed, but is socially constructed and therefore contingent (Jorgensen & Phillips 2002: 25; Laclau, 1999: 334). The discourse-theory of Laclau and Mouffe is indeed characterised by an anti-essentialist ontology. Laclau and Mouffe argue that there is no pre-given, (self)-determining essence capable of structuring and fixing identities (Torfing, 2005: 13), be it God, reason, the desire to survive, or the laws of capitalism. In Laclau and Mouffe's discourse theory, the consequence of discarding the idea of a determining centre is not total chaos and flux, but rather a *"playful determination of social meanings and identities within a relational system"* (Torfing, 2005: 13). Below, a number of dimensions inherent to the post-structuralist ontology of Laclau and Mouffe are set forth.

2.1.2.1 Constructionism, realism and materialism

Similar to the work of Derrida, the discourse-theory of Laclau and Mouffe has encountered the critique of lapsing into an extreme relativism and an idealism (Geras, 1987: 65) that reduces the social to discourse. However, the discourse theory of Laclau and Mouffe, like a variety of other constructionist traditions, does not contest or deny the *"primal givenness of the cosmos"* (Reason & Bradbury, 2006: 7). Laclau and Mouffe present their discourse theory as both 'realist' and 'materialist'. The constructivism of Laclau and Mouffe is materialist in questioning the symmetry between the 'realist object' and the 'object of thought', rejecting both the essentialisation of the 'realist object' and the 'object of thought'. Instead, Laclau and Mouffe's non-idealist constructivism presupposes *"the incompleteness of both the given world and the subject that undertakes the construction of the 'object'"* (Torfing, 1999: 45-48). Laclau and Mouffe's constructionism is also materialist in that it assumes that discourses are not any less 'real' than the material world, as they indeed have 'real' impacts and exist 'for real' in our life world. Laclau and Mouffe's discourse theory is realist in the sense that it acknowledges a 'reality' that exists external to thought and interpretation and independently of any system of social relations. Glynos (2012) further explains how discourse theory has 'realist grounds' in that is deconstructs the separation between matter and meaning, thereby covering against the relativist reasoning that 'anything goes'. It is widely acknowledged in discursive reasoning, according to Glynos (2012), that we can only comprehend the material world trough our systems of meaning. The argument that some ways in which the material becomes embodied in discourse are more likely than others - for the very properties of the material constrain and enable our discursive interpretations in specific ways - has been echoed much less frequently. It is precisely this argument, however, that brings in a 'new materialist' point that although our world is discursively mediated, it is certainly not reducible to discourse (Glynos, 2012). Connolly (2002: 19) nicely illustrates this point with the example of anthracite:

> "True, anthracite, merely a black rock in some contexts, becomes a crucial energy resource in a different ideational setting. But the shift from rock to energy source is not only ideation. Try burning gravel in a potbellied stove to heat up your cabin".

2.1.2.2 Hegemony and Contingency

Crucial to Laclau and Mouffe's discourse theory is the idea that discourses have to be partially fixed, since the profusion of meaning would otherwise make any meaning impossible: *"a discourse incapable of generating any fixity of meaning is the discourse of the psychotic"* (Laclau and Mouffe, 1985: 112). At the same time, the stabilisation of discourses is temporary and never total, as discourses are engaged in permanent struggle, attempting to achieve, maintain or dislocate hegemonic positions. Here, Laclau and Mouffe build on the Gramscian notion of hegemony, referring to a collective wills produced through an intellectual and moral reform, the aim of which is to construct a new 'common sense' (Howarth, 2000; Howarth, 1998: 279-280) in which power relations are naturalised against which people can be mobilised to rebel. The Gramscian notion of hegemony also stresses the importance of the suprastructure in the creation of hegemony, thereby weakening the grip of economic determinism that is very much present in the Marxian notion of ideology.

In Hegemony and socialist strategy (2001, originally published in 1985), Laclau and Mouffe radicalise the (already contingent nature of the) Gramscian notion of hegemony. Starting from the idea that there is no objective structure underlying the social, Laclau and Mouffe's view on hegemony refers to the temporal crystallisation of meaning, which also implies the contingency of society and its development. This fixation results in the creation of a dominant 'horizon' that naturalises particular (systems of) meanings. Hence, any discursive organisation aims at becoming a horizon of interpretation that "*is not one among other objects but an absolute limit which structures a field of intelligibility and is thus the condition of possibility of the emergence of any object*" (Laclau 1990: 64). In describing such hegemonic formations, Laclau introduces the concept of the social imaginary, "*[which] is a myth in which the fullness of the surface of inscription continues to dominate*" (Torfing, 1999: 305). Successful hegemonic projects, then, establish new social orders (Howarth, 1998: 279) in which other possible meanings are forgotten and (temporary) disappear behind the horizon. Laclau uses the concept of ideology to draw attention to the totalising will of discourses (1990: 92). Despite this will to totality, however, and because of the fullness of the field of discrusivity and the inability of discourse to fix meaning permanently, discourses always remain receptive to disintegration, destabilisation and dislocation.

Laclau and Mouffe's poststructuralist ontology – their 'logic of the contingency' (1985: 7), brings us an important step closer to a definition of discourse at its most abstract level: the discursive as a relational, contingent and socially constructed structure in which meaning is constantly negotiated and struggled over. In this sense, the notion of 'the discursive' is more encompassing than the definition of discourse as a semiotic or linguistic dimension of the social (Fairclough, 2003, Jorgensen & Phillips, 2002). In

Laclau and Mouffe's discourse theory, the discursive is not (merely) a linguistic dimension, but a reality *"prior to the distinction between the linguistic and extralinguistic"* (Laclau 1999: 335). At the same time, Laclau and Mouffe's conception of the social as a *"web of processes in which meaning is created"* (Jorgensen & Phillips, 2002: 25) does show similarities to structural linguistic theories, which are mainly associated with the work of De Saussure and his idea that there *"are no positive terms in language, only differences"* (Laclau, 1999: 333).

2.2 Discourses

Whereas the notion 'discourse' at its most abstract level refers to a discursive reality in which meaning is constantly negotiated, 'discourse' at a more concrete level refers to the particular systems of meaning this discursive reality is made out of. Discourses as relational systems of signification (Torfing, 2005: 14) appear in different formations and function in different ways within different historical periods. On the pages below, I will zoom in on a number of concepts that are crucial to deepening our understanding of the logics of discourses.

2.2.1 Articulation, floating signifiers and nodal points

Central to the discourse theory of Laclau and Mouffe is the concept of articulation, as it is through the process of (re)articulation, indeed, that all meaning and identity emerges. In the attempt to fix meaning, discourses articulate a series of contingent signifying elements. Laclau and Mouffe define the notion of articulation as *"any practice establishing a relation among elements such that their identity is modified as a result of the articulatory practice"* (Laclau & Mouffe, 1985: 105). The result of this practice is the structured totality of the discourse that becomes hegemonic when it provides *"a credible principle upon which to read past, present, and future events, and capture people's hearts and minds"* (Torfing, 2005: 15). Crucial to the (hegemonic) attempts of discourses to fix meaning is the ambition to transform 'floating signifiers' into 'nodal points'. A floating signifier is defined in terms of being "*overflowed with meaning*" (Torfing, 1999: 301). This implies that floating signifiers can have different meanings in different discursive contexts. These floating signifiers are the subject of hegemonic forces and discursive struggles; different discursive projects try to ascribe a particular meaning to these signifiers and at the same time try to fix this meaning. The aim is to create 'nodal points'. A discourse, Laclau and Mouffe argue, is constructed by the partial fixation of meaning around certain *nodal points.* This concept should be understood in analogy with the Lacanian notion of *points de caption;* privileged sings around which other signs are structured (Jorgensen & Phillips, 2002: 26).

Nodal points, themselves constructed trough articulation, bind a discourse together (Howarth, 2000: 118). Every unfixed 'element' is thereby transformed into a fixed 'moment'. This transformation comes about through a reduction of possibilities; that is, by the exclusion of all other meanings a sign could possibly obtain. All these other possibilities that a discourse excludes, is what Laclau and Mouffe call "*the field of discursivity*" (Jorgensen & Phillips, 2002: 27). Even though nodal points occupy a central place in a discourse and sustain its identity by "*constructing a knot of definite meanings*," (Torfing 1999: 88-89), nodal points are not more saturated with meaning than another signifier. Quite on the contrary, because nodal points are characterised by a certain emptying out of meaning, which is exactly what accounts for their structural role in the unification of discourse[16].

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[16] In his later work, Laclau has further developed his model by introducing the category of the *empty signifier.* This notion points to the structural impossibility of signification as such (Laclau, 1996: 37). Laclau and Mouffe elaborate the notion of the empty signifier using the Hobbesian example of the state of nature as a condition of radical social disorder:

> *"In a situation of radical disorder 'order' is present as that which is absent; it becomes an empty signifier, as the signifier of that absence. In this sense, various political forces can compete in their efforts to present their particular objectives as those which carry out the filling of that lack. To hegemonise something is exactly carry out this filling function."(Laclau & Mouffe,1985: 167).*

2.2.2 Identities and subject positions

Partial fixation and closure of meaning, according to Laclau and Mouffe's discourse theory, is both inevitable and necessary: without temporal and partial closures, no meaning whatsoever would be possible (Howarth, 2000: 117-119). At the same time, a discourse can never be totally stable and fixed because it depends for its coherence and constitution on the exclusion of an 'other', which makes the excluded in fact constitutive (Howarth, 2000: 103). The concept of the constitutive outside draws attention to the way an identity is made meaningful in relation to other identities and to the way these other identities are constitutive of that identity[17] (Laclau 1990: 33; Mouffe 2000: 147). In a very similar fashion, and inspired by Laclau and Mouffe, Hall (1996: 3) writes:

> "Above all, and contrary to the form in which they are constantly invoked, identities are constructed through, not outside, difference. This entails the radically disturbing recognition that is only through the relation to the Other, the relation to what it is not, to precisely what it lacks, to what has been called its constitutive outside that the 'positive' meaning of any term – and thus its 'identity' – can be constructed."

Arguably, all identities are in a way always instable and even 'failed' (Glynos & Howarth, 2008; Howarth 2000: 106; Laclau & Mouffe 2001: 125). Because of the constitutive outside, the 'other' is always present and prevents the full closure of any identity (Torfing 2005: 16).

The notion of empty signifier, then, points to the fact that total fullness of society is unachievable. Nevertheless, this fullness functions as an impossible ideal. Societies are thus organised on the basis of this ideal. It is precisely for the function of these ideals that the production of empty signifiers is necessary (Howarth, 2000: 8).

[17] Laclau and Mouffe borrow the term 'constitutive outside' from Derrida (Laclau, 1990: 33).

For discursive elements that relate to the subject, Laclau and Mouffe use the specific notion the subject position rather than the notion of identity. The notion of the subject position refers to the way subjects are positioned within a discursive structure (Laclau and Mouffe, 1985: 115):

> "Whenever we use the category of 'subject' in this text, we will do so in the sense of 'subject positions' within a discursive structure. Subjects cannot, therefore, be the origin of social relations - not even in the limited sense of being endowed with powers that render an experience possible - as all 'experience' depends on precise discursive conditions of possibility" (Laclau & Mouffe, 1985: 115).

Laclau and Mouffe remark that one should speak about an 'ensemble of subject positions' within discourses (Isin & Wood, 1999: 10); a subject is likely to be positioned in several ways (Howarth, 2000). A result of this multiplicity of subject positions is that excising identifications are always incomplete and (partially) undermined by other identities. This *"logic of the subvertion of the rationality of the determinate"* is what Laclau (with Zac) (1994: 16) calls overdetermination. Laclau borrowed the concept of determination from Althusser, who uses the concept over-determination to argue that there is no possibility of reaching full saturation in meaning. Unlike Althusser, who strongly reduces the autonomy of social agents to the mere effects of economic structures, Laclau and Mouffe state that when dislocation occurs, the subject requires the possibility to act, to renew its subjectivity and to form new identities. Dislocation, then, refers to the (political) processes by which the contingency of discursive structures is brought to the surface and existing identities and discourses are disrupted (Howarth, 2000: 109). It is with the concept of dislocation that the discourse theory of Laclau and Mouffe takes position in the structure-agency debates, allowing discourse theorists to *"sketch a moment away from the idea of subjectivity as simply a certain position within a discourse"* (Glynos & Howarth, 2008: 162). Take the following quote from Laclau (1990: 60), where he explains that "t*he opposition between a society that is completely determined in structural terms and another that is entirely the creation of social agents is not an opposition* *between different conceptions of the social, but is inscribed in social reality itself"*. The complex dialectic between structure and agency follows from the fact that the subject exists because of dislocations in the structure. Glynos and Howart (2008: 162) pick up on this point, arguing that subjects become active political subjects precisely when they can no longer go on in their normal and routinised fashion. In suchlike situations, they go on to argue, subjects are urged to identify with new discourses and subject positions in order to fill the lack brought to the surface through dislocatory events.

Chapter III: Discourse theory and media studies

The discourse theory of Laclau and Mouffe is in origins a political theory, and has largely remained within the confines of political research (Carpentier and Spinoy, 2008: 2). If we approach Laclau and Mouffe's discourse theory as a way to look at social and political realities, rather than as a theory inherent to one specific discipline or applicable to one specific field of social inquiry, discourse theory can be applied to conduct research into meanings in a variety of fields, including the field of media studies. Bringing discourse theory into media studies is largely a matter of injecting a discourse-theoretical dimension into the various moments in the meaning-making circuit of mass media. An early attempt to look at the meaning-making circuit of mass media from a discourse-theoretical perspective is provided by Torfing (1999: 210-224), who criticises the classical sender-receiver model from a discourse-theoretical point of view. Torfing identified three ways in which discourse theory can be put to work in the field of media studies (see also Carpentier & De Cleen, 2007: 274). First, there are the *discourses about mass media*; political and/or theoretical considerations about the function of mass media in society. Second, there are the *discourses operationalised in mass media*; the contents produced by various kinds of media. Third, there is the approach of *mass media as discourse*, where the institutional forms of production, distribution and consumption, as well as political regulations of mass media and economic forms of ownership and control are taken into account.

This dissertation focuses on two moments in the meaning-making circuit of mass media; the contents produced by mass media (i.e. the mass media representations), where discourses become operationalised, and audiences' receptions of these contents, where individuals allocate meaning to media representations and thereby identify with more encompassing discourses. Interpreting the circulation of meaning within the circuit of mass media from a discourse-theoretical perspective points in the direction of three *signification or meaning-making flows*. These flows are visualised in the following figure:

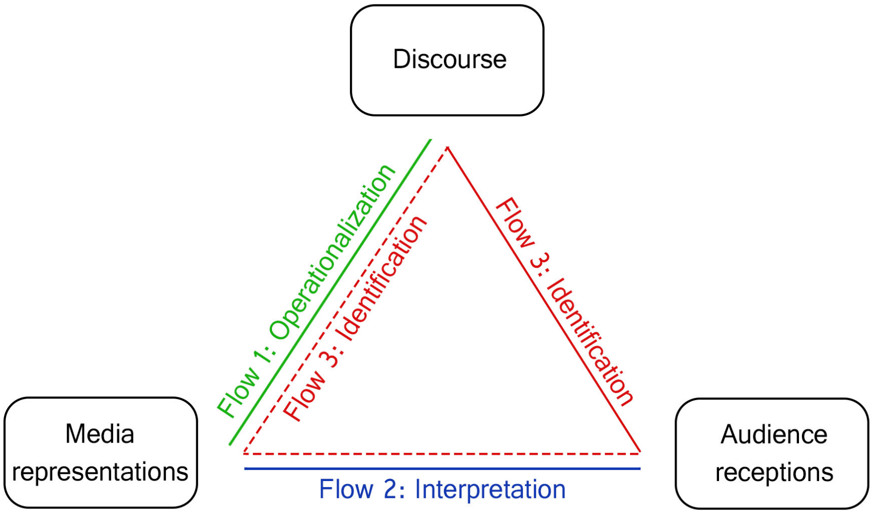

Figure 4: Flows of meaning-making in the circuit of mass media.

First, there is the *operationalisation flow* (green line) that connects discourses to media contents; referring to the way discourses circulating in the social are imported and materialised in media representations. The *interpretation flow* (blue line), second, refers to audiences' practices of allocating meaning to these representations. And the third flow, the *identification flow* (red line), brings a discourse-theoretical dimension to the relation between the media text and the moment of reception, referring to the way audiences identify (or dis-identify) with more encompassing discourses during the (discursive) practice of media reception. Identification often goes 'via' the media text (red hatched line) during the process of interpreting media representations, when audiences (dis-)identify with discourses operationalised in media texts. During the moment of reception, audiences sometimes move far away from the media text, and identification then (at least to certain extents) becomes a process that occurs 'unmediated' by the media text.

On the pages that follow, I elaborate on the three meaning-making flows (operationalisation, interpretation, and identification) in more detail.

1. The operationalisation of discourses in media representations

Media operate as 'discursive machineries'; discourses are imported into the contents produced by mass media, where they are operationalised in specific ways. Media messages contain very specific 'material traces' (McKee, 2003: 15) of discourses. The notion of materiality, it should be noted here, refers to ways in which discourses are made 'visible and tangible'. In order to come to a discourse-theoretical understanding of the way discourses are operationalised in media messages, we must turn our attention to two key issues: the discursive/hegemonic working of media contents and the 'mechanisms of representations' inherent to mass media.

1.1 The discursive/hegemonic working of media representations

It is widely acknowledged in the field of cultural studies, discourse studies and critical theory that mass media serve as powerful socialising agents, bringing into circulation sets of dominant values, beliefs and norms (Croteau & Hoynes, 2014). Stuart Hall (1982), the leading voice of British cultural studies, has analysed the hegemonic working of mass media and concluded that mass media are one of society's key arenas where the work of hegemony is exercised and performed. Mass media bring representations of the social reality in which they operate into circulation and are thereby involved in the 'politics of signification'; referring to the way media (re-)produce meaning and particular definitions of reality. As he (1997: 25) puts it:

> "representation is a very different notion from that of reflection. It implies the active work of selecting and presenting, of structuring and shaping; not merely

> the transmitting of an already-existing meaning, but the ore active labour of making things mean".

In presenting certain ideas as the 'truth', media messages marginalise, deny or dismiss competing truth claims. Mainstream media tend to bring into circulation the dominant belief systems by drawing on common-sense assumptions about the world (Croteau & Hoynes, 2014: 161). Inspired by the discourse theory of Laclau and Mouffe, we may argue that media, being engaged in the operationalisation of discourses, (potentially) contribute to the formation of a 'social imaginary'. Media are sites where struggles over meaning sometimes fiercely take place, where resistance towards the hegemonic is articulated and where meaning is negotiated. They are one of the domains where we can witness discourses attempting to transform floating signifiers into nodal points. The way dominant (and/or alternative) discourses appear in media content is – at least generally - not the result of media-makers and media professionals consciously wanting to impose their value- and belief systems on audiences (Croteau & Hoynes, 2014: 157). Indeed, though media makers, like all of us, 'knit along' in the production of discourse (Jager, 2001), no individual media-maker or group of media-makers 'determines' the systems of meaning that are operationalised in media contents. This, however, does not mean that the agency of media-makers is denied; it is indeed through the agency of the media-maker (which is of course always embedded in a particular context, where a variety of other (economic, sociologic, and cultural) factors play a role too) that discourses are imported into media contents. Discourses are always, as explained earlier, mediated by human agency. This agency is best conceptualised in terms of a media professional drawing on and deploying discourses that are available in society; discourses that – mediated by the agency of the media professional – become operationalised in the media text[18].

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[18] This is why I choose not to draw a one-direction arrow from the level of the discourse to the level of the media text, for the process of operationalisation is bi-directional and involves human agency.

1.2. Media-specific mechanisms of representations

The way discourses are opertionalised in the media text is specific, and occurs on the basis of particular and media-specific 'mechanisms of representation'. *Media-specific*, indeed, because while media are often not the *origins* of discourses or of discursive struggle, they are specific and can be described as discursive machineries with their own and specific rules and logics. There are of course many media-specific mechanisms that result in a particular way of operationalising discourses, linked to a variety of factors (e.g. the nature of news sources, journalistic routines, market logics and so forth). Below, I highlight those mechanisms of representation that are particularly relevant to this research and its focus on the representation of the medicalised end of life.

A first key aspect that marks the operationalisation of discourses in media contents is mass media's privileging of the conflictual over the consensual. Consequentially, social issues that are deeply embedded in conflict are likely to become covered more extensively. The media's privileging of conflict, moreover, often makes that debates on social issues are debated in rather polarised terms (Croteau and Hoynes, 2014: 155). This can work in a restrictive way, reducing and simplifying complexity, but also in a mobilising way. Media messages indeed have the potential of facilitating and encouraging the dislocation of particular discursive regimes, thereby opening the floor for (political) agency – precisely because they emphasise conflict and encourage audiences to choose sides. Media might also be one of the domains where novice dislocation becomes rapidly visible, precisely because of the media's preference for conflict.

Related to the privileging of the conflictual over the consensus is a preference of mass media for covering events rather than processes, which goes back to media's tendency to narrate events in a simplified way, with a limited number of actors involved with whom audiences can easily identify and dis-identify[19] (e.g. the hero, the villain, the victim etc.) (Jewkes, 2015; Liebes, 1994, see also Seale, 2003 and McInerney, 2006). This, in turn, cannot be seen in isolation from the tendency of media (and particularly of popular and human interest media) to *stage* events in an attractive way; making a particular event – like dying – into a (staged) performance with a certain illusion of reality, causing people to often perceive media as a privileged access to reality. Here, Couldry's concept of 'the myth of the mediated centre' (2005) is particularly relevant, as it refers to the belief that what is 'really' going on can be accessed and observed *"through a door marked 'media'"* (Couldry, 2009: 440).

Related to the above is yet another media-specific mechanism of representation that contributes to a specific politics of operationalisation; the tendency to personalise stories. From a discourse-theoretical point of view, it can be argued that personification - referring to the privileging of a personal entry-point over a political, ethical or medical one - offers audiences a diversity of subject positions to identify with. While stories with non-personal entry points of course also construct particular subject positions, personalised story-telling often allows for the (re-)production of subject positions (such as the terminally ill patient) that 'speak to the heart' and with which audiences can easily identity or dis-identify. Media stories with a personalised entry-point not rarely go hand in hand with a focus on aspects of people's private lives – as is often the case in coverage on the end of life and end-of-life decision making. This emphasis on the private sphere has been described as a trend towards intimisation (Dalghren et al 1992; Stanyer, 2013; Van Zoonen, 1997).

Personal entry-points and a focus on the intimate and the private are key features of so-called new journalism (Wolfe, 1973) and human-interest journalism (Harrington, 1997, Meijer, 2001); two alternative journalistic projects embracing subjectivity, authenticity, and 'getting inside the story' (Carpentier, 2005; Van Zoonen, 1997). Typical for new journalism and human-interest journalism is the way they strongly

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[19] Scholar have especially pointed out media's tendency to simplify in covering crime.

rely on literary techniques of narration, such as scene-by-scene reconstruction; the use of dialogue in full, the use of a third-person point of view etc. (Fishwick, 1975; Schudson, 1978) The use of 'narratives' is not restricted to new journalism and human-interest journalism. A narrative, indeed, can be seen as a cultural code of story-telling relying on elements such as progressive sequence and binary oppositions. Also 'hard news', then, relies on narratives, albeit on less 'developed' narratives constituted for instance by a three-part structure: setting, event, and outcome (Richardson, 2007). In the context of the media message, the narrative can be seen as a particular discursive device. The idea of narratives as 'carriers' of discourses is assumed by Richardson (2007: 34) who holds that media narratives tend to reflect broader and more general cultural assumptions on the important, the trivial, the tragic, the good, the evil etc. That is not to say, however, that 'any discourse' fits 'any narrative'. The content of a concrete narrative can indeed not be separated from its form. As Laclau suggests, content and form mediate each other, hence, *"it is impossible conceptually to grasp form independently from content"* (2000: 64). Arguably, the form of the media-narrative and the content of the media-narrative do not exist independently from one another. Rather, the form of the media-narrative - for instance the mode of telling a story with a high emphasis on conflict, or with a focus on the personal sphere of those involved – facilitates the importation of certain systems of meaning while impeding the importation of others. Media narratives, then, are not 'neutral' externalisations of discourses; they put discourses to work in specific ways.

2. Interpreting media representations

Media representations are read by audiences, who interpret these messages and thereby allocate meaning to them. The notion of interpretation finds its origins in the field of cultural studies, where it is used to study the way audiences actively construct the meaning of media messages – thus assuming textual 'openness' and the possibility of multiple meanings or polysemy. In what follows, I start from the cultural studies framework on media reception and (re-)interpret this framework from a DT point of view.

The idea of an active audience arose in response to the notion of an all-encompassing ideological domination, finding its origins with the Althusserian focus on the ideological messages in media contents and the perception that the media text is the ultimate location of meaning. It is only since the 1980's, when cultural studies (alongside feminism) introduced an interest "*the personal as political*" (Stokes, 2005: 132), that the idea that the meaning of texts is created through audiences' reading and interpretation practices started to emerge. In the framework of the cultural studies tradition, the process of interpretation can be defined as:

> "the process whereby media messages come to mean something to us; it is how we derive pleasure, comfort, excitement, or a wide range of intellectual or emotional stimulation." (Croteau & Hoynes, 2013: 262).

According to Birmingham School theorists such as Stuart Hall and David Morley, media reception is always a site of potentially different interpretations of the same media representations (Moores, 1993). Cultural studies scholars use the term of polysemy, 'many meanings', to describe the idea of multiple meanings in media messages. Hall's decoding model captures the polysemic nature of media messages. More concretely, Hall identifies three different decoding positions a reader may occupy in interpreting media contents. A fist position is a dominant-hegemonic one; here, the reader decodes the media message in terms of the code in which it has been encoded; he adopts the dominant code. A second position Hall distinguishes is that of the negotiated reading in which the reader often understands and recognises the dominant code and in a way validates the general hegemonic message while, at the level of particular applicability, (partly) contesting the message (Hall, 1999: 515-516: Kitzinger, 1998: 195). Negotiated meaning, then, *"contains a mixture of adaptive and oppositional elements";* it validates the hegemonic definitions in the media message, but at the same time works with 'exceptions' to the rule. As Hall (1974: 14) himself puts, negotiated meaning "*accords the privileged position to the dominant definition of events, whilst reserving the right to make a more negotiated application to 'local conditions', to its own more corporate situation*" (Hall, 1974: 14). It other words, in the case of negotiated reading, the reader accepts the broad message, but either adopts or rejects elements of it because these elements do not fit with the own experience of the world (Devereux, 2013: 129). Finally, there is the decoding position of the oppositional coding, where the reader decodes the message in a globally contrary fashion (Hall, 1999: 515-517; Kitzinger, 1998: 210). The idea of (the possibility of) radical resistance is also found in the work of Fiske (1989), who argues that media contents are always open to anti-hegemonic readings, as well as in Eco's concept of aberrant decoding (1965) (which in fact inspired Hall), referring to the mismatch of meaning between the encoder and the decoder.

More recently, a tendency towards rejecting the "*interpretative liberalism*" (Stokes, 2005: 135) has been emerging. Stokes (2005: 135) argues that it now becomes increasingly recognised that "*the insistence on privileging the moment of reception over that of production distracts us from the material reality that meaning production is largely the domain of media makers*". There have also been attempts to modify the concept of polysemy; not through rejecting the very idea of the active audience, but by stressing the way audiences often understand the actual contents of media messages in similar ways. As Croteau and Hoynes (2013) for instance argue, some meanings are easier to take from a media text because they convey sets of widely shared cultural values and assumptions. While audiences may evaluate the media message is (radically) different way, they often share a reading of its "*preferred meaning*" (Hall, 1973: 13), referring to that what the majority of the audience supposes it to be (Livingstone, 1998). A discourse-theoretical approach to the practice of interpretation comes close to this kind modification of polysemy. Inspired by Laclau and Mouffe's discourse theory, it can be argued that interpretation implies agency, but that not 'anything goes'. Indeed, media messages contain materialisations of discourses; the meanings inherent to particular discourses are imported into the media text while meanings inherent to other discourses are (at least to certain extends) excluded. What meanings are imported into the media message cannot be isolated from media-specific mechanisms of representation (see earlier). Indeed, these mechanisms facilitate the importation of certain meanings while hindering the importation of others.

We could say that the 'openness' of the media text depends on the degree to which meaning is fixated in the text. When the discourses materialised in the media message have achieved a high degree of hegemony, i.e. when they are part of a social imaginary, the possibility of oppositional readings becomes smaller – thought not impossible.

Interpretation is not only about the possibility of oppositional readings however. It also refers to the way the meanings inscribed in the media text speak to audiences' 'hearts and minds'; the way media texts inspire, irritate, anger, move audiences. Interpretation is thus, at least potentially, a very emotional and affective process. Audiences bring their personal experiences into the encounter with media texts and in so doing identify with discourses materialised in the text and circulating in the social. These discourses can be used and drawn on to endorse, negotiate and criticise the meanings the media text brings into circulation.

3. Identifying with discourses

The notion of identification is quite crucial to a discourse-theoretical understanding of interpretation. More concretely, the notion allows bridging agency (of the audience) and discursive structures. Identification – here particularly relevant in the context of media reception - refers to the way audiences attach meaning to discourses and subject positions in a discursive structure. The process of identification implies agency, but at the same time self-determination is not unlimited. Indeed, the notion of identification creates connection with discursive structures and subject positions within these structures that are outside the subject itself (Carpentier, 2011: 178; Laclau, 1990). Media representations mediate between the subject and the discursive structure; these representations contain meanings triggering audiences to connect their personal experiences to more encompassing discursive structures. As every discursive structure is marked by a fundamental lack, the success of any interpellation – i.e. the process through which discourses construct subject positions for individuals to identify with - is indeed not guaranteed. When interpellation and identification succeed, individuals are likely to govern themselves according to particular discourses and subject positions. Yet, when interpellation and identification fails, individuals promote new subject positions. Identification relates to individuals' embodied engagement with the world surrounding them, which makes that the act of identification – taking place during the process of interpretation - is not necessarily 'coherent', precisely because identification is very much an affective and emotional act. Audiences identify with bits and pieces from potentially different, sometimes conflicting discourses, depending on the discourses' capacity to provide an interpretative framework through which the own experiences can be understood. Despite this agency, audiences are still reliant on the discourses that 'available' (in the media text and in society); discourses that provide them with subject positions to identify with which in turn allow them to 'speak'.

Identification not only bridges the subject's agency and discursive structures. It also brings in the social context in which the reader is embedded and the positions he/she occupies therein. Fish (1980) introduced the concept of 'interpretive communities' to refer to the norms that are characteristic of a given community which influence the way its members take meaning from texts. Although Fish's definition of interpretive communities can be criticised on a number of levels (for approaching these communities as 'fixed', for instance (see for instance Walton, 2007), it does rightfully point to the importance of social context to the practice of interpretation and consequentially, to acts of identification. Croteau and Hoynes (2014: 278) argue that audiences are certainly active, but that they also respond to social contexts and situations. A variety of structural and contextual forces, then, including *"our ages, occupations, martial and parental status, races, genders, neighbourhoods, educational backgrounds, and the like*" (Croteau and Hoynes, 214: 267) impact on the way interpret media contents. These contextual factors, formulated in slightly more discourse-theoretical terms, increase the chances that individuals with for instance a similar occupation identify with similar discourses when interpreting media representations. At the same time it is crucial to note that subjects often are and feel part of multiple communities where, as Laclau and Mouffe also argue, they occupy a variety of subject positions. Media messages can hence be read and interpreted by subjects from a variety of subject positions (for instance as a catholic, as a patient, as a doctor,…), all resulting in different acts of interpretation. Consequentially, no 'predictions' can be made about how a message will be interpreted based on one community an individual audience member is part of.

PART B: THEORETICAL FRAMEWORK: THE DISCURSIVE FIELD OF THE GOOD DEATH

> "the good death is one in which I make my own choices about my last days" (Walter, 2003: 219).

Death, in all its capacities and properties, is surrounded by a wealth of discourses that allocate meaning to what its means 'to die'. This dissertation, guided by the research questions formulated in the introduction, focuses on the discourses surrounding the medical(ised) death and on the discursive construction of the master signifier of the good death. Before turning our attention to the discursive construction of the good death in the circuit of mass media, this second part of the dissertation sets out to develop a theoretical framework in support of the analysis of media representations of the end of life (see part D) and their audiences' receptions (see part E). The development of the theoretical framework is guided by the theoretical research question formulated earlier: "What are the discourses on (the medical) death and the good death, what are their constitutive signifiers and how are they engaged in a discursive struggle over what it means to die well?"

The development a theoretical framework that formulates answers to this theoretical research question occurs through a discourse-theoretical re-interpretation of existing (thanatological) literature. The discourse theory of Laclau and Mouffe is deployed, then, to support an exploration of the discourses surrounding death and the good death, as well as their contingent nature and their embeddedness in discursive struggle. The different chapters of part B set out to develop specific arguments in favour of the discursive and contingent nature of death and the good death.

First, chapter IV looks into the Western discourses of death. Serving primarily as a prelude, the chapter draws attention to the contingency of the Western ideas of death and dying, which makes us aware of the Western perspective in which this dissertation is grounded. Chapter V to VIII theoretically develop what is at the core of this dissertation's research interest: discourses on the medicalised death and the articulation of the good death. Chapter V zooms in on the historically contextualised discursive field of the medical death. The chapter focuses on the discursive shift from a medical-rationalist discourse of death towards a medical-revivalist discourse of death, which in turn affects the discourses on medicine and medical ethics. Chapters VI and VII deal with the discursive construction of the good death and respectively zoom in on the signifiers that are identified as nodal points of the late modern articulation of the good death: autonomy and dignity. Chapter VIII draws attention to the political dimension of the good death by discussing the way two social movements that dominate debates about end-of-life decision-making, the hospice movement and the right to die movement, are engaged in a discursive struggle over the meaning of the good death. Both movements articulate autonomy and dignity differently, thereby illustrating the way the meaning of the good death is ultimately fluid and contingent – even within the confines of the medical-revivalist discourse. Chapters IV to VIII provide theoretical support for the analysis of the construction of the good death in media representations and audience receptions. In a final theoretical chapter (chapter IX), we shift focus from discourses on death and dying to discourses on *death in the media*. Chapter IX, then, offers a theoretical exploration of the different discourses that normatively evaluate the representation of death in the media, which is crucial in providing theoretical support for the analysis of the construction of 'good journalism' in media representations of the end of life and their audience receptions.

Developing a theoretical framework inspired by discourse theory, as mentioned earlier, implies that existing literature on death and dying produced in a variety of fields - including thanatology, cultural studies and media studies – is consulted and interpreted from a discourse-theoretical point of view. Sometimes, the consulted literature is paradigmatically far removed from the premises of discourse theory, which implies that this literature is analysed, deconstructed and translated in/to discourse-theoretical terms. Other bodies of literature, including the work of Foucault on medicine and the body, are much more in line with the premises of discourse theory, which means that they are consulted in a more 'direct' or 'first-line' way; being less mediated by a discourse-theoretical 'translation' procedure.

Chapter IV: The Western discourse of death

The discursive construction of the good death is at the core of this dissertation's research interest. Consequentially, the theoretical chapters of the thesis are in the first place dedicated to the identification of discourses on death and the good death. The overall argument is that discourses on death and the good death are contingent and that specific cultural and historical contexts have an impact on the discursive articulation of (the good) death over time. An argument of contingency also applies to the (Western) discourse of death, and in order to fully understand the contingent nature of discourses on death and the good death, it is of interest to first turn our attention to the Western understanding of death as such as a discourse. Death, indeed, is - at least in Western societies - a discourse that tries to capture human decay, and its meaning consists of a series of often taken-for-granted elements, such as end/cessation/ termination, negativity, irreversibility, inescapability, and undesirability, and closer scrutiny of these articulations shows the contingency of the discourse of death, with almost every discursive element opening up a range of gaps, complexities, and unfixities[20].

The history of death in concrete cultural frameworks is well documented, especially in the work of Phillipe Ariès (1974, 1977, 1981) - who calls himself a *"historian of death"* (1977: 9) - and later in the work of Seale (1995, 1998, 2002, 2004) and Walter (1994, 2003, 2006, 2008, 2009). These works provide the material to reconstruct a more discursive version of (the history of) death and the good death. However, questions on 'what death is' remain largely absent from these accounts. We must turn to philosophic writings to comprehend death *as* a discourse.

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[20] This argument has also been made in Carpentier & Van Brussel (2012).

1. Death and Humanity

In the writings of Bauman (1992), Heidegger (1971) and Derrida (1993), it is generally accepted that a series of essentialisms lie at the basis of the way humanity encounters death and dying, including a universal fear of death and a universal desire for both survival and immortality (see for example May, 1950 and Becker, 1973). These essentialisms are considered the foundations of culture through which humans deals with their own mortality. According to Edgar Morin (Quoted in Bauman, 1992: 31), for instance, culture would be impossible without the continuing risk of death that people experience:

> "The unavoidable continuity of the death risk has acquired in the course of history also a total cultural and anthropological meaning: the risk of death in human adventure as such. Without the risk, everything would be too facile, therefore useless, therefore impossible. Life, action, success, not only individual but collective as well, would not be more than limp jokes. Culture has no meaning outside the life-and-death struggle against nature, bestiality and barbarity, waged simultaneously outside and inside the human person"

The foundation underlying all cultural practices, it is often argued, is the unique relationship between humanity and death. Heidegger (1971), Becker (1973), Elias (1985) and Bauman (1992) all point to the unique capacity of human beings to not only know that they are dying, but also to know *that* they know; being aware of being aware (Bauman, 1992: 12). In his argumentation, Heidegger (1971: 107-108) emphasises the uniqueness of the human awareness of death by opposing it to the way animals encounter death: "*Mortals are they who can experience death as death. The animal cannot do so. But the animal cannot speak either*". Heidegger privileges the human experience of death over the animal experience by strictly distinguishing 'the ending of the living' from death as experienced by human beings (Derrida, 1993). The mode of being characteristic of human beings, *Dasein*, introduces the possibility of 'properly dying' or *"eigentlich sterben"*, which he distinguishes from "unproperly dying" or "*verenden"* (perishing). This latter form of dying, Heidegger argues, is reserved for living beings other than humans. Things that are merely living (*nur Lebenden*), such as animals, are not aware of their own finitude and mortality and that is why they perish instead of die (Derrida, 1993; Calarco, 2002: 20). For Heidegger, it is the assumed unique capacity to speak - the capacity of language - which is the key to 'proper dying'.

In the tradition of his attention for what he calls "the question of the animal", Jacques Derrida presents a critical discussion of Heidegger's work. In "Aporias: dying-awaiting", Derrida (1993) questions Heidegger's rigid distinctions between human and animal experiences of death and dying. More specifically, Derrida questions the role of language as the key to a 'proper' death and critically approaches the anthropocentric Heideggerian discourse that denies any relationship between animals, death and language. In the following lines, Derrida explicitly questions the humanism in which Heidegger's analysis is grounded:

> "Against, or without Heidegger, one could point to a thousand signs that show that animals could also die. Although the innumerable structural differences that separate one "species" from another should make us vigilant about any discourse an animality or bestiality in general, one could say that animals have a very significant relation to death, to murder and the war (hence to borders), to mourning and to hospitality, and so forth, even if they have neither a relation to death nor to the 'name' of death as such […]. Who will guarantee that that the name, that the ability to name death (like that of naming the other, and it is the same) does not participate as much in the dissimulation of the "as such" of death as in its revelation, and that language is not precisely the origin of the nontruth of death, and of the other?" (1993: 75-76)

Arguably, Derrida illustrates the way death is constructed by hegemonically articulating it as unique and elevated above non-human ways of dying, hence deconstructing this hegemonic articulation by essentially questioning it. The specific value of Derrida's critical reading of Heidegger lies with the assumption that death cannot be detached from processes of meaning-making and signification. It is through these meaning-making practices, I want to argue here, that death is discursively constructed around a series of borders. A first border is the distinction between human death and animal death discussed above. A second - perhaps more important - border, is the border between life and death. Life, in this way, becomes the key signifier around which death as a discourse is constructed[21].

2. Life and Death

In "Celebrations of life", Huntington and Metcalf (1979: 2) observe that life cannot exist without death and vice versa. Life, they argue, "*becomes transparent against the background of death*". Arguably, death is constructed as life's ultimate 'Other' or ultimate 'Outside'. As both Walton (1979) and Luper's (2009: 41-48) philosophical discussions show, death is articulated negatively with signifiers of life and existence ('life's end' – 'ceasing to exist')[22]. Death, Walton (1978: 44) for instance argues, is seen as a negative state; the negation of life rather than a positive state in itself. In his termination-thesis Feldman's (1991: 99) similarly articulates death with the termination of existence.

According to Bauman (1992: 24), one of the most universalised outcomes of the binary opposition between life and death is *"the spatial separation between life and death through the exclusion of the dead*". He refers to funerals, which are - despite their diversities – all acts of exclusion, which make the dead *"cease to exist*" (p. 24) by expelling them from the company of the living, the normal and the innocuous; hence labelling the dead as

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[21] The parts on the contingency of the undesirability of death (2.1) and on the contingency of death as 'the end of life' have partially been published in: Carpentier, N. & Van Brussel, L. (2012). On the contingency of death: a discourse-theoretical perspective on the construction of death, Critical Discourse Studies, 9 (2), 99- 116.

[22] See Carpentier & Van Brussel (2012: 102).

abnormal, dirty and to be avoided. Cemeteries, likewise, spatially (and symbolically) exclude the dead from the land of the living. Especially from the eighteenth century onwards, when cemeteries gradually moved from the centre of the city towards the (industrial) edge of the city, cemeteries have increasingly become spaces of symbolic exclusion.

Death is articulated negatively with life, and needs the latter as its constitutive outside. Interestingly, and paradoxically, death can never be thought of 'outside' life. Death cannot be experienced from within death, and is inevitable always viewed from within life and experience[23]. Because of this very impossibility to escape the construction of death in relation to life, it seems that the articulation of death as opposed to life escapes the logics of contingency and discursive construction. This does not imply, however, that the logics of contingency are irrelevant. The contingency of the discourse of death indeed shows when looking into the (construction of the) borders between life and death. The discussion below zooms in on the contingency of the undesirability of death - which relates to the evaluation of life and death, i.e. on what is on both sides of the border that separates the living from the dead - and the contingency of death as the end of life - which boils down to the question of how fixed and rigorous the border between life and death precisely is.

2.1. The contingency of the undesirability of death

Within the binary logic of the opposition between life and death, life is privileged over death[24]. 'Thou shall not kill' has been a key rule throughout history on which a whole range of religious, ethical, medical and legal principles to protect life are build. Death, as the ultimate 'other' of life, is both tragic and traumatic: it represents the ultimate life crisis. When death occurs, it is met with a wide variety of ritualised practices that serve a mobilisation of an array of domains of material objects which allow the dying

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[23] See Carpentier & Van Brussel (2012 : 102).

[24] See Carpentier & Van Brussel (2012).

person as well as his/her social environment to come to terms with and accepts the imminent death and the feelings of loss and adjustment death engenders (Hallam & Hockey, 2001: 1).

The articulation of life as privileged over death is most clearly manifested in the condemnation of suicide. An articulation of death as subordinate to life indeed creates problems for those who do not wish to live (anymore), and above all for those who also act upon this desire. Through the emphasis on its violent nature, suicide is often pushed outside the landscape of the ordinary death. In some languages (like for instance Dutch or German), the signifier 'self-homicide' (*zelfmoord* or *Selbstmord*) is used to strengthen this violent association. As suicide is often seen as a violation of the assumed unnatural opposition against the natural desire for survival, it is generally met with disgust and misunderstanding[25].

Essentialist approaches would explain the problematisation of suicide as the logical consequence of the universal desire to survive. However, these approaches seem to fail in explaining the contingency in the articulation of life as privileged over death. Cultural varieties in the way death and life are evaluated can be determined and bear witness of the presumption that the articulation of death does not escape the discursive logics of contingency. To capture the contingency in the way life, death and their relationship are evaluated, it is again fruitful to look at the construction of suicide, as the latter includes an in-depth re-articulation of the desirability of both life and death.

The ancient Greeks' open tolerance towards suicide offers a good illustration of a re-articulation of the undesirability of death. Most Greek philosophical schools – with Plato as a pioneer – argued that individuals have the right to make autonomous decisions regarding the time and manner of their own deaths. The trust in human reason and the respect for individual autonomy were the key philosophical notions in

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[25] See Carpentier & Van Brussel (2012 : 104-105).

which the tolerance towards suicide was grounded. While most Greek philosophical schools – including the school of Plato - did privilege life over death, however, the Stoics - a Greek philosophical school influenced by Socratic ideals founded in 300 B.C - considered life and death as two *"morally equal states"* (Atwood Gaily, 2003: 26). Seneca, one of the most famous Stoics defended the individual's freedom to end life: *"Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life".* (Seneca quoted in Atwood Gailey, 2003: 26) Similar to the ancient Greek, the ancient Romans did not condemn suicide. Instead, they elevated it to 'high fashion'.

The articulation of life as essentially privileged over death made its entrance as the influence of the Christian Church spread over Europe. It is indeed Christianity that radically rearticulated the value of life. The idea of life as a gift from God that led to the Christian definition of life as 'inviolable' and 'sacred' grounds this re-articulation. In the bible, however, a relative support for the practice of suicide in both the Old and New testaments can be found (Atwood Gailey, 2003: 28). Mullens (1996: 63) notes that *"of the eight cases of euthanasia in the Old Testament and one in the New Testament, none are condemned".* It was only from the fifth century onwards, when suicide was declared as a moral sin, that suicide was condemned and defined as *felo de so* (self murder) (Atwood Gailey, 2003: 29). At this time, the Church started to excommunicate people who committed suicide and deny them a Christian funeral (Atwood Gailey, 2003: 29). Protestantism argued that suicide was directly linked to the devil; it was a dreadful sin and the antithesis of life, faith, and hope (MacDonald, 1991: 87). With the growing influence of the Church, legal frameworks were established to support the thesis of suicide as a violation of life; the bodies of people who committed suicide were interred in public highways or at crossroads, pinioned on a stake in the grave or exposed to hungry animals (Atwood Gailey, 2003: 29: MacDonald, 1991: 86).

Christianity's articulation of suicide is not without contradictions. Martyrdom seems to escape the dominant articulation of suicide as an ultimate sin and of life as fundamentally privileged over death. As Doerflinger (1995: 149, quoted in Atwood

Gailey, 2003: 28) argues, Christians always maintained *"a firm acceptance of martyrdom, of testifying to the faith even if it would mean an unjust death at the hands of others"*. It is precisely in this martyrdom - not only in Christianity, but equally in other religions such as the Islam - that the afterlife often becomes privileged over life itself, thus inversing the hegemonic dominance of life over death (Ma-sumian, 1995)[26].

2.2. The contingency of death as 'the end of life'

Traditionally, death is regarded as both irreversible and unchangeable (Carpentier & Van Brussel, 2012); strictly separated from life. A considerable number of definitions indeed articulate death as permanent and irreversible. Bauman (1994: 175) asserts that *"a being that ceased to be will not be again*". Barlett (1995: 270) explicitly emphasises irreversibility as the key component all definitions of death, despite their particularities, share: *"The formal requirement is the same for every definition and, that is, irreversibility. This is true simply as a matter of language. It is how we speakers of English have come to use the word 'death'."*

At the same time, there are articulations that (often symbolically) oppose the absolute irreversibility of death. First, there is the construction of the dead as somehow 'alive'. Statements of remembrance such as 'he is dead, but his work continues' illustrate how the logic of remembrance functions as a re-articulation of the borders between life and death (Bauman, 1992). In some cases, the logics of remembrance are further strengthened by material components such as statues, street names and graves (Azaryaku, 1996; Hallam & Hockey, 2001; Jones, 2003; Wojtkowiak & Venbrux, 2010: 19). Arguably, the dead are kept alive through a wide array of materialisations[27].

Second, there is the logic where the finitude of the individual's presence on earth does not matter that much as it does not threaten the immortality of humanity as such. 'Being' as such, Bauman (1992: 25) explains, does not stop with the death of

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[26] See Carpentier & Van Brussel (2012)

[27] Both Shakespeare and his anonymous lover are blessed with eternal immortality through Sonnet 18: "*So long as men can breathe, or eyes can see, so long lives this, and this gives life to thee*."

individuals. Rather, *"the change-over of individuals, each with his contribution to make, is exactly what guarantees the permanence of existence".*

In Hinduist belief, the acceptance of the everlasting continuity of existence makes that life and death are seen in terms of exchangeable forms of eternal being. The duration of these stages does not count for much in the light of the continuity of existence (Bauman, 1994: 25). In several other religious traditions, the logic of the eternal afterlife rearticulates the border between life and death in terms of the immortality of the soul (Bauman, 1992: 26). In more scientific variants of this articulation, it is the passing on of the genetic material that can be regarded as a re-articulation of the borders between life and death. This is the logic of procreation, where the passing of genetic material, strengthened by the notion of (physical) resemblance, is seen as a manner to overcome the irreversibility of mortality and a way to ascertain continuity of human existance (Bauman, 1992: 29)[28].

Also in nationalist discourses, a re-articulation of life and death can be found in the belief of the immortality of the 'Volk'. Individual heroes in folk memory as well as nationalist cries such as 'For the glory of our Nation', and 'For our beloved leader' illustrate the way the border between life and death becomes re-articulated in terms of a species that survives despite the death of its individual members. Sometimes, these nationalist re-articulations even render meaningful, valuable and legitimate the surrender of individual life, assuming that individual's death would enhance and revitalise the collective and national life (Bauman, 1992: 27).

Finally, re-articulations of the irreversible border between life and death emerge through new medical developments. Due to the use of new medical technology, patients who lost their brain functions can be kept alive for an increasingly longer period. Hence, irreversibility becomes a "*relative, context-dependent term, whose proper application will vary according to the conditions that contain at the time"* (Barlett, 1995: 3). As Lizza (2005: 55) also suggest, the meaning of irreversibility is not fixed over time, but transforms with the emergence of new medical options. In contemporary medical

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[28] See Carpentier & Van Brussel (2012).

contexts, it is the concept of brain death that rearticulates not so much the irreversibility of 'being' death as such, but rather the irreversibility of the dying process. Indeed, through the use of machines for artificial ventilation, the dying process can be significantly lengthened in time. It is in more radical re-articulations, in arguments of freezing, suspension, revival and restoration, that the irreversibility of death itself is called into question (Barlett, 1995: 3; Walton, 1979: 29).

Chapter V: The medicalised death: from medical rationalism to medical revivalism[29]

The previous chapter focussed on the instability of two key elements of a Western discourse of death: the undesirability of death and death as the end of life. In this chapter, an argument for the contingency of discourses on death is based on a discursive shift that illustrates the changing meanings of death over time. Death is assigned meaning to through signifying processes that are embedded within specific cultural and historical contexts. In this chapter, two main discourses on death are identified and discussed, each of them embedded within a specific historical and cultural context: the medical-rationalist discourse and the medical-revivalist discourse. These discourses are identified by drawing on thanatological literature and more specifically, on literature produced in the field of the sociology of death and dying. In more concrete terms, I distillate from this literature arguments in support of the identification of a medical-rationalist discourse and a medical-revivalist discourse.

It is argued in this chapter that the medical-rationalist discourse that dominated the attitudes towards death in modernity became (to a high degree) replaced by a medical-revivalist discourse in contemporary Western late modern societies (Walters, 2004). Through this shift, so it is argued in this chapter, openness, control and awareness become nodal points of a late modern revivalist discourse – which in turn impacts on the construction of death and of the subject position of the dying individual. Considering this thesis' focus on the medical death, the chapter also sets out to explore the discourses on medicine under medical-rationalism and medical-revivalism. Here, a shift from a discourse of medical-paternalism to a patient-centred discourse is identified. A patient-centred discourse has quality of life and patient

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[29] Parts of this chapter have been published in: Van Brussel, L (2012). Autonomy and Dignity: A Discussion on Contingency and Dominance, Health Care Analysis, 22 (2): 174-191, Van Brussel, L. & Carpentier, N. (2012). The construction of the good death and the dying person: a discourse-theoretical analysis of Belgian newspaper articles on medical end-of-life decision making, Journal of Language and Politics, 11 (4): 479-499.

autonomy as its nodal points. A discursive shift towards a patient-centred focus, it is finally argued, allows for and facilitates a particular discursive articulation of the good death.

1. Medical-Rationalism

Identifying a medical-rationalist discourse on death and dying inevitably begins by drawing on Ariès work on death and dying (1974, 1981). According to Ariès, death in the early middle-ages and before – when identities remained stable throughout the life course of an individual - was a familiar part of life. Ariès (1974) labels this as the epoch of the 'tamed' death. In his well-known 'death denial' thesis (1981), Ariès argues that the modernisation process, strengthened by an ongoing development of individualisation and de-traditionalisation, was accompanied by a shift from this 'tamed' death towards an increasing denial of death. Ariès upholds the idea that ever since the beginning of the twelfth century, alongside the emergence of individualism, attitudes towards death transformed in a fundamental way. This shift has a material dimension; plagued by a series of epidemics, mortality rates were high. This triggered people to become more conscious of the fragility of their lives (Kearl, 1989: 37). Strengthened by an increasing individualisation, they also became more and more aware of their "*own unique selves*" and began to discover their own deaths (Kearl, 1989: 37).

Illich (1976: 183) builds his analysis of changing attitudes towards death and dying on this context of individualisation. He suggests that with the modernisation process death ceased to be the responsibility of the broader community. Rather, it became the task of each individual to deal with the burden and existential pain of his or her own mortality (Atwood Gailey, 2003: 32). For both Ariès and Illich, it is at this point in history that death became constructed as unacceptable and undesirable, and was met with an increasing anxiety. Macabre images of death illustrated the growing feeling of death anxiety. Towards the end of the fifteenth century, Kearl (1989: 37) argues, death derived a certain sexual(ised) meaning; death for instance 'raped' the living. During this same period, when people became aware of 'my death', the *Ars Moriendi* (the "art of dying") became a best-seller. The book provided dying people and their relatives with instructions about how to behave when death would arrive shortly. It included, amongst other, instructions about the proper arrangement of loved ones around the deathbed and the proper facial expressions of the dying (Kearl, 1989: 37; Atwood Gailey, 2003: 32-33). The dying, for instance, had to direct relatives and bystanders *"to keep the doors open to make it easy for death to come, to avoid noise so as not to frighten death away, and finally to turn their eyes respectfully away from the dying […] to leave him alone during this most personal event"* (Illich quoted in Atwood Gailey, 2003: 33).

By the eighteenth century, the notion of the marriage of love made its entrance, and traditional economic engagements between family members were replaced by more emotional attachments. At this point in history, Ariès argues (1974: 56), people became increasingly concerned with the death of the 'other' (Ariès, 1974: 56). Ariès (1974) labelled this epoch the area of the 'thy death', which was argued to be characterised by a resistance to the death of other. In Victorian England, this resistance was manifested in the form of rituals of sentimentality, including romanticised deathbed rituals, long periods of mourning, and richly decorated grief cards and personal tombstones (Atwood Gailey, 2003: 33).

To develop the 'death denial' thesis, Ariès traced the history of the social rituals of dying. He observed a major transformation in attitudes towards death in the middle of the nineteenth century, when the dying patient was - under the control of the doctor - moved to the hospital to die in an institutionalised setting rather than at home (Lupton, 2010: 48). This change, according to Ariès (1981:562), reflects a tendency in which death became hidden and denied, mystified and *"driven into secrecy"* (Aries, 1981: 562). From the mid-nineteenth century onwards, Ariès further asserts, death became surrounded by a great silence and denial: *"[…] the completion of the psychological mechanism that removed death from society, eliminated its character of public ceremony, and made it a private act."* (Ariès, 1981: 575).

The denial of death is linked to a more encompassing process of 'sequestration of experience' (Giddens, 1991), referring to the separation of the sick, the mad and the dying from everyday life (Williams, 2003: 130). Ariès argues that the modern 'forbidden' death reflects a *"brutal revolution"* (1974: 86) in our attitudes towards death and dying while Illich (1975: 180) asserts in a similar way that the epoch of the tamed death was certainly over when death came increasingly under the influence of the medical system. Elias (1985) echoes these sentiments when stating that medicine might provide us with the latest biomedical knowledge, it simultaneously comes with descending (medical) concern with feelings of anxiety death engenders. Also Bauman (1992) acknowledges a same evolution. In modernity, he argues, a particular strategy to deal with death emerged; the deconstruction of mortality. Deconstruction, Bauman asserts, does not per se deny death, but it leaves it stripped of any significance: *"Death is nothing but waste in the production of life; a useless leftover, the total stranger in the semiotically rich, busy, confident world of adroit and ingenious actors. Death is the other of modern life" (Bauman, 1992: 131).*

According to advocates of the 'death denial' thesis, a new image of death was constructed in modernity; an image of death as indecent, dirty and polluting. This idea was strengthened by the cultural conviction that death comes 'from the outside'; as Bauman puts it: a person does not die, he is killed by something (Bauman, 1992: 137). Before the late eighteenth century, death was seen as an unavoidable part of life. Afterwards, however, death became constructed in terms of a wide diversity of separate deaths, each with its own avoidable cause. Of course, the idea that death – eventually - cannot be escaped, was not denied. Rather, it was believed that it could be postponed through a hygienic and healthy lifestyle. When an individual was dying, then, he was regarded as being affected with an extreme example of illness and was thus accused of impotence and as undisciplined (Bauman, 1992: 136-137).

It seems legitimate to argue that death in modernity was constructed as 'wild', 'dangerous', 'dirty', and 'polluting'. However, arguing that death was 'denied' seems to ignore the fact that image of death should in fact be regarded as a specific articulation of death, embedded in a particular discursive configuration. Support here can be found with Armstrong's (1987) article "Silence and Truth in Death and Dying". Inspired by a Foucauldian archaeological and genealogical analysis, Armstrong challenges the argumentations of the 'death denial' thesis asserting that since the mid-nineteenth century, rather than a silence on death and dying, there has been an explosion of narratives around death and dying as they moved from the private to the public sphere. Armstrong (1987: 651-57) argues that death in modernity was only a public affair for the immediate family and the community in which the dying person lived. After the introduction of the death certificate and the removal of the dying to hospitals, Armstrong (1987: 652) states, death became a more publicly controlled event: *"In the old regime knowledge of death was restricted to within earshot of the church bell: beyond there was silence; in the new regime no death was to be unknown".*

Rather than a simple replacement of speech by silence, then, a new discourse of death emerged. In this new discursive configuration, new rituals and social procedures were developed to cope with death and dying. In the old regime, these rituals existed above all in a domestic environment while in the new regime, it were the administrative authorities, particularly in the form of medicine, that claimed the ritual of death registration (Armstrong, 1987: 651-57). In this context, Seale further argues that the death certification is the key symbol of a medical construction of death as located within the body of the dying person (1998: 79). Arguably, instead of characterising the modern period as an epoch of 'death denial', it is perhaps better to speak of an epoch when death was constructed in a **'medical-rationalist' discourse**. The medical dimension evidentially refers to the way death came increasingly under the control of the medical field, while the rationalist dimension refers to the way death became publically controlled, registered and managed, but also to the way it became approached in a technological and scientific way - triggered by the strong belief in medical science. It goes almost without saying that this rationality does not exclude the emotional, for indeed a medical-rationalist discourse – as argued earlier – constructs death in very emotionalised terms; as dirty, polluting, wild and dangerous.

In positive terms, medical-rationalism resulted in an improvement of life expectancy and in an expansion of the options for sustaining the life of the terminally ill accompanied by the emergence of a strong belief in progress in medicine (see further). Yet, the medical progress came hand in hand with the so-called technological imperative became increasingly dominant: a 'high-tech' and rational professional solution rather than a 'reflexive' one was sought for every medial problem (Cohen, 2007: 7). Under the medical-rationalist discourse, with rationality as a nodal point, dying was constructed as something instrumentalist, impersonal, and the dying processes became a highly technical matter, stripped from its existential and personal significance. Moreover, in an area in which medicine knowledge and technologies developed rapidly, death came to be seen as the ultimate enemy of medicine (Atwood Gailey, 2003: 38). As every medical development further expanded medicine's influence over death, it reinforced the construction of death as the ultimate failure of medicine (Atwood Gailey, 2003: 40).

The 'high-tech' death is essentially linked to a broader process that has been described as the "medicalisation" of society (Conrad 2007). Just like a series of other natural human practices and behaviours (e.g. childbirth, ageing, menopause and homosexuality), death and dying increasingly became redefined in order to conform to the dominant medical disease model (Atwood Gailey, 2001: 42). In a medical-rationalist way, medicalisation "*spawned confusing new categories of death, including death from disease, death from removal of life-support systems, and death resulting from the purposeful administration of "palliative" (pain-killing) narcotics"* (Atwood Gailey, 2003: 43). The rationalisation of death thus also affected the definition of death itself. Defining the dying process as a sequence of technical steps and phases obscures the moment of death. At this point, medicine began to (re-)engage with the question as to when death occurs (Atwood Gailey, 2003: 43). Particularly the introduction of the concept 'brain death' (see for instance Barlett, 1995 and Walton, 1979) in the medical literature called into question traditional definitions of death, which had always been rather straightforwardly determined by cessation of the heartbeat (Lazar et al. 2001).

Importantly, a medical-rationalist construction of death and the dying patient also marked an important reconfiguration of what could and could not be said. From the late eighteenth century onwards, a tendency to withhold the prognosis of imminent death from the patient developed. Physicians and nurses were not trained to care for the dying and were uncomfortable with the idea of a patient dying. Often, both the medical staff and the family knew the truth about the condition of the patient, but withheld him from it (Connor, 2009: 3). According to Ariès, this was *'the lie'* that dominated between the mid-nineteenth and mid-twentieth century. Again, the 'death denial' thesis neglects a crucial discursive dimension; a lie only exists in relationship to a regime of truth (i.e. the 'types of knowledge a society accepts and makes function as true' (Foucault, 1980: 131)). Arguably, what is a lie now, is in another society, within another 'regime of truth', not necessarily identified as one. For Armstrong, the discovery of 'the secret'- referring to the truth that is withheld from the patient - reconfigured the boundary between the truth and the lie. Keeping death a secret was legitimate because patients were believed to rely on the hope that the secret provided. Both the doctors who did not want to speak of death because it was distressing and the patients who did not want their worst fears confirmed desired silence. The secret, according to Armstrong, could not be made explicit, but neither was it a lie. The secret could indeed – in mysterious ways – be known by doctor and patients without explicit communication (Armstrong, 1987: 653-54).

2. Medical-Revivalism

During the late 1950's, the 'secret' became exposed as a 'lie' (Armstrong, 1987: 653). There has been a major shift from believing that patients are best kept ignorant to believing that patients must be told the truth about their conditions and prognosis (Walters, 1994: 31) and should be given full information *"so that they are empowered to assess the risks of various treatment options"* (Seale, 1998: 97) Today, in many Western countries, dying patients' basic human rights are indeed often considered violated when they are kept ignorant about their condition (Kearl, 1989: 438). The renewed openness surrounding death and dying, spoken of in terms of a 'revival' of death and dying (Seale, 1998; Walter, 2004) coincides with a material reality where life expectancy is rising drastically, triggered by for instance the reduction of infant mortality and early childhood deaths (Seale, 2000: 918). Also the end of the great epoch of infectious diseases, assisted by and combined with improvements in education, housing, water supply and food contributes to the increases in life expectancy (Turner, 2003: 19). There are of course still considerable differences in mortality both within and between societies (Seale, 2000: 918). But generally speaking, the proportion of elderly people is rising and the experience of dying is increasingly becoming a feature of old age in most Western countries (Seale, 2000: 918). Major causes of death such as pneumonia, bronchitis and tuberculosis have been replaced by degenerative illnesses such as heart diseases and cancers at older age (Seale, 2000: 919-922). This shift from infectious to degenerative diseases is accompanied by a lengthening of dying trajectories (Seale, 2000: 920).

These material changes are again not outside discourse. From the later twentieth century onwards, the negative side effects of a blind belief in medical progress become increasingly visible. Also the idea that curative treatment is necessary beneficial has become challenged in late modernity. These challenges started to dislocate the rationalist discourse of death and dying, and introduced a new approach; one where death is (again) constructed as an inevitable aspect of life (Cohen, 2007: 6-7). What marks this new approach to death and dying is a growing criticism against futile medical intervention that aim to postpone the moment of death for as long as possible and that often result in a high-tech sustaining of life. Today, 'quality of life' is generally considered at least as important as quantity of life, and indeed becomes an increasingly prominent concept in both medical and political/legal debates about the end of life and end of life decision-making. Unsurprisingly, however, we witness a continuing tension between the growing criticism against futile medical treatment and the importance of a 'good death' (see further) on the one hand and the modernist belief in medical progress in further increasing life expectancy on the other – which indeed suggests how a medical-rationalist discourse still partially shows through and how discursive shifts are in essence always slow and ambiguous.

Despite an ongoing belief in medical progress and medical knowledge, the construction of death as something familiar that should be talked about without embarrassment is becoming increasingly dominant. A **medical-revivalist discourse** has openness as one of its nodal points. The former taboo of 'conspiracy of silence' that was characteristic of the medical-rationalist discourse indeed slowly vanished in history (Seale, 1998: 99). This resulted in a shift from the *"interrogation of the corpse"* to the *"interrogation of the dying patient"* (Armstrong, 1987; Turner, 2005: 131). According to Williams (2003: 131), death is now embodied in the words of the dying individual, rather than located in the anonymised and abstracted corpse. In this context, a series of practices and organisations arose during the last decennia, answering and contributing to the changed discourse on death and dying. One of these practices and organisations includes the modern day hospice directed towards managing the distress of the dying patient (Prior, 1989: 12). Other practices are legal-political developments such as the Euthanasia laws in the Benelux and the Patient Self-Determination act in the US that stress the value of a reflexive and aware planning and controlling of the own dying process. This aspect of reflexive and conscious planning is central to revivalist discourse as it emphasises such planning as a project of self-identity (Seale, 1998; 2000).

Control and awareness, then, is a second nodal cluster of the revivalist discourse. In order to control one's own death, it is deemed necessary to have the knowledge about the own condition. This implies that the subject position of the dying person is articulated as being aware and avoiding a state of denial. In contemporary Western societies, an open awareness is regarded as highly desirable. Open awareness refers to an open communication between the patient, the family, the doctor(s) and the professional caretakers. Open awareness is first of all required for the dying person to make his/her own end-of-life decisions in an autonomous way (Walter, 1994, 31; Sandman, 2005; Seale, 1998). Second, being aware of the imminent death is considered valuable because it allows the dying person to focus on the things that bring value to the time left and enables him to use the time left in a better way (Sandman, 2005: 70-71). Peter Noll (1985), a Swiss professor of Law, for instance claims the following in his "Diktate über Sterben und Tod mit Totenrede" (in Sandman, 2005: 71):

> "You will ask: What have I neglected? What should I spend more time on? What would give more meaning? Which moments have I not used sufficiently, which should be used more? […] Show those who care for you more love, devote less attention to those who do not care for you"

Being aware of the imminent death, the dying person can reconcile with friends and relatives, make confessions, (re)tell and/or reconstruct personal biographies. In this way, the revivalist dying process becomes *"a case study in the reflexive formation of a profoundly individualistic form of self-identity, of the sort described evocatively by Giddens"* (Seale, 2004, 967).

3. Discourses on medicine under medical-rationalism and medical-revivalism: from medical-paternalism to patient-centeredness

The shift from *medical*-rationalism to *medical*-revivalism cannot fully be understood without taking into consideration changing discourses on medicine, which are both constitutive of and constituted by this shift. It is through discourses on medicine that 'good medicine', the 'good doctor' and the 'good patient' as well as the relation between the doctor and the patient become constructed, and these constructions inevitably impact on the meaning of (the good) death in a medical environment. Medical-ethical frameworks, which can be defined as frameworks through which discourses aim to normatively evaluate medical practices and relations[30], in more concrete terms operate as (disciplinary as well as emancipatory) machineries for the discursive construction

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[30] see also Carpentier's (2014) for a discourse-theoretical perspective on the ethics in death and dying.

and distribution of meaning. This section zooms in on the shift from medical-paternalism to patient-centeredness, as it is precisely this shift that facilitates a specific articulation of the good death; one where the wellbeing of the dying patient takes precedence over concerns of curing and the prolonging of life.

If we want to theorise the contingency of discourses on medicine, we must (inevitably) turn our attention to Michel's The Birth of the Clinic (1963), which comprises a discursive history of medicine and its transformation towards the end of the eighteenth century. For Foucault, the history of medicine is always embedded in a specific cultural, political, social and economic context (White, 2002: 119). The new medical discourse that emerged at the end of the eighteenth century is the product of a specific historical period marked by several events, phenomena and transformations as for instance the spreading of epidemics accompanied by poorly trained medical practitioners and a lack of funding for hospitals. In this specific context, the institution of the clinic emerged, the latter referring both to its physical appearance and the transformed discursive practices of clinical medicine. The establishment of the clinic led to improved recovery rates of patients and contributed to an increasing level of medicalisation accompanied by a rise in the status of the profession of medicine (Foucault, 1963; Lupton, 2010: 89), which entailed the emergence of the medical *gaze,* which Foucault (1963: 8) explains as follows:

> "the doctor's gaze is directed initially not towards that concrete body, that visible whole, that positive plenitude that faces him—the patient—but towards intervals in nature, lacunae, distances, in which there appear, like negatives, 'the signs that differentiate one disease from another, the true from the false, the legitimate from the bastard, the malign from the benign'"

Through the medical gaze, patients' bodies are abstracted from the individual involved and are constructed as particular archetypes of illness. The emergence of the gaze came hand in hand with the development of biomedical medicine, which relies on the systematic measurement and identification of visible diseases and illnesses. The construction of alternative knowledge about health and illness as 'inferior' and 'amateurish' finds its roots in the rational medical gaze discourse, which demonstrates that discourse not only produces meaning, but also knowledge that assumes the authority of the truth (Hall, 1997: 49). With the hegemonisation of 'conventional' medical statements, the patient's account of his symptoms to diagnose illness was replaced by technologies such as stethoscopes, microscopes and X-rays to construct knowledge about the body and to administer and regulate it. Based on detailed physical or clinical examinations rather than on the spoken words of the patient, hidden underlying causes were exposed (Williams, 2003: 11).

Through the medical gaze, then, the disease became detached and isolated from the patient involved, and the doctor communicated directly with the disease – located at the patient's opaque body - rather than with the patient himself, who was subjected to a medical 'reading' (Foucault, 1963: 8). The specialised knowledge and skills doctors had to obtain in order to successfully 'read' the patient's body, created a relation of imbalance that can be described as inherently paternalistic (McCoy, 2008: 786). The 1847 version of the American Medical Association (AMA) Code of Ethics, which called for complete obedience from the patient, illustrates this paternalistic discourse:

> "The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous, and even fatal." (quoted in Katz, 2002: 232)

This paternalistic vision affected medicine's attitude towards the dying patient. Like other types of illness, also terminal conditions became completely located in the body and detatched from the person involved. It is through the medical gaze that the patient's body was constructed and labelled as a 'dying'. According to Ripper (1994), the dying patient's competence was defined in terms of obeying the rules of the medical system (Ripper, 1994). Scholars such as Zola (1972) and Illich (1976) argue that dying therefore became completely inhumane; an alienated experience (Kellehear, 2007: 157). Kearl (1989: 424) argues in a similar way by pointing to the way patients are subjected to medical specialists who do not treat them as whole persons and who don't bother explaining their examining in everyday language.

A medical paternalistic discourse remained dominant until the second half of the twentieth century. Until then, bodily medical conditions of illness and dying were largely isolated and detached from the person involved. In this perspective, the doctor possessed of the right to take over and dying became a meaningless activity and was constructed as the 'natural enemy'. From the mid twentieth century onwards (i.e. in late modernity), however, a patient-centred discourse gradually became dominant within the medical field. Although the medical gaze is still perceived as the only 'true' way of defining and constructing different types of ill and dying bodies, the new patient-centred discourse also represents resistance to the side-effects of the processes of medicalisation and objectification (Ripper, 2000). Embedded within a further individualising and de-traditionalising society and triggered by the practices of the movement for patient's rights, an approach became demanded in which the wellbeing of the patient prevails. The signifier of quality of life captures this concern with wellbeing. Today, quality of life of the patient is often given priority over the urge to sustain and prolong his life at all costs. While quality of life functions as a nodal point of a patient-centred discourse, it is at the same time crucial to note that its meaning is still fluid and very much depends on the way a patient-centred discourse is articulated with other discourses. In combination with a hospice discourse (see chapter VIII), quality of life – and quality of death - above all refers to being free of pain, being free of fear, and being surrounded by loving care, while in combination with a right to die discourse – quality of life is much more defined in terms of independence and self-reliance.

Patient-empowering projects, which emphasise the notion of quality of life and the right to quality of life, began to challenge the paternalistic and objectifying discourse. From the 1950's and 1960's, the practices and actions of Elizabeth Kubler-Ross[31], Cecile Saunders[32], the hospice movement – which can be seen as an answer to poor care of the dying during the mid-20th-century (Kellehaer, 2007: 157) - and later the discussions about euthanasia and the 'right to die', contributed (and at the same time answered) to the emergence of the late modern medical discourse on death and dying (Ripper, 2000). These (dislocatory) political actions and practices not only rearticulated the subject position of the dying patient, but also the subject position of the medical professional. More specifically, it is the notion of patient autonomy - functioning as another nodal point of a patient-centred discourse - that reconfigures the subject positions of the patient and the medical professional.

The dying patient, in a patient-centred discourse, becomes constructed as a competent and autonomous person; a person who is not subjected to the power of professionals, but who can choose and organise what happens in his environment like any other individual and who can participate in creating the conditions of his own death (Ripper, 1994: 7). In a patient-centred discourse, the empowered patient is defined as having the following characteristics: information strong, information seeking, non-authoritarian and increasingly demanding. Dying patients, then, no longer show a blind faith in professional authority and no longer put professionals on pedestals. Hence, a trend away from the passive patient toward a more critical and increasingly demanding 'customer' can be identified (Traulsen & Noerreslet, 2004).

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[31] Elizabeth Kubler-Ross (1926-2004) was a Swiss- born psychiatrist. She's the author of 'on death and dying' in which she elaborated the different phases of the mourning process (what is now known as the 'Kubler-Ross model').

[32] Cecile Saunders (1918-2005) was an Anglican nurse, physician and writer. Saunders is best known for her role in the birth of the hospice movement.

The shift towards a patient-centred discourse impacts on the subject position of the medical professional as well. In and through a patient-centred discourse, the 'good doctor' is a doctor who respects the decisions of the patient, who carefully listens to the patient and is attentive for his wishes. According to Lupton and McLean (1998), this has resulted in a 'de-mystification' of the doctor and in a decline of medical dominance. This evolution, they argue, shows itself also in contemporary media representations where the doctor is no longer solely portrayed as the *"saintly (male) hero in the white coat"* (p. 947), but in a more diverse and critical way, where personal failings and problems of the doctor, cases of medical negligence, sexual harassment or assault by a physician and failures of medical treatment have also receive attention.

Seale points to the changing power relations *between* health care professionals as another outcome of the de-mystification of the doctor. He more specifically highlights the professional position of nurses, whose engagement with emotional labour has achieved the status of a specific form of expertise in *"tending to the inner lives of patients and their families"* (1998: 95). He goes on to explain how the doctor increasingly shared his expertise with a growing number of categories of health professionals like social workers, occupational and physiotherapists and so forth - often organised in a multidisciplinary team with the patient's wellbeing identified as the main priority.

Elsewhere, Seale (2003: 169) acknowledges the rise of alternative or complementary medicine, which further challenges the continuing domination of traditional medicine, as another outcome of this de-mystification process. In a similar way, the increasing tradition of asking a second opinion from another doctor - through which the patient 'shops' until he finds what he is looking for – can be regarded as part of the 'de-mystification' process of medicine.

Yet another aspect of the de-mystification of doctors and the medical profession in general can be found in the possibility of 'self-diagnosis'; with the aid of online media, patients become their own doctors. The possibilities of the internet, then, further encourage the emergence of the (subject position of the) patient as an active costumer of health information (see e.g. McMullan, 2005).

4. Discourses on the good death

Under medical-revivalism, people are increasingly concerned with dying 'well'. In a context where dying has increasingly become a medicalised experience, questions on the 'good' death often revolve around the issue of human/medical intervention in dying. Despite the explicit concern with dying well in contemporary Western medicalised societies, implicit and not always openly pronounced ideas about what a good death should and should not include predate discussions on medical/human intervention in dying.

Some of the definitions of a good death have become hegemonic and universalised. The Institute of Medicine's[33] definition of a good death summarises some of these ideas. Not surprisingly, this definition remains very vague: *"a decent or good death is one that is: free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families wishes; and reasonably consistent with clinical, cultural and ethical standards"* (Emanuel & Emanuel, 1998: 21). Other circumstances such as dying at the end of a long and fulfilled life, in which children and grandchildren have been raised and are provided for, and dying at home surrounded by family and community are valued high in almost every culture as well (Seale, 2004; Seale & Van der Geest, 2004). Also a death that is in one way or another experienced as 'meaningful' is generally accepted as a condition for a good death (Callahan, 1993; Emanuel & Emanuel, 1998). As Callahan (1993: 195) for instance argues; "*I want to find meaning in my death or, if not a full meaning, a way of reconciling myself to it*". On the other hand, dying in pain, alone and/or in the company of strangers are considered bad ways of dying in most societies (Seale, 1995). Moreover, dying in an accident and dying of overdose are also frequently labelled bad deaths (Kearl, 1998: 121).

Obviously, there are many other aspects of what a good death should and should not include that are more culture specific. Indeed, the discursive construction of a good

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[33] The Institute of Medicine is a non-for-profit, nongovernmental American organisation founded in 1970. Its purpose is to provide national advice on issues relating to health, medicine and biomedical science

death cannot be isolated from the way death itself is constructed in particular cultural and historical contexts. If we briefly look at ancient Greek and Roman times, we can find one example in the work of Vettius Vales, an astrologer from the second century, who describes a physically good death as follows: *"[…] falling asleep from food, satiety, wine, intercourse of apoplexy"* (Quoted in Van Hooff, 2003: 975). However, the idea of a good death was not limited to a painless death in pre-modern societies; it also indicated a happy end of a good and fulfilled life in which education, friendship, respect, political position, richness and having children were highly valued (Van Hooff, 2004: 975-976). Another crucial aspect of dying well in pre-modern times was 'moral perfection': to die at peace with God. Having family and friends around the deathbed and being conscious of passing into the next world, were important bonuses. A religious emphasis remained dominant until the rise of modern science and medicine in the late eighteenth and early nineteenth centuries. In pre-modernity, death was not something people feared, nor was it seen as alien, wild and dangerous. Rather, death was something familiar; it was a part of life. The ideal of a peaceful death in the company of family and friends and in peace with God corresponds to the pre-modern attitude towards death and dying Ariès described as the tamed death (Walters, 2004: 405).

With the process of modernisation and medicalisation, death became something to be medically prevented, and its occurrence was regarded as a failure. As discussed above, there are opposing theories regarding the modern attitudes towards death. Yet, opposing views on the 'visibility' of death in modernity still agree on the idea that death became highly medicalised in the modern period. This medicalisation was accompanied by a new discourse and a new regime of truth characterised by the withholding of the prognosis of imminent death from the patient (Connor, 2009: 3). As a result, a modern good death was first of all a death that happened without the patient noticing it; dying suddenly after a good meal or quietly in one's sleep were considered good deaths. As it was believed that every individual cause of death could be avoided through a healthy lifestyle and medical intervention, a good death was also a death that did not happen yet. In this way, death was always projected into a future that cannot be imagined (Walters, 2004: 405).

From the second half of the twentieth century, and alongside the hegemony of a medical-revivalist discourse, the discourses on the good death started to change again. According to Walters (2004), death is no longer a taboo subject in most late modern societies. Several authors describe this assumed 'de-tabooing' with reference to a movement towards increasing death-awareness (see for instance Bryant, 2003:53-54; Littlewood, 1992: 35). By the late 1990's, the death awareness movement became increasingly institutionalised. Not only through the influence of palliative care on the medical world and the discussions of the right to die (see chapter V), but equally through the organisation of large-scale events concerning death-related topics. For instance, it is now common for government agencies to send crisis teams and grief counsellors to sites of sudden and traumatic death (Bryant, 2003: 54). Moreover, the new awareness of death – or the revival of death – is argued to be reflected in the mass media, where death features as a main theme in films, TV series, plays and novels (Walters, 2004: 405; Bryant, 2003: 54).

The thesis that death is no longer a taboo subject is not uncontroversial, however. Kearl, for example (1989: 47), states that our cultural obsession with youth can be understood as a huge and collective death denial. Moreover, the hegemony of late modern 'aware death' is not total and is still challenged by a discourse where death and dying are hidden away and avoided. Nonetheless, the dominance of a (relatively stable) revivalist discourse naturalises a particular construction of the good death, in opposition to the core values of the modernist good death. Anchored in a broader cultural context of individualisation, secularisation and de-traditionalisation, dying (well) has increasingly become a feature of self-identity. Consequentially, there is an increasing concern about *how* we die and - considering the improved life expectancies - less concern about *when* we die. Awareness and acceptance of the imminent death as well as quality of life can therefore be considered conditions and features of a good death/dying process (Clark, 2002). As discussed above, awareness and acceptance allow the dying individual to be self-determining when it comes to end-of-life decision-making, to focus on the valuable things in life and to preserve a sufficient degree of quality of life, to make final arrangements and finally, in Seale's words, to enter the script of a heroic death. These properties of a late modern good death – awareness, acceptance, quality of life – can be brought under the umbrella of higher-level abstract concepts; concepts around which discussions about medical decision-making often (either explicitly or implicitly) revolve. These concepts can be understood and thought of as privileged signifiers of a late modern discourse of the good death. A first concept is autonomy, referring to the urge to be autonomous in deciding over and participating in the own dying process – for which being aware of the imminent death is a condition. A second concept is dignity, which is indeed inextricably linked to the notion of a good death and is even often used as a synonym for the latter. Dying with dignity refers to a wide array of possible attributes of the good death; dying in (full) awareness, accepting the imminent death, quality of life, dying autonomously. At the same time, the notion of 'a dignified death' remains essentially vague.

To understand the way both autonomy and dignity function as nodal points of the late modern discourse on the good death, it is necessary to comprehend these signifiers as such. Indeed, deepening our understanding of these concepts and the way they are explained in existing bodies of academic literature adds to our understanding of the way they are appealed to in discussions about end-of-life decision-making. The following chapters zoom in respectively on autonomy and dignity, focussing on their discursive varieties and illustrate that they, despite their privileged position in the discourse of the good death, still function as floating signifiers and are thus anything but saturated with meaning.

Chapter VI: The late modern good death: Autonomy

Discussions about end-of-life decision-making often revolve around the question of the right to self-determination in deciding over the own death. These discussions are anchored in a broader medical-ethical and social-political climate, where the ideal of autonomy - and of patient autonomy more specifically - becomes increasingly dominant. In general terms, the concept of autonomy is associated with - or even taken to be equivalent to - a number of other concepts, like independence and self-determination (Agich, 2003), which makes autonomy a very encompassing but also vague and multi-layered concept.

Autonomy, together with a series of these related concepts, has gradually gained significance within an array of social spheres – including, as mentioned above, the sphere of medicine and of medical-ethics more specifically. To understand the central place of arguments structured around the concept of autonomy in debates on medical end-of-life decision-making, this chapter draws attention to the (modern) origins of the contemporary autonomy ideal that is dominant in most Western societies. The pages that follow zoom in on two intellectual projects that fundamentally shaped current Western ideologies on autonomy and that are particularly relevant in the light of end of life debates. These include Kant's philosophical elaboration of autonomy and the focus on individual autonomy in liberalism.

When approaching both the Kantian and the liberal model of autonomy from a discourse-theoretical perspective (and thus, when reading existing literature where these concepts are elaborated through the lens of DT), we can identify them *as* discourses, structured around a number of nodal points. In a Kantian discourse of autonomy, rationality and freedom function as nodal points. By articulating autonomy with these signifiers, autonomy derives a very restrictive and disciplining meaning. The liberal discourse of autonomy also has freedom as a nodal point, but here the articulation of autonomy and freedom results in an emphasis on personal choice. Despite the dominance of a liberal autonomy discourse, the liberal discourse of autonomy is not uncontested. Communitarianism, presenting a radically different articulation of autonomy, is discussed in this chapter as a counter-hegemonic project.

In the specific context of the medicalised death and discussions about medical end-of-life decision-making, discourses on autonomy become actualised and their nodal points articulated with a number of other signifiers. Grounded in a liberal discourse, a 'ratio-personal' discourse of autonomy, stressing the individual's right to decide over the own dying process, has become increasingly dominant in debates about medical end-of-life decision-making. With its focus on care rather than on self-determination and autonomy, however, communitarianism presents a relatively powerful alternative.

1. Kant's moral deontology: a rational-restrictive discourse of autonomy

Kant's moral deontology is one of the most well known (modern) theories of autonomy. For Kant, the notion 'autonomy' points both to men's ability and responsibility to know what it means and implies to act morally and to his obligation not to act immorally (Sullivan, 1989: 47). An articulation that connects autonomy to the duty not to act immorally works in a disciplining and restrictive way, and it is above all the concept of 'rationality' that restrictively guides moral decision-making.

Rationality operates as a nodal point in Kant's moral deontology of autonomy (which is defined here as a rational-restrictive discourse), as the latter refers to the property of the rational will "*by which it is a law to itself (independently of any property of objects of volition*") (Kant, 2008: 42, translated by Abbott). Autonomy thus requires an individual who makes his own laws and is not subjected to any pre-or other given laws (Secker, 1999: 45). However, the *self-given* law cannot just be any law. Self-given laws, rather than promoting and satisfying our desires, should be given by rationality. Following Kant, acting free from any influence, except for the influence of reason, means acting autonomous. For an individual to act autonomous, he must act only on the basis of the law given by reason, and certainly not for the sake of the ends of any goal (Spriggs, 2005: 10).

The rational-restrictive discourse of autonomy finds its origins in Kant's notion of the categorical imperative. According to Kant, self-given laws need to be in accord with the categorical imperative. Under the categorical imperative, individuals are obliged to act only according to those moral laws they believe should become universal laws (Sullivan, 1989: 346). And a moral law – as we saw – can never be selfish are guided by personal preferences. The categorical imperative tests whether an act is autonomous or not, whether is has moral value or not. A law passes the test when it is judged as an action that is objectively necessary it itself and not as a means to other goals or end (Spriggs, 2005: 14). An autonomous person, therefore, is a person who is not merely *self*-legislative, but who is also *universally* legislative. In a Kantian rational-restrictive discourse, the key to proper autonomy is the self-discipline deemed necessary to adopt rules by which individuals transcend their individuality in favour of universality (Sullivan, 1989: 347).

Another nodal point of a Kantian rational-restrictive discourse is freedom. Kant believes that all rational beings have the capacity to act autonomous because freedom belongs to all rational agents and that *"every being which cannot act otherwise than under the idea of freedom is thereby really free in a practical respect"* (Kant quoted in Banham, 2003: 270). Kant upholds the idea that if human beings are free, they are capable of autonomy and hence bound by the rule of morality. In this way, autonomy becomes an obligation rather than being a right in itself (Sullivan, 1999).

A Kantian rational-restrictive discourse does not regard external coercion as incompatible with autonomy, for to say that a moral agent acts freely does not mean that the agent acts lawlessly. For Kant, freedom does not mean 'to do what we want' for this would result in savage chaos and disorder. Kant indeed holds the view that if we do not impose laws to ourselves, the outside will impose them upon us (Spriggs, 2005:

11). Acting free means acting on the basis of laws that are given only be reason. Rules provided by reason, for Kant, are the only objective rules: they are rules that do not promote any personal advantages, but rather hold for all rational individuals only and simply because they are rational. Prudential rules, on the other hand, serve desires which lie outside reason.

Summarising Kant's principle of pure rationality, Sullivan (1989: 48) formulates Kant's Law of Freedom and Autonomy: *"A moral agent is an agent who can act autonomously, that is, as a law unto himself or herself, on the basis of objective maxims given by his or her reason alone"*. Kant acknowledges that human beings are often tempted not to act 'reasonable' and 'morally'. Hence, the law of autonomy and all particular moral rules appear to us as imperatives. At the same time, since these imperatives are grounded in reasons and because they require us to consider our desires as irrelevant, they are 'genuine laws'.

2. Liberalism and autonomy

The liberal discourse of autonomy is inspired by Kant's philosophy of autonomy, but – given its political nature - defines autonomy in less abstract terms. Political projects that strive for the realisation of autonomous citizens find their origins in Ancient Greek, where the notion of autonomy was used to allocate certain rights to a city-state, even when the city-state depended on a mother-city or other outside powers (John Macken, 1990). In *Politics,* Aristotle (2013, original publication circa 350 BC) compared citizens to sailors of a ship. The ruler, he argues, is like the helmsman of the ship steering within the context of a broader set of external conditions and considerations. For Aristotle, external forces are not considered a threat to the individual's capacity to rule per se. As long as these external influences merely *guide* how the individual acts, they pose no genuine threat to his ability to 'rule' (May, 2005: 307-308).

Throughout the Enlightenment, in which contemporary liberalism is grounded, 'autonomy' referred to the rights of individuals to manage their own affairs within the remits of a particular legal framework (Macken, 1990). Recent theories, as for instance presented by John Rawls (1993) and John Christman (2005), are highly based on the idea that external influences pose a threat to human autonomy.

Contemporary liberalism, of which John Locke is generally considered the founding father (see for instance Berkowitz, 2000; Hirschmann, 2009), echoes the ideal of a free individual (whose freedom is limited only when it threatens the freedom of others) versus a limited power of the state or church. Freedom and choice function as a nodal point of the contemporary liberal discourse of autonomy. In contemporary liberalism, autonomy is indeed referred to in terms of freedom (of choice) of action, speech and thought and provides the foundation of a series of political, legal, civil and human rights on the basis of which individuals can reject the interference of external authorities or powers (Agich, 2003: 1).

A crucial division within the liberal discourse that has been emerging during the last decennia is the distinction between a 'political' and a 'perfectionist' approach and bears directly to the concept of autonomy. This division deals with the question whether autonomy can be conceptualised without reference to particular values and ideals (Christman, 2005: 285-286; Gaus, 2005). Procedural theorists and substantial theorists answer differently to the question whether a person who is strongly committed to a particular value system that limits his/her freedom can be considered autonomous.

According to a procedural approach, a person is autonomous when he or she is well aware of the values that move him or her to act. When a person is capable of acknowledging particular aspects of the self and when this acknowledgement does not entail an internal division or conflict, he/she is autonomous. Important, here, is that one must be able to imagine choosing otherwise. For proceduralists, a person is autonomous when he/she meets the conditions of procedural autonomy as described above. However, the content of these procedures - the values and desires that are embraced by the individual - do not affect the question whether or not an agent is autonomous. Therefore, the procedural approach is often called 'content-neutral'. Following a procedural appraoch, a person who in some way or another commits himself to an obedient role is autonomous if (s)he satisfies the conditions of procedural autonomy. In a substantional approach, however, procedural models are insufficient. Substationalism argues that a person who lacks significant choices over significant areas of life cannot be autonomous, no matter just how self-aware and reflective he/she is about his/her own obedience (Christman, 2005: 279-284; Furrow, 2005: 25).

The differences between procedural and substantional views on autonomy correspond to two sub-discourses of liberalism: a political discourse and a perfectionist discourse (Christman, 2005: 285). Political liberalism can be understood as providing a 'modus vivendi' that acknowledges that other views on what is good and desirable exists, while keeping the main themes of liberalism intact (Agich, 2003: 16). In political liberalism, the notion of neutrality functions as an important signifier. As a liberal concept, neutrality means not to regard the own moral view as superior to others (Christman, 2005; Gaus, 2005; Galston, 1991). Neutrality functions as a political ideal through which the state procedurally protects individual freedom (Agich, 2003: 17).

Neutrality is closely connected to the notion of pluralism (Galston, 1991), which is indeed another important signifier constitutive of political liberalism. Pluralism refers to the view that there are many viable concepts of the good life (and the good death). Political neutrality is not absolute as moral commitments are often considered required to make sure that others – which possibly do not endorse liberal principles – respect the right of every individual to be free and to be left alone (Agich, 2003: 15-17). Difference, in a political liberal discourse, is both unavoidable and ineliminable. In a context of difference where conflict and disagreement inevitable arise, tolerance of the views of others is required.

Political liberalism matches the procedural approach on autonomy in the sense that it presents a rather open perspective on what it means to be autonomous, centralising the idea that people who do not endorse values of autonomy and are well aware of the fact that they do not endorse those values, can perfectly be considered autonomous. It is the duty of the state, then, to protect the right of every individual to choice whether or not he or she chooses to live autonomous. At the same time, tolerance towards those who choose not to live autonomously is not without contradictions. Indeed, 'tolerance' maintains a highly dual notion that tolerance is some kind of power exercised on those who hold irrational views:

> "For tolerance to be necessary, there must be a prior belief that the person to be tolerated has an intrinsically undesirable characteristic, or that they are not fundamentally entitled to the benefits which are to be allowed them. […] Tolerance is the exercise of largesse by the powerful, ultimately on behalf of the powerful. It is the generous extension of forbearance towards someone who is intrinsically objectionable or net serving the privileged being allowed" (Husband, 1994: 65)

Perfectionist liberalism (Rawls, 1993) get rids of this dualism by explicitly calling for the identification of autonomy as a 'superior' value in guiding political decision-making (Galston, 1991: 79). Perfectionism opposes the political view by foregrounding the argument that people who hold 'reasonable' and 'true' beliefs about fundamental value questions are, in the political liberal model, in fact ask to put aside or even ignore their commitments in favour of toleration (Rawls, 1993). As Christman (2005) remarks, however, both 'reasonableness' and 'truth' are essentially normative notions. He argues that Rawls' (1993: 54-55) argument of reasonableness, which refers to the ability of 'reasonable' people to acknowledge and accept 'reasonable' pluralism, could indeed legitimate imposing values of freedom and tolerance to 'unreasonable' persons who do not subscribe to these values. These persons, Christman (2005: 293) argues, *"will be viewed like children or the insane, as 'unreasonable' and 'politically irrelevant'"*.

Despite the differences between the political and perfectionist discourse, they still share freedom (of choice) as a nodal point. Whilst a liberal autonomy concept is increasingly dominant in most Western societies, it continues to be challenged by counter-hegemonic projects. One that is particularly relevant here is the communitarian discourse. Drawing on the concept of 'autokoenomy' or 'self-inside-community' (Hoagdland, 1988), the communitarian discourse presents an alternative to liberalism. Discursively built up around the nodal points of community and connectivity, communitarianism emphasises the idea that individuals are not independent centres of decision making, but that they are social creatures, living in communities, who have concrete relations with others. In the communitarian discourse, the self derives its identity in and through membership in concrete communities. Therefore, individuals can never be autonomous, but exist above all through identification with others, which makes them dependent on one another. As Campbell (1991: 105) illustrates the communitarian discourse in her re-articulation of independence: *"To be a creature is to be born of other, to know ourselves through them, to depend upon them and create dependency, to know the pain of losing them and finally to be the instance of that pain to others".*

Another nodal point of the communitarian discourse is care. Communitarianism embraces the ethics of care, as originally formulated in the feminist-inspired psychological theory of Carol Gilligan's 'In a different voice' (1982). The ethics of care calls for an upgrading of 'feminine' capacities like mercy, care, and empathy and envisages providing an alternative to a dominant 'rational' and 'male' focus on the individual as well as to the dominance of theories, like Kant's theory of autonomy and liberalism, focussing on the individual. The ethics of care emphasises the importance of relationships between people and of the family and the community rather than individual rights (Held, 2005).

3. Discourses on autonomy in the context of medical (end-of-life) decision-making

We can now turn our attention to the question of autonomy in the context of medical end-of-life decision-making. The field of medical end-of-life decision-making can be seen as a specific context where different discourses of autonomy become actualised.

Two key discourses on autonomy structuring the field of medical decision-making can be distinguished: a ratio-personal discourse (grounded in a more encompassing liberal discourse of autonomy) and a communitarian discourse. In the field of medical (end-of-life) decision-making, ratio-personalism and communitarianism operate as ethical frameworks aiming to normatively evaluate the practices of medical (end-of-life) decision-making vis à vis the issue of autonomy. Ratio-personalism and communitarianism, consequentially, hold different views on what it means to die well.

3.1. Ratio-personalism

A Kantian discourse in its 'pure' form seems to be too abstract to become actualised in concrete contexts of medical decision-making (Campbell, 1991: 105). Applying a 'pure' Kantian discourse of autonomy in the context of medical decision-making would imply that patients are expected to act only according to the categorical imperative. Such an expectation would in turn imply that patients who act on the basis of the own preferences are not to be considered autonomy (Secker, 1999). Rather, a less abstract and restrictive alternative that focuses on autonomy in terms of respect for personal preferences is far more dominant in medical decision-making contexts. While rationality functions as a constitutive signifier of both the restrictive and the personal approach, the main difference between a ratio-restrictive articulation and a ratio-personal articulation is that the former is concerned with the question of 'is this what I ought to do?' while the latter revolves around the question of 'what do I want to do?' (Secker, 1999: 48). While the ratio-restrictive articulation of autonomy means rational self-legislation, the personal alternative argues that autonomous agents govern "*their own actions in accordance with rules of their own choosing*" and hence highly focuses on self-determination and self-direction (Secker, 1999: 48; Mappes and DeGrazia, 1996: 28).

The rationalist-personal discourse on autonomy finds its roots in the concept of 'negative freedom', which has gradually become hegemonic with the dominance of liberalism in the West. Considering the idea of personal preference that is widely associated with the concept of negative freedom, the rational-personal discourse mainly deals with the rational pursuit of desires or preferences, on the basis of the own choice, while for the rational-restrictive discourse, *"rationality requires logical and volitional consistency such that one could will that the maxims of one's actions become universal laws"* (Secker, 1999: 48). Likewise, O'neill (1991: 184) recognises the difference between the Kant-based approach and the more personal approached by stressing the preference-based nature of the former:

> "Many of them offer no account of the virtues, or even deny that an account is possible; many treat rights rather than obligations as fundamental; nearly all rely on a preference-based theory of action and an instrument account or rationality, all of which are incompatible with Kant's ethics."

A ratio-personal discourse in the field of medical ethics has choice as its nodal point, and thus corresponds to a more encompassing liberal autonomy concept. The specific context of medical end-of-life decision-making, however, makes the concept of autonomy in the ratio-personal discourse complex and multi-layered. Autonomy thus carries different meanings, and each of them provokes resistance grounded in alternative discourses.

First, autonomy refers to the right to make the own end-of-life decisions; the right to choose for a particular end-of-life trajectory. It comes a no surprise that a ratio-personal discourse of autonomy is above all drawn on by advocates of the legalisation of euthanasia and assisted suicide; making the own end-of-life decisions is considered an individual right. A good death, here, is a death controlled by the patient – who has the right to be self-determining and autonomous. In many countries, euthanasia and assisted suicide are legally forbidden, but also in countries where euthanasia and/or assisted suicide are legally regulated, certain determined conditions restrict the autonomy of the individual. One example is the condition of 'unbearable suffering', a legal category determining that the patient's suffering has to be unbearable in order to classify for euthanasia. Autonomy, in the context of euthanasia, is thus never a fully established autonomy. A legal framework, it is important to note at this point, is not detached from discourse but rather crystallises discourses in a legal register[34]. The Belgian euthanasia law, for instance, materialises the view that the right to die is not absolute in a medical context, but that unbearable suffering and medical hopelessness are conditions that make euthanasia justifiable and legitimate. At the same time, autonomy is still the key signifier on which right to die activists build in echoing their argument that individual's have the right to make their own end-of-life decisions.

A ratio-personal emphasis on the right of the individual to make his own end-of-life decisions, including his right to die, has provoked a number of critiques. Sandman (2005: 78) for instance, draws on a maximalist approach to self-determination (grounded in a procedural approach to liberalism) in formulating a case for acknowledging the individual's autonomous decision to rely on others for decision-making or, for instance, to deny imminent death rather than to acknowledge and accept it. Another critique is expressed by Agich (2003); while he acknowledges the merits of the liberal focus on independence and negative freedom in the acceptance of patients' rights to refuse life-sustaining treatment or – in some countries – the right to request for life-ending or life-shortening medication, he equally argues that it is necessary to design concrete systems that actively support the autonomy of the elderly and the sick.

Second, autonomy in a ratio-personal discourse refers to, and is articulated with, independence – where the latter is defined both in terms of independence of action and (physical) independence from care of others. Independence of action refers to the right to choose autonomously over when and where to go and what to do. In the articulation of autonomy as independence of action, institutionalisation (in a hospital or hospice) is considered a main threat, as it for instance limits the choice of the individual about what to eat and when to eat it, when to sleep and to wake up etc. Independence from

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[34] This crystallisation is rather solid, which implies that legal frameworks often slowly change and respond to shifts in ways of thinking.

care of others emphasises the ideal of being self-reliant; not depending on care from others. Here, ageing, illness and disability are considered threats as they increase the possibility to become dependent on care of others. The articulation of autonomy as independence of action and physical independence makes that autonomy in an end of life context is essentially an *embodied* experience – hospitalisation and physical dependence indeed impact on our "bodily-being-in-the-world" and our "lived body" (Williams & Monnaghan, 2013: 63).

Again, a ratio-personal articulation of autonomy as independence provokes critiques. Secker (1999) points out that patients inevitably find themselves in a position of dependency and goes on to argue that autonomy is often equated with independency, which means that very few patients meet the criteria of autonomy. She further states that, as patients are often in valuable positions and are unable to act on their decisions and desires, it is required that measures of positive freedom are taken on their behalf. Non-interference, she argues, is insufficient for a patient who requires the assistance of a medical professional to realise certain decisions. Campbell (1991: 101) argues along similar lines. For Campbell, the main problem of equating autonomy with independence is that it often entails a problematisation and stigmatisation of those who find themselves in a state of dependence:

> "Fragility and vulnerability, rather than being seen as appropriate parts of life from the cradle to the grave, become obstacles to be overcome by the self-sufficient man or woman. The "successful" patient is always the one who transcends the state of patienthood" (1991: 106).

Campbell further asserts that the weak and needy are increasingly seen as burdens to the strong, independent and successful. Arguably, dependency becomes a state to be avoided (1991: 101). Agich (1990: 12-13) endorses Campbell's argument when he says that the equation of autonomy with independence engenders a series of defences against dependence: "*denial of need, hostility towards helpers even in the face of disabilities that require assistance from others, contempt for the real or imagined weakness of others*". Such a negative evaluation of dependence, Agich (2007: 71) argues, is highly paradoxical as contexts of medical care and decision making are often characterised by all sorts of dependence and incapacity.

3.2. Communitarianism

Communitarianism presents an alternative to ratio-personalism in the context of medical (end of life) decision-making. In an end of life context, care becomes the most important nodal point of the communitarian discourse. Through a strong engagement with the ethics of care, communitarianism emphasises the individual's right to care instead of his/her right to self-determination. Medicine, and more specifically end-of-life care, is indeed one of the most important fields where the ethics of care have been applied – especially from a feminist nursing perspective (e.g. Fritz Cartes & Lauritzen, 2002; Stephany, 2012) and sometimes from a Christian perspective (e.g. Gastmans, 2006). In the specific context of end-of-life decision-making, arguments that draw on communitarianism often oppose euthanasia and assisted suicide because they would neglect care and human relationships and interconnectedness. The notion of interconnectedness, then, functions as an another important signifier in the communitarian discourse on medical (end of life) decision-making. A good death, then, involves a dying process in which the patient obtained good care and was lovingly surrounded.

According to Secker, recognising the importance of interconnectedness brings about the possibility to focus on the question whether patients are capable of making autonomous decisions, rather than on the question whether patients are able to effectuate their decisions. The main concern thus becomes whether all that could be done to facilitate and support autonomous decision-making capacities has been done (Secker, 1999: 59). Other authors such as Carol Gilligan (1993) and John Hardwig (2014) are not so much concerned with the question how to enhance autonomy within medical decision-making contexts, but – from a communitarian point of view - plea for a weakening and reduction of autonomy itself. In these accounts, it is claimed that the concept of the self that has been developing ever since Kant and in liberalism cuts off the self from others (May, 2005: 299). As John Hardwig (2014: 32) for instance argues*: "I am a husband a father, and still a son, and no one would argue that I should or even responsibly could decide to take a sabbatical, another job, or even a weekend trip solely on the basis of what I want for myself"*. As communitarianism often embraces religion (Agich, 2003: 32), the opposition against euthanasia is further strengthened by traditional religious arguments of the scarcity of life. It comes a no surprise, then, that opposition against euthanasia is particularly dominant in religious contexts (including Christian political parties, non-profit organisation and (medical) institutions).

Agich (2003) warns against communitarianism as an alternative to the dominance of rational-personal discourses underlying contemporary bioethical thinking. He argues that both discourses make a common mistake by embracing ultimate sources of authority. While a rational-personal discourse embraces the individual as the ultimate authority, communitarianism does the same with the community. Agich presents contextualism as an alternative to both the ratio-personal discourse and the communitarian discourse in the context of medical (end of life) care. Contextualism, he argues, includes the view that actions can be legitimised in a rationally defensibly way without appealing to absolute principles or theories (2003: 34). Concretely, Agich retains from communitarianism the idea that humans are essentially social creatures who develop a sense of identity through interaction with others rather than through independence. At the same time, he holds on to the legal protections and rights the liberal ratio-personal model provides (e.g. the right to refuse treatment). The idea of tradition and community as absolute moral sources is rejected from the contextual account while the importance of positive freedom to encourage autonomy in concrete, everyday life contexts is added (Agich, 2003). The contextual approach, Agich (2007: 85) asserts, presents a fruitful alternative for the more abstract and theoretical models of autonomy that dominate bioethical thinking. Thomas May (2005: 305) seemingly agrees with Agich, as he acknowledges that living up to a liberal notion of autonomy would make our daily experiences highly austere because they would miss many of the things we consider important aspects of a rich and happy life. To fulfil the wishes of a loved one only because it is what he or she desires, May argues, would for example not meet the requirement of self-sufficiency. May (2005) thus poses the argument that an autonomous (wo)man would not be very nice to know. At the same time, however, he (2005: 301) stresses the importance of the political right of patients not to base decision-making on their interpersonal relations:

> "If I were to make medical decisions that affected my family without regard for the decision's impact on those interests, I would surely be judged in a negative manner, just as I would be judged negatively if I were to make decisions about changing job, for example, solely on the basis of what I want for myself. But in neither cases am I required to consider the interests of others"

According to May, the liberal political framework is vital in medical decision-making contexts. He concludes that *"the conception of autonomy reflected in liberal political frameworks […] does not proscribe decision making based on social bonds, relationships, and consensus: It merely protects against the impositions of these bases for decisions primarily affecting the individual in question"* (2005: 306). Hence, May's view brings to the fore the idea that while we may encourage a patient to decide whether to accept or reject treatment considering the impact of this decision on the family or the community, we may not require this (May, 2005: 302). In brief, neither dependence nor independence can be privileged as the ultimate 'good'. Rather, both the choice to act completely independently as the choice to consider the feelings of others and thus, to only partly act independently, are equally valuable in the context of medical decision-making.

Chapter VII: The late modern good death: Dignity

While the notion of dignity is a frequently recurring concept in contemporary discussions on the end of life and particularly in the right to die movement, its meaning is often unclear and, according to sceptics, its appeal is no more than an 'empty rhetoric' (Beyleveld and Brownsword, 2001: 1). Sandman (2002: 177), for instance, says that dignity is an example of a *"thick concept"* with both descriptive and normative aspects, while for Macklin (2003: 1419), dignity is a *"hopelessly vague"* concept. Macklin goes on to argue that dignity is a particularly vague concept in the field of bio-ethics, where *"appeals to human dignity populate the landscape"* (Macklin, 2003: 1419). In discussions on the permissibility of human intervention in dying, opponents as well as advocates of active euthanasia and/or assisted suicide apply the notion of dignity. Just like autonomy, then, dignity can in itself be regarded as a floating signifier; articulated differently within different discursive settings.

In order to achieve an in-depth understanding of the use of dignity as a nodal point of a late modern discourse on the good death, it is crucial to acquire a more profound understanding of the concept as such. This chapter, then, sets out to identify existing discourses on dignity and their relevance within the field of medical (end-of-life) decision-making. An exploring literature review points in the direction of two encompassing approaches. A first approach encompasses discourses of intrinsic or innate human dignity. Two discourses are defined here: a religious discourse and a Kantian discourse. It is particularly the latter that derives further elaboration, both given its complexity and given its impact on contemporary bioethical thinking. A second approach defines dignity as something humans possess of to a greater or lesser degree and as something that can either be obtained or lost. Three discourses are identified that build on an extrinsic human dignity approach: a discourse of social rank, a discourse of moral conduct, and a discourse of self-identity. It is particularly this last discourse that is crucial in the light of the medicalised death.

Each of the approaches mentioned above - intrinsic human dignity and extrinsic human dignity - will be discussed in detail on the pages that follow, first in more general terms and then applied to the specific context of the medical end of life, where the notion of dignity appears as a very crucial signifier that allocate meaning to a good death.

1. Intrinsic or innate human dignity

The concept of dignity started to gain significant attention after the Second World War when international instruments of human rights were being developed. Whereas the European Convention on Human Rights (ECHR) and the US Bill of Rights made no explicit reference to the notion of dignity, the Universal Declaration of Human Rights of 1948 (UDHR), the International Covenant of Economic, Social, and Cultural Rights of 1966 (ICESCR) and the International Covenant of Civil and Political rights of 1966 (ICCPR) did explicitly declare human dignity as a fundamental idea. In both the ICESCR and ICCPR it is acknowledged that *"these rights derive from the inherent dignity of the human person"*. Likewise, Article 1 of the UDHR declares that "*All human beings are born free and equal in dignity and rights"* (Beyleveld & Brownsword, 2001: 12).

The dominant way of defining dignity in the human rights declarations described above is tied to a key logic that defines dignity as inherent to every human being. It is because humans intrinsically possess of dignity, that they should have access to human rights. In this way, it can be argued that dignity is the *"rock on which the superstructure of human rights is built"* (Beyleveld & Brownsword, 2001: 13). The way a definition of innate human dignity is anchored in human rights finds its roots in two discourses. First, there is a religious discourse of innate human dignity, where humans are believed to be created in God's image and therefore have equal dignity; human dignity reflects the dignity of God. The principle of intrinsic human dignity is not exclusively religiously inspired however. The philosophy of the Enlightenment philosopher Kant is a second an important origin of the very idea of innate human dignity. In Kant's philosophy, the concept of dignity refers to the capacities crucial to human beings; they are self-conscious and they are capable of autonomous decision-making (Nordenfelt, 2004: 78). It is particularly this Kantian discourse of dignity that requires further elaboration, for indeed contemporary bio-ethics (including debates about end-of-life decision-making) are very much inspired by Kant. When looking at Kant's philosophical thoughts on dignity as a discourse, attention is drawn to autonomy and respect as nodal points a Kantian discourse of dignity.

1.1. Dignity (versus value) and autonomy

An important assumption underlying a Kantian discourse of dignity is the difference between dignity and value. In his "groundwork of Metaphysics of Morals" (original publication: 1797), Kant argues that in the "Kingdom of Ends", everything has either value (or price) or dignity. Things have a price and human beings have dignity. Things, according to Kant, have only a subjective value. Only if a human being happens to desire them, can things be regarded as good or valuable. For Kant, the dignity of human beings lies with their capability of autonomy. Autonomy indeed functions as a first nodal point in the Kantian discourse of dignity. It is the human capacity to make rational autonomous choices that gives human beings with dignity. It is through our morality, through our capacity to act autonomous and not on the basis of self-interests, that we reveal our dignity (Spriggs, 2005: 11).

In contrast to things and animals (who are not capable of autonomy and morality) human beings should be regarded as having objective, absolute and innate value. The dignity of human beings is intrinsic and independent from the fact whether they are desired or contribute to someone else's happiness. Therefore, human beings should not regard themselves nor other persons only or merely as an object of desire (Beyleveld & Brownsword, 2011: 52-55; Sullivan, 1989: 193-198). The idea of human dignity brings us to Kant's Formula of the "End in Itself": *"Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end"* (1964: 95, translated by Paton). A series of cotemporary scholars have taken up the Kantian idea of human dignity. George Kateb (2011: 5), for instance, argues that *"the human species is indeed something special […] It has higher dignity than all other species, or a qualitative different dignity from all of them".*

Kant's view that animals have value rather than dignity implies that animals are instruments; they are means to an end. Humans must, consequentially, not respect animals as ends in themselves. We must treat our animals good, but only because this is an indirect duty to humanity. If we threat our animals badly or cruelly, we damage our own dignity. Kant uses the example of a dog who has served his master long and faithfully (Spriggs, 2005: 12). This dog, Kant argues, must be cared for, even if he is no longer of any use:

> "If a man has his dog shot, because it can no longer earn a living for him, he is by no means in breach of any duty to that dog […] but he thereby damages the kindly and humane qualities in himself, which he ought to exercise in virtues of his duty to mankind" (Kant quoted in Spriggs, 2005: 12-13)

It seems hardly surprising that Kant's and his followers are often accused of lapsing into a form 'speciesism', i.e. of an arbitrary privileging of the human species over other species. Sandman (2002: 178), for instance, argues that she is not comfortable in accepting the idea that human beings hold an exceptional and privileged position, while Badcott (2003: 124) argues that such a privileging of humans over other living beings is *"entirely normative".* Werner Wolbert (1998: 18), however, defends Kant's conceptualisation of dignity from the accusation of speciesism by arguing that Kant does not locate dignity with the human being simply as a member of the biological species. According to Wolbert, the relevant feature is not the membership of the species ‘homo sapiens’. Rather, it is the moral capacity (of autonomy) of human beings. For Kant, we find dignity in the capacity of rational beings to reason their way towards the moral law.

A Kantian discourse of intrinsic human dignity is partly emancipating as it clearly condemns any situation where a person is treated as if he or she is not (fully) human, capable of autonomous decicion-making. Examples of contexts where human dignity is violated are easy to find. Beyleveld and Brownsword (2001: 18-20) give the examples of Slavery and Apartheid. No matter how ‘enlightened’ particular slave-owners treat their slaves, they argue, slaves remain the ‘property’ of the slave-owner, which essentially reduces the slave to a mere ‘thing’ which has value rather than dignity. Apartheid, in the same fashion, violates human dignity by treating groups as inferior. As a survivor of the Nazi concentration camps, psychologist Victor Frankl recalls an incident when a guard threw a stone at him because he was resting for a moment from his work on a railroad track: “*That, to me, seemed the way to attract the attention of a beast, to call a domestic animal back to its job, a creature with which you have so little in common that you do not even punish it*” (1984: 43).

At the same time, however, a Kantian discourse of intrinsic human dignity is also restrictive as it is not only the lack of respect for the dignity of others that violates human dignity, but also a lack of respect for the own dignity. As Kant indicates in the Metaphysics of Morals:

> “Every human being has a legitimate claim to respect from his fellow human beings and is in turn bound to respect every other. Humanity itself is a dignity; for a human being cannot be used merely as e means by any human being…but must always be used at the same time as an end. It is just in this that his dignity (personality) consist, by which he raises himself above all other beings in the world that are not human beings and yet can be used, as so over all things. But just as he cannot give himself away for any price (this would conflict with this

> duty of self-esteem), so neither can he act contrary to the equally necessary self-esteem of other, as human beings, that is, he is under obligations to acknowledge in a practical way, the dignity of humanity in every other human being. Hence there rests on him a duty regarding the respect that must be shown to every other human being" (2005:173, translated by Abbott).

1.2. Dignity and respect

A second nodal point in a Kantian discourse of dignity is respect, through which a series of restrictive obligations are imported into the discourse; respecting the dignity of the other and respecting one's own dignity.

Kant's intrinsic-restrictivism requires us to consider ourselves as well as every other person as having dignity. Self-respect and respect for others rests on the notion of dignity. The notion of respect, then, functions as an important signifier in the Kantian discourse of dignity, as it is precisely this concept that limits individual's freedom to act. Respect, Kant argues, is a moral attitude we owe to all persons regardless of their individual merits and achievements. In terms of respect for others, then, we are required to acknowledge that every person is equal. We need to respect each person, even while we can judge him or her as having behaved in a morally bad way (Sullivan, 1989: 199). Here, Kant (quoted in Sullivan, 1989: 203) distinguishes between respect and honour:

> "The concept of the respect we are obliged to show other man… is only a negative duty. I am not obligated…to show [others] positive high esteem. The only reverence to which I am naturally obligated is reverence for the law as such; and to reverence the law is man's universal and unconditional duty to others, which each of them can demand as the respect originally due him; But it is not a

> duty to hold other man as such in honor or to give them some service in this way"

According to Kant, we must never use a person as merely a means, that is, by acting in a way that violates anyone else's self-respect. Indeed, respect for others is grounded in treating the other as a morally responsible agent who makes rational and autonomous choices. Kant's "law of love" summarises his deontology of respect for others. What Kant means by 'love' is 'moral' love; a practical attitude towards others to - regardless of whether we feel any affection for them - act so that we take pleasure in their happiness and feel pain because of their suffering (Sullivan, 1989: 206).

For Kant, it is equally vital to respect one's own dignity. Kant argues that we violate or own dignity by treating ourselves as mere things that have only an instrumental value (Beyleveld & Brownsword, 2001: 65; Sullivan, 1989: 200). Not recognising oneself as a moral agent, capable of autonomous decision-making, then, violates our self-esteem. In the context of his protest against the class-divisions in eighteenth-century Germany, Kant says: *"Be no man's lackey - Do not let other thread with impunity on your rights"* (quoted in Wood, 2008: 172). *"Bowing and scraping before others is to behave in a manner unworthy of a human being"* (quoted in Sullivan, 2008: xxiii).

For Kant, we also violate our own dignity when we threat ourselves as means, rather than as an end. Avarice, for instance, would violate our self-esteem because it implies that we regard our existence as valuable only as a means to accumulate things (that have no dignity). In a similar vein, committing suicide is seen as a violation of our self-respect: if we commit suicide, we do this to escape a painful and stressing situation. This means that we regard ourselves as merely a means to a tolerable quality of life rather than respecting ourselves an intrinsic ends. Kant also condemns sexual activity for mere lust and pleasure. Having 'such' sexual intercourses, Kant argues, means that we use ourselves or the other as merely means to the satisfaction of our desires (Sullivan, 1989: 201-202).

1.3. (Bio-ethical) articulations of intrinsic dignity and medical end-of-life decision making

The notion of dignity has gradually become a key signifier in bio-ethical debates. The notion is sometimes used in arguments against biogenetical research, such as research on the human genome, but also against matters of 'beginnings and endings' like abortion and euthanasia (see Dilley & Palpant, 2013; Beyleveld & Brownsword, 2001). Not respecting the sanctity of life equals not respecting innate human dignity. These arguments are generally religiously inspired and echo the idea that God is the creator of life and that every human life should be respected. 'Every' human life includes the life of every person, regardless of his character and merits as well as life in every form, whether it be unborn, young or old, able or disabled, conscious or non-conscious etc. Also in mainstream bioethics and medical ethics, however, the concept of dignity dominates the landscape, where is serves to protect people's human rights. In Unesco's Universal Declaration on the Genome and Human rights (1977), for instance, it is stated that research on the human genome "*should fully respect human dignity, freedom and human rights*". Dignity has also received a more central place in the legislation of health care. An example is the Swedish Health and Medical Services act (1997), setting out that: "*care shall be given with respect for the equal value of all human beings and for the dignity of the individual*" (Nordenfelt, 2004: 70). These documents, in putting forth a articulation of dignity in terms of intrinsic to all humans, are inspired by Kant's philosophy.

Applying a Kantian discourse of intrinsic human dignity in the context of medical end-of-life decision-making is more complex than the above-mentioned documents might suggest, however. Actualising a Kantian discourse in the field of end-of-life decision-making indeed comes with an important paradox. As - at least according the Kantian discourse - the human capacity of autonomy is the ground of human dignity, euthanasia should be respected, and can thus be considered a good and dignified death whenever it is the outcome of an autonomous decision given by the individual's practical reason. At the same time, however, the decision for euthanasia - following a Kantian reasoning – violates human dignity because it would reduce the person involved to mere 'thing' that is only valuable when its 'quality of life' is considered sufficient. Following this reasoning, the self-chosen death is essentially a bad death. While a Kantian ratio-restrictive articulation of autonomy (see earlier) would at first sight support the individual's choice for euthanasia if it is based on pure reason, a Kantian intrinsic-restrictive articulation of dignity is incompatible with euthanasia, as well as any other decision based on arguments the individual owning his/her own body:

> "Man cannot dispose over himself because he is not a thing; he is not his own property; to say that he is would be self-contradictory; for in so far as he is a person he is a subject in whom the ownership of things can be vested, and if he were his own property, he would be a thing over which he could have ownership. But a person cannot be property and so cannot be a thing which can be owned, for it is impossible to be a person and a thing, the proprietor and the property" (Kant quoted in Williams, 2013: 282).

Another problem arises when we take an even closer look at the tensions between the Kantian concepts of autonomy (see chapter VI) and the intrinsic-restrictive notion of dignity in end-of-life decision making contexts. When strictly following a restrictive reasoning as developed by Kant, the question arises as to what extent people who are not capable of autonomous reasonable decision making - including for instance severely brain damaged patients and patients with Dementia or Alzheimer - possess dignity. Arguing that Kant's notion of dignity has failed and is simply impossible, Beyleveld and Brownsword (2001: 68) call for a less restricted approach to dignity; one that basically acknowledges that medical professionals should simply consider the life of every patient as equally dignified (Wainwright & Gallagher, 2008: 51) without connecting the notion of dignity to questions of reason and autonomy.

2. Extrinsic dignity

Opposite to the view of innate human dignity is an approach that defines dignity in terms of a feature humans to greater or lesser extents possess of and that be lost or obtained. Several authors have made the distinction between these two articulations of dignity in some way. Somerville (2001) as well as Aranda and Jones (2010) speak about human dignity as opposed to social dignity, while Sandman (2002) refers to the latter as contingent dignity. Badcott (2003) distinguishes intrinsic from extrinsic dignity and Feldman (1999) calls the latter the 'subjective' aspect of dignity by which he refers to *"an expression of an attitude to life which we as humans should value when we see it in others as an expression of something which gives particular point and poignancy to the human condition"* (1999: 687).

There are different discourses that build on an extrinsic human dignity approach. A first discourse is one of social rank, and was particularly dominant before the Enlightenment, when the dignity – as the mark of a social rank – of kings and nobles was highly celebrated (Beyleveld & Bronsword, 2001: 50). In the Roman republic, the Latin notion of 'dignitas' referred to excellence and distinction; properties that were generally associated with senators and other people of high rank. In a number languages, the semantic relationship is still there; the English word 'dignitaries' and the Spanish word 'dignidad' refer to persons of high rank (Nordenfelt, 2004: 71). With the Enlightenment trajectory, a tendency away from hierarchy towards the *"equal recognition of individual human dignity"* (Meyer, 1992: 7) made its entrance. Today, the discourse of social rank appears foremost in the form of 'dignity as merit' (Nordenfeld, 2004) and refers to the merits of a person rather than to his or her (genetically determined) social rank. A cabinet minister and a doctor, for instance, as well as artists, scientist and athletes are generally acknowledged for their merits and achievements and are often looked up to (Nordenfelt, 2004: 72).

A second discourse is one of moral conduct. Long before the Enlightenment, Aristotle (1992, original publication circa 350 BC) spoke about dignity as one of the fourteen virtues constitutive of a good life. It seems that through human history, dignity as a virtue has been closely connected with one's attitude towards adversity. More concretely, dignity is associated with a number of aristocratic character traits when dealing with adversity or any difficult situations for that matter. As Kolnai (1995: 56) summarises:

> "The qualities of composure, calmness, restraint, reserve, and emotions and passions subdued and securely controlled without being negated or dissolved […] qualities of distinctness, delamination, and distance; something that conveys the idea of being intangible, invulnerable, inaccessible to destructive or corruptive or subversive interference"

Beyleveld and Brownsword (2001: 50, 58) illustrate the discourse of dignity as a moral conduct by referring to Socrates and Nelson Mandela, who both balanced the will to resist with the will to submit - all of this without losing self-control. Self-control can indeed be seen as an important signifier in the construction of dignity as a moral conduct. A more recent example Beyleveld and Bronsword (2001: 58-59) give, and that bears witness of the importance of self-control, is the well-debated case of the English Diana Blood who was refused to have access to the sperm taken from her terminally ill husband. There was wide public agreement on the fact that Diane Blood handled the case in a 'dignified' way; she did not loose her self-control despite her disappointment and the emotional distress but rather 'quietly' continued her struggle.

In contemporary (Western) societies, a third discourse that builds on an extrinsic human dignity approach becomes particularly crucial and thus requires further elaboration: the discourse of (dignity as) self-identity. In the discourse of self-identity, dignity is articulated as a crucial *feature of* self-identity, and two nodal points (in addition to the concept of dignity itself as a nodal point) are particularly crucial here. A first one is autonomy. Autonomy, in the discourse of self-identity, is articulated in terms of a crucial aspect of self-identity; when our autonomy is affected, so is our dignity. According to Nordenfelt (2004: 78), a dignity as self-identity articulation is largely a matter of how we see ourselves as autonomous persons with a history and a future who have relationships with other human beings. Nordenfelt goes on to argue that our self-respect, based on the way we see ourselves as autonomous persons, can easily be shattered by a variety of factors. Often, for instance, people experience their sense of self-identity violated when they are denied access to participation in social life – including the labour market. Also the restriction of autonomy is often considered a threat to people's integrity and sense of self-identity. As Nordenfelt (2009: 34) again argues: *"Intrusion in the private sphere is not only a violation of integrity; it entails a change in the person's identity"* (2009: 34). He goes on to explain that "*The person's autonomy can be tampered with, when the person is prevented from doing what he or she wants to or is entitled to do"* (2004: 76).

Just like experiencing a violation of one's autonomy (see chapter VI), experiencing a violation of one's dignity and sense of self-identity are highly embodied experiences. This embodied dimension becomes even more vital in a context of end-of-life care, which generally involves illness and old age – conditions that strongly restrict people's autonomy, block their access to participation in social life and so on. The body, then, functions as another point in the discourse of self-identity. Given the very privileged place of the body in the discourse of self-identity (which is particularly relevant in the light of this research' focus on the medicalised end of life), and considering the fact that the body is a relatively new concept in this dissertation, it is deemed necessary to draw our attention to the notion of the body – and its articulation with dignity and other signifiers – in a more comprehensive way, which is precisely what is done below.

2.1. Dignity, self-identity, the body (and the mind)

Following a discourse-theoretical line of thinking, the body can - despite its obvious material dimension - be approached as a socially constructed artefact; the product of innumerable discursive practices that produce and construct the body as a culturally recognisable feature (Coakley, 1997: 19). The embodied individual (Shilling, 2005: 152), accordingly, refers to the individual's 'bodily-being-in-the world' as a main site of meaning and discourse (Gabe & Monaghan, 2004).

Religious discourses are probably amongst the most important belief systems that allocate meaning to the body. Under influence of religion, the body has - at least in the West - long been approached as a threatening and dangerous phenomenon, a vehicle of unruly and irrational passions and desires and therefore needful of adequate control and regulation. The dominant ethos of many monotheistic religions including Christianity, Judaism and Islam still largely builds on a repression of the human body (Coakley, 1997; Turner, 1996). The hegemony of Christianity has been accompanied by an approach towards the body as potentially evil. In this way, the body came closely associated with the notion of the flesh, thus with animality. Consequentially, a body/soul dichotomy clearly became foregrounded in Christian discourses; while flesh/body became highly associated with animaltiy, the soul became seen as the symbol of rationality (Turner, 1996: 12).

The subordination of the body and the necessity to control the body was/is not only a theme within (Western) religion. It equally has been a key topic throughout Western civilisation and philosophy. In Greek civilisation for example, Foucault (Quoted in Coakley, 2000: 20) argues, *"a certain association of sexual activity and evil, the norm of preoperative monogamy, the condemnation of relations with the same sex, the exultation of continence"*, were fundamental themes. Also the (early) enlightenment philosophy of Descartes made a significant distinction between the soul and the body, regarding the body merely as a machine, directed by the soul (Turner, 1996: 9). The main features of Cartesianism were indeed the strict separation of mind and body, the subordination of the body to the mind, and the dominance of rationalisation. In this sense, the slogan 'I think, therefore I am', was illustrative of the Cartesian social world (Turner, 1996: 48). According to Turner (1996: 12), then, there was a cultural match between theology (mainly in its protestant manifestation) and Cartesian secularism in the seventeenth century; indeed, rationalisation and calculation of the Enlightenment highly depended on the theology of the Christian moral control:

> "Rationalisation involved the secularisation of culture, the erosion of superstition, the decline of magic, the intellectualisation of everyday life through the control and imposition of scientific reasoning, the calculation and regulation of bodies in the political interest of greater control and more efficiency, the control of everyday life through the development of micro bureaucratic techniques and practices."

In their analysis of the Enlightenment, Adorno and Horkeimer (1979) further suggest that the Western privileging of the mind over the body has brought about a denial of human emotionality, which served the establishment of a regime of rational regulation and control. Adorno and Horkheimer state that the process of rationalisation went hand in hand with a growing control over the human flesh, which is argued to be the source of sexuality and irrational emotions and passions (Turner, 1996: 13).

Alongside processes of increasing individualisation, de-traditionalisation and secularisation in Western societies (processes that have been going on since the (late) eighteenth century, but that are often argued to have reached their heydays 20th, early 21sth centuries), the body slowly became emancipated and liberated from its former subordinated position. This emancipation of the body is also closely connected to post-industrialism and post-fordism; the increasing importance of service industries is closely associated with the reduction in length of the working week, compulsory retirement, an increasing number of holidays, and a greater emphasis on recreation, enjoyment and consumption.

It is very crucial to note that the mind is still regarded as fundamentally distinguishing men from animals. As a nodal point of the discourse of self-identity, the body cannot be isolated from the concept of the mind – which continues to be extremely crucial. The human capacity to think, which is in turn linked to the capability of autonomy, is believed go give humans their 'human identity. At the same time, and this is the main point here, the body no longer is considered a dangerous phenomenon in late modernity (at least not in dominant discourses). Rather, in late modern societies, bodies are re-appreciated and regarded as vehicles of pleasure and enjoyment (Featherstone, 1982). 'Having' a body, then, is no longer a necessary evil. In contemporary societies, indeed, bodies are being 'done' and 'performed'. Of course, all of this does not imply that the revalorisation of the body as a vehicle for pleasure has become uncontested. Religious discourses and conservative discourses, for instance, have certainly not disappeared and still (to certain degrees) emphasise the (sexual) emancipation of the body as a dangerous process that either threatens to outshine the relationship between the human soul and God or threatens social order and harmony. Especially amongst the older generation, a (sexual) emancipation of the body is not always evident and is often regarded as a dangerous process, leading to bodily excesses.

The dominant re-appreciation of the body and bodily experiences does not straightforwardly imply that the body is no longer regulated and disciplined. A consumerist culture that constructs the body as a feature of self-identity can be regarded as a regime that operates in both an emancipating and a disciplining fashion. According to several authors, such as Lupton (2010), Turner (1996), Coackley (1997) and Sennet (1974), the consumer culture of late modernity engendered the belief that appearance and bodily presentation reflect, express and represent the inner-self. This belief seems to stand in sharp contrast with the idea that the body is detached and separated from the inner-self, which was dominant until the late eighteenth century.

According to Sennet (1974), the emergence of modern consumerism in the nineteenth century - which he links with the emergence of the department store - has been crucial to the process which led to the new approach towards the body as a crucial feature of self-expression and identity. In order to look good, individuals are often involved in body maintenance activities that keep their bodies not only in shape, but also highly 'civilised'. The civilised body, according to Lupton (2003: 57) is *"tightly contained, its boundaries stringently policed, its orifices shut, kept autonomous, private, and separate from other things and other bodies"*. This 'civilised' body is understood to be a body that is self-controlled and self-regulated. In contrast to this ideal is the 'uncivilised' body; the body that lacks self-control and self-discipline.

2.2. Dignity and the end-of-life: ageing, illness and dying

Dignity, as we saw earlier, is a concept that occupies a central place in bio-ethical debates, including debates about end-of-life decision-making. There seems to be consensus, in Western secularised societies, on the idea that everybody deserves equal respect in medical care, which illustrates how an articulation of innate human dignity is widely accepted and internalised – at least when it comes to the right to medical care. When looking at the systems of meaning that surround illness and ageing, however, it becomes clear that they often draw on articulations of extrinsic dignity, and particularly two discourses are relevant to an end-of-life context. A first one in the discourse of moral conduct, which engenders a certain construction of encountering death with dignity – associated with certain character traits. Death often comes unwanted, provokes feelings of resistance and can thus, in an extrinsic human dignity approach, be regarded as a very difficult situation that people to greater or lesser degrees handle 'with dignity'. Sandman (2005) observes that a dignified death is a silence death, where emotions are well-managed and controlled. He argues (2005: 49-50):

> "a dignified death is silent, surrounded by lit candles and grave and serious persons dressed in dark colours giving exalted and exalting speeches […] it is not obvious (not me, at least) what this is a better death than a death surrounded by a bunch of noisy people, talking and joking and drinking, dressed in whatever they fancy, openly displaying their feelings".

Sandman (2005) mainly refers here to the behaviour of the grievers, but his analysis also applies to the dying individual, who, after an intense period where emotions of denial, anger and sorrow are experienced and expressed (albeit in a well-controlled way), accepts his death and finally dies 'in peace' or dies a good death.

A second discourse that is particularly relevant to an end of life context is the discourse of self-identity. People at the end of their lives are often ill and generally old; conditions that bring them to the "*extreme edge of mainstream society*" (Zeilig, 2012). Illness and old age affect the individual's autonomy. The lack of autonomy, Nordenfelt (2004: 76) argues, increases the risk of intrusion into the private sphere for the sick and the old who cannot take care of themselves anymore and are relegated to the care of other people. As Kearl (1989: 437) also argues, dignity – and a dignified or good death - cannot be asserted if one is totally institutionalised and loses the control over his or her own fate. The importance of control over the own fate is also illustrated by Lamm (quoted in Kearl, 1989: 437), who quotes a terminally ill old woman saying: *"Who owns my body, Medicare*[35]*, the hospital, the state, or me?"*

The quote above indicates the embodied nature of individuals' sense of self-identity and dignity at the end-of-life, which comes as no surprise given that ageing, illness and dying are indeed highly embodies experiences, inevitably mediated through the

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[35] The social insurance programme of the US Government

body. When further looking into the articulation of dignity and the body at the end of life, it seems that a civilised body discourse (see earlier) plays a crucial role. The old, ill and dying body, indeed, tends to conform far more closely to the 'uncivilised' or 'grotesque' body than the 'civilised body'. Ill and dying people in this sense are 'the others'; those from which the healthy, young and able-body is differentiated (Lupton, 2003: 57-58). In addition, the ideal of a body that represents and reflects the inner-self also underlies the concept of dignity in an end-of-life context. This in turn implies that both the body and the inner-self (i.e. the mind) must function properly. It can be argued that an individual's dignity, and the possibility for him to die well and with dignity, is considered threatened, when there is an assumed split between the inner-self (the mind) and the body. Indeed, as Nordenfelt also argued, it is the sense of "ceasing to be who we were" which is often experienced as a violation of our dignity. As he explains:

> "The beautiful woman, whose identity has literally consisted of her beauty, is through age gradually transformed into a much less attractive person. Likewise, the athlete, whose fame is wholly dependent on achievements on the track, is over time gradually transformed into a weak, disable person who is left out of the community of old days" (Nordenfelt, 2004: 76)

Whereas the concept of self-identity can more easily be projected upon the healthy body; the ill, old and dying body potentially brings about an incapability to represent and express the inner-self through the body (Howarth, 2007). It is a 'colonisation' and 'corruption' of the 'authentic' body/self by the old and ill body that is considered a key threat to a dignified existence and accordingly, a dignified and good death. This is why, for instance, cancer - the dread disease (Paterson, 1987) - is often experienced as a threat to dignity. Cancer, indeed, 'colonises' (Sontag, 1991) the body and, for instance as the result of treatments that make the patient bold, detaches the body from the inner-self. A reverse logic applies to dementia, another disease that is often seen as fiercely affecting the individual's dignity. Here, the body becomes an 'empty shell';

deprived from its inner-identity. On a social level, then, people with dementia run the risk of isolation and solitude or 'social death' (Van Gorp & Vercruysse, 2012), which evidentially contrasts a good death.

The notion of dignity at the end of life occupies a central place in debates about dying 'at the right time', which basically boils down to dying before one is left with little identity and after a long and fulfilled life (Kellehear, 2007: 236). To die at the right time implies a synchronisation of the social and the biological aspects of death. To avoid social death – an embodied experience of interpersonal irrelevancy or rejection by others – it is attempted to coordinate and manage the biological process of dying so that the dying patient as well as the people around them and society still perceive the dying person's life in terms of social (as well as economic and/or political) value (Kearl, 1989: 122, Kellehear, 2007: 237). There are different discursive approaches towards what it means to die 'at the right time' and towards what it means to die well and with dignity. These approaches are linked to two movements that are at the forefront of the debates on end-of-life decision-making: the hospice movement and the right to die movement. The following chapter looks into these movements and the discursive struggle over the good death (including the articulation of 'autonomy' and 'dignity') they are engaged in.

Chapter VIII: The (political) struggle over the good death: hospice and the right to die

The previous chapters of the theoretical framework explored the discourses and discursive shifts that structure the field of the medical(ised) death, and identified the late modern discourse of the good death with its respective nodal points: autonomy and dignity. This chapter focuses on the political dimension of the good death by looking into the discursive struggle over the meaning of the good death and its nodal points. More concretely, this chapter zooms in on the main discursive actors in the discussions and debates about medical end-of-life decision-making, which are indeed very important arenas where the struggle over the meaning of the good death takes place. Doing this illustrates how autonomy and dignity are floating signifiers not only at the level of the discourses discussed in chapters VI and VII, but also at the level of the political projects of social movements and their discourses. Two movements, more concretely, are at the forefront of these discussions: the hospice movement and the right to die movement.

Both the hospice and the right to die movement are embedded in a medical-revivalist and patient-centred discourse and strive to give patients access to a 'good death'. Both movements deploy and actualise the discourses of autonomy and dignity elaborated in the previous chapters; their medico-political projects make them concrete in the capacity of a series of medical and political demands. In articulating the nodal points of autonomy and dignity with a number of other signifiers in a specific way, a relatively structured totally comes into being – and precisely this is why the political projects of hospice movement and the right to die movement are to be seen as discourses. These discourses are diffused throughout the social sphere, which means that they are anchored and inscribed in a variety of social fields and texts circulating therein – including programs of political parties and pressure groups, the policy of medical institutions, but also – which is particularly relevant in the light of this dissertation - in media representations.

The hospice discourse and the right to die discourse are thus not limited neither to the hospice movement and the right to die movement where they find their origins, nor to organisations that explicitly identify with the hospice movement or the right to die movement. This implies that the struggle for signification is perhaps best thought of in terms of a right to die discourse versus a hospice discourse, rather than in terms of struggle between the right to die movement and the hospice movement. At the same time, the hospice discourse and the right to die discourse are inextricably connected to the hospice movement and the right to die movement and their (political) demands for another way of dealing with death and dying. Moreover, the struggle for signification over the concept of the good death is the fiercest and most concentrated within the confines of the movements. In any case, the hospice discourse and the right to die discourse cannot be understood without locating them in the hospice movement and the right to die movement and the struggle over the meaning of the good in which they – as the foundations of the hospice discourse and the right to die discourse – are engaged.

This chapter zooms in on respectively the hospice movement and the hospice discourse and on the right to die movement and the right to die discourse. After shedding more factual light on the (history of the) movements, the chapter goes on to focus on the way the hospice discourse and the right to die discourse articulate the nodal points of autonomy and dignity differently – thus shedding light on the struggle for signification in which they are engaged. First of all, however, it is crucial to comprehend the political dimension of both movements and their demands.

1. The right to die movement and the hospice movement as political projects

The 'end-of-life' has become a highly politicalised category as a variety of political frameworks regulate medical decision-making at the end-of-life. This politicisation cannot be seen in isolation from a more encompassing politicisation of issues that were considered private matters for a long time. Giddens (1991: 214) refers to this as life politics, which concerns issues that are to be seen in the context of processes self-actualisation and de-traditionalisation. Life-political issues include questions about how we should and should not live and provide the moral foundation on which should be decided (Heaphy, 2007: 90). Life politics includes for instance ecological questions, the changing nature of the family (Mouffe, 2007: 43) and also matters of death and dying. Triggered, more specifically, by both discursive shifts (e.g. the shift from medical-paternalism towards patient-centeredness) and material shifts (e.g. increasing life expectancies, the increasing number of people dying from degenerative diseases, and technological possibilities of prolonging life), institutionalised politics started to engage with issues on illness, death and dying. But the (life-)political is not restricted to institutionalised politics. In this dissertation, the political refers to the antagonistic struggle for meaning or, to use Mouffe's (2007: 9) words, a space of "*power, conflict and antagonism*" that runs through the social. This maximalist approach towards the political thus encompasses not only the actions of 'traditional' political actors and institutions, but also, for instance, the power relations between doctor and patient and the interventions of (new) social movements.

Adopting a maximalist approach towards the political as a space of power, conflict and antagonism further urges us to define the hospice movement and the right to die movement as political projects on a twofold level. A first level emphasises the hospice movement and the right to die movement as a joint political project that articulates resistance against a medial-rationalist discourse (see chapter V). Like other social movements, the hospice and the right to die movement arose from a certain condition of unrest and dissatisfaction with the current form of life (Blumer, 1994: 60). Both the right to die movement and the hospice movement articulate resistance against the medical-rationalist approach towards death in that they place death in the forefront of consciousness and urge the aid of medical science to bring it under human control (Walters, 2004). Moreover, both movements present a response to the conditions of 'high-tech dying' (Illich, 1976: 271) through which patients 'expired' rather than died (Connor, 2009: 3). Finally, both movements draw on the broader cultural process of individualisation. As Tony Walter (2003: 219) argues: *"Both find support in individualistic societies that promote personal autonomy – the right of individuals to make their own choices about how they should live and die. […] the good death is one in which I make my own choices about my last days".*

Articulating resistance against the high-tech end of life, the hospice movement and the right to die movement and their discourses have played (and still play) important roles in the destabilisation of the medical-rational discourse. They destabilise the medical-rational discourse in operationalising a patient-centred approach and in centralising the concept of the good death – which they both articulate around autonomy and dignity as nodal points. At the same time - and this relates to the second level at which the hospice movement and the right to die movement are to be seen as political projects – a discursive struggle over the meaning of the good death takes place *between* the right to die movement and the hospice movement. Both movements, indeed, articulate autonomy and dignity differently in their discourses and thereby construct the good death differently. In popular perceptions, hospice is often seen as the domain of religiously motivated people and the right to die that of agnostics and atheists (Bernheim et al. 2008), but the struggle between the hospice alternative and the right to die alternative of the good death goes beyond a faith-based antagonism. One could argue that the inter-discursive struggle between the right to die movement and the hospice movement above all boils down to a different articulation of autonomy and dignity, which in turn shows that these nodal points act as floating signifiers (Laclau & Mouffe, 1985: 171), signifiers "*overflowed with meaning*" (Torfing, 1999: 301) which can have different meanings within different discursive contexts. The hospice movement and the right to die movement, then, bear witness of the political dimension of the good death in that they are engaged in a struggle over the meaning of what it means to die well.

2. The hospice movement: a brief factual contextualisation

The hospice movement finds its roots in the 11th century when the Knight hospitallers of St. John of Jeruzalem build a station for sick pilgrims (Bryant, 2003: 53; Connor, 2009: 3). Originally, indeed, the word hospice refers to a sideway place of shelter or rest for pilgrims. In 1309, the hospitallers founded a hospice where the sick and incurables were cared for and treated *"with great dignity and the fines food, linens, and treatments' the knights could offer"* (Connor, 2009: 3). In the 17th century, the sisters of Charity were founded in Paris and opened a series of houses where the sick and dying were nursed[36]. In the 19th century, Cicely Saunders – a trained nurse and social worker who is generally considered as the founding mother of hospice and palliative care - came working in the St. Joseph hospice for the dying poor in London (founded by the sisters of charity). Saunders further developed the basic ideas of hospice and established the philosophy of using a team to care for and treat the 'whole' or 'holistic' person. Saunders redefined the word 'hospice' as a concept of care that includes the demand to bring the dying process under the patient's control rather than under medical-rationalist control (Bryant, 2003, Connor, 2009).

The first modern hospice was founded in Londen by Saunders in 1967: St. Christopher. Saunders envisaged creating a homelike atmosphere and a holistic,

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[36] Alongside the tradition of hospices, the Red Cross also played an important historical role in the establishment of care for the wounded and dying. The Red Cross has military roots that go back to the battle of Solferino in 1859, where the Swiss banker Henri Dunant nursed and cared after the wounded soldiers. In the aftermath of his testimonies of the lack of basic supplies and medical care, the Geneva Convention was laid down in 1864, determining that every wounded soldier, in an armed conflict, has the right to obtain medical care by a neutral organisation.

family-centred way of allowing dying patients to live life as fully and possible without extensive pain (Bryant, 2003; Connor, 2009; Seale, 1998).

2.1. Hospice and palliative care

It has been explained that the hospice movement can be seen as an expression of resistance against a modernist ratio-medico approach to the end-of-life. According to Saunders and Kastenbaum (1997), the growth of the hospice movement in its contemporary appearance can more specifically be seen as a reaction against a number of trends inherent to such a ratio-medico approach. First, advances in technology driven medicine focused on cure rather than on care, even if the patient involved for was no longer responsive to or did no longer benefit from curative treatment. Dying patients were not acknowledged and people were kept alive at all costs (Connor, 2009: 3). In this climate, relatives of dying people became increasingly frustrated with the depersonalised care to which their beloved was subjected. The same holds true for a lot of health professionals, who found themselves imprisoned by the high-tech model of care. Second, hospice resonated with a broader (sub)cultural tendency of anti-consumerism and the urge to return to nature. The idea emerged that individuals should take control over their lives and death, and that this control can best be achieved in natural organisations (Connor, 2009).

The type of (nature-based) care the hospice movement advocates goes by the name of palliative care and builds on the ideals of a holistic family-based care. The main aim of palliative care is to provide a 'peaceful death', which also refers to dealing and coming to terms with feelings of fear and loneliness associated with the end of life (Sandman, 2005). Sandman (2005: 48) further argues that a basic ethical premise of palliative care is that all humans deserve a good life, and that offering terminal patients a good life is precisely the main goal of palliative care.

Palliative care can be seen as both a practice of and an approach to care for the terminally ill based on the principles of the hospice movement.

As a *practice*, palliative care encompasses a wide variety of actions and medical decisions made at the end of life. What decisions are accepted under the term of palliative care, however, differs significantly across countries. While in Belgium, for instance, palliative sedation – the practice of sedating the patient with the aim of pain control, with the result that the dying process is fastened (death often occurs after several hours or sometimes a couple of days) – is well accepted as a practice of palliative care (when it is the request of the patient himself), this same practice is in other national contexts judged as being a form of 'clandestine euthanasia'. This observation illustrates how the hospice movement and the practice of palliative care it supports are not homogeneous. At the same time, palliative care as an *approach*, binds the hospice movement together worldwide. The World Health Organisation defines the palliative care approach as follows:

> "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"

As an approach and a practice, palliative care - as defined by the WHO - has become (well-)established in several European countries, both in terms of the organisation of health care and in terms of health care policy (Echteld et al. 2008: 12). Especially the patient-centred approach inherent to palliative care as well as its guarding over the patient's quality of life have become widely accepted (Van Den Block, 2008). At the same time, and despite the growing attention for palliative care in most European countries (for instance in the education of medical professionals) palliative care continues to be largely unknown to many health care professionals – not in the least to the older generation of professionals. The hospice movement continues to be a political project that advocates the further implementation of a palliative care approach to death and dying. As the hospice movement advocates an approach to death and dying rather than concrete end-of-life decisions and given that the main principles of the movement are generally accepted, the hospice movement is conceived in less 'politicalised' terms than the right to die movement. At certain moments, however, the political nature of hospice is (re-)emphasised, and this above all happens when a hospice discourse is drawn on to protest and demonstrate against euthanasia and/or assisted suicide. In concrete clinical and medical practice, palliative care and euthanasia are not necessarily translated into strict divisions, and euthanasia can for instance – as is the case in Belgium – be thought of in terms of the last phase of a palliative care trajectory. Practices indeed always partially escape discourses (see De Certeau, 1988)[37]. At the same time, it remains important to note that the sphere of conflictuality in which the end of life is embedded, is grounded in competing variations of the medical-revivalist discourse, which are built on either a hospice discourse or a right to die discourse. This, in turn, shows the contested nature and contingency of the articulation of the good death.

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[37] Belgium offers a particular example of palliative care and euthanasia as being part of one joint framework based on patient autonomy and caregiver beneficence and non-maleficence. The Flemish Palliative Care Federation explicitly expresses a pluralistic stance: "Palliative care and euthanasia are neither alternatives nor antagonistic […] euthanasia may […] be part of palliative care" (2003, www.palliatief.be/teksten/Euthanasie%20-%20standpunt%20Federatie.doc). Bernheim et al. (2008) point to the joint development of the hospice movement and the right to die movement in Belgium.

3. Autonomy and dignity in the hospice discourse

In the hospice discourse, autonomy and dignity derive their meaning in relation to a number of other signifiers. Autonomy, first, is articulated with 'control' through the concept of palliative care, which Kearl (1989: 439) describes as a method of care in which *"one may retain control of one's life until death"* (Kearl, 1989: 439). Control, in the hospice discourse, is not a synonym of autonomy. In the hospice movement, as became clear earlier, control is defined in terms of getting rid of the medical yoke that is directed towards *curing* the ill body rather than *caring* for the dying person. Control, in this sense, means taking control of the environment in which one dies. In the hospice movement, this environment ideally is a homelike environment of care in which the dying is no longer a dying *patient*, but becomes a dying *person*, who is approached in holistic terms. At the same time, however, control is limited in the sense that it does not involve control over the exact timing of death (by choosing for euthanasia). Rather, control in the first place refers to control over the (both physical and psychological) symptoms that accompany the dying process. The hospice discourse defines autonomy of individual patients in terms of fulfilling their wishes about *how* and *where* they choose to die (Walters, 2004: 406). In the hospice discourse, awareness of the imminent death is seen as a crucial condition of a good death as it allows the terminally ill to exercise control over the time left and the conditions of the dying process.

The main reason for opposing end-of-life interventions that actively end the patient's life, and permit the latter to decide over the timing of death, boils downs to the hospice discourse's focus on 'nature', which indeed functions as an important signifier in it. The focus on nature and the natural shows in the way actors building on and identifying with a hospice discourse frequently refer to the ideal of the 'natural death'. In the hospice discourse, the natural death becomes (implicitly) articulated with acceptance, as the following definition of the natural death indeed suggests the ideal of accepting the imminent death: *"a gradual passing away unmarred by fear, denial or technological* *encumbrances"* (Banjeree, 2001: 4). To say that dying is 'natural', is saying that death occurs when nature initiates it and not when the dying individual determines it to happen - for dying is indeed a process that the body is prepared for. Banjeree's study (2001) involving participant observation of hospice care and interviews with hospice workers concluded that analogies to birth and the "miracle of life entering the world" were often used. This illustrates how hospice workers identify with and operationalise a hospice discourse. Another study, conducted by Rinaldi and Kearl (1983), provides another example; he observed that hospice workers indeed stress the importance of a natural acceptance of death. As expressed by one hospice worker; it "*seems a move towards acceptance of death as a natural part of the life cycle in a culture which has more and more denied the reality that we are mortal"* (Kearl, 1989: 439).

The hospice discourse often strengthens its celebration of dying naturally with religious arguments (which comes as no surprise given the religious roots of the hospice movement). It is indeed often the religious belief that life is a gift from God that strengthens the opposition against both the active ending of life and vitalism (the preservation of biological life with all available technologies) in the hospice discourse. The contemporary WHO definition of hospice and palliative care is an example of a place where the hospice discourse's focus on the natural death is materialised: *"an approach that [...]provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death.* (Quoted in Van Den Block, 2008: 19).

It is the main objective of hospice to provide good and holistic care for the terminally ill, who preferably die a natural death. As a signifier, care is indeed at the core of the hospice discourse. It is through the emphasis on care that hospice's link with communitarianism (see chapter VI) becomes particularly clear. Concretely, the family-based model of the hospice tradition seems to celebrate a 'negotiated autonomy' grounded in the ideal of the 'self-inside-the-community'. As such the hospice discourse endorses critics on a liberal autonomy concept that deplore it for celebrating independence and problematising dependence. In the hospice discourse, dependence and the need for care are indeed not regarded as ‘failures’, but as part of a natural dying process.

The concept of care not only affects the meaning of autonomy in the hospice alternative, it equally impacts on the meaning of dignity. In the hospice discourse, dignity is mainly regarded as intrinsic to all human beings, regardless of their personal character and personal merits. As nicely illustrated in the Swedish context, where the Parliamentary Report on Palliative Care (quoted in Sandman, 2005: 46) states:

> “Palliative care should rest on ethical premises based on the principle of equal human (innate) dignity […] Human (innate) dignity is tied to the human being as a person, disregarding any functions or features this person might have; All human beings have an equal dignity.”

Subscribing to a view of innate human dignity, the hospice discourse emphasises a ‘peaceful death’, free of pain and free of existential fears.

At the same time, articulations of extrinsic dignity also emerge in the hospice discourse – albeit in a more latent way. First, Nordenfelt’s concept of ‘dignity of identity’ seems vital in the hospice discourse. Hospice aims at alleviating feelings of loss of identity and authenticity by approaching each individual as a person with a unique history and identity. Arguably, hospice wants to respect the wishes of the dying that enhance their feelings of self-identity and self-respect; be it in the form of making sure that the dying individual has access to a hair dresser or making sure that the dying person gets his/her cup of coffee or tea served with a saucer. In this fashion, hospice wants to guard over the quality of life of the dying (by providing good care), and push social death back as far as possible until biological death occurs (Kearl, 1989; Seale, 1995).

Second, the concept of dignity as a particular way of behaving in the encounter with the imminent death emerges in the hospice discourse. Here, hospice’s emphasis on accepting death is crucial. In Kübler-Ross (1969: 100), we find the following definition of acceptance: *"[Acceptance] is as if the pain had gone, the struggle is over and there comes a time for 'the final rest before the long journey'"*. According to Kübler-Ross (1969), acceptance is the final stage we reach in dying after we have moved through all the different stages (including denial, anger, bargaining and depression) and makes for a good, peaceful and dignified death (Sandman, 2005). This approach towards acceptance suggests a particular view on dying with dignity; one where facing the imminent death creates an opportunity to transform the dying process from a time of suffering and deterioration to an opportunity for personal growth, where the dying person eventually comes to terms with the imminent death: accepting it peacefully and in serenity. The way dying is often seen and spoken of as a journey (Banjeree, 2001: 8-9) should be understood against the background of the 'acceptance ideal'.

Like any discourse, the hospice discourse has a disciplining potential. According to a number of authors (see Field, 1996; Sandman, 2005), the hospice ideal of acceptance sometimes becomes rather compelling. As Field (1996: 260) expresses it: *"Although hospices are committed to allow and enable people to die in the way they want to, it is difficult to die an overtly angry death in a hospice as the "hospice smile" can be very constraining upon those who want to "rage against the dying of the light"!"* Walter (1994) voices a similar critique, stating that hospice does encourage a certain amount of resistance against death, but that this resistance often remains restricted to talking about one's anger rather than expressing it.

4. The right to die movement: a brief factual contextualisation

The 'right to die' or 'requested death' movement, like the hospice movement, articulates resistance against the reduced capability of individuals *"to respond to and cope with their own and others' dying and death"* (McInerney, 2000: 141) resulting from the increasing medicalisation and institutionalisation of death and dying. The right to die movement demands the patient's right to have a physician deliberatively bringing about his death at his own invitation.

Already in the late nineteenth century, marked by the rise of Darwinism alongside an increasing individualism, an opportunity was created for the right to die movement to emerge (McInerney, 2000). The first pubic reference in the US to medical decisions that aim at fastening or ending the life of the patient appeared in a medical journal where a doctor stated that physicians should be allowed *"to stand aside passively and give over any further attempt to prolong a life which had become a torment to its owner"* (Emanuel quoted in Atwood Gailey, 2003: 52). It was around the turn of the century that in Europe as well as in the US speeches and debates on euthanasia and assisted suicide became increasingly common. In 1930, the English doctor Millard publically advocated euthanasia. Between 1920 and 1930, a series of 'mercy killings' strengthened and further encouraged the public debate on euthanasia. In the US, the earliest organised attempt to legalise euthanasia goes back to the establishment of the Society for the Right to Die and the Euthanasia Society of America in 1938. In the UK, the voluntary Euthanasia Legislation Society was founded in 1935 (Atwood Gailey, 2003: 51-52). In the course of history, innumerable organisations that call for the legalisation of euthanasia have been founded throughout the (Western) world: the 'vzw Recht op Waardig sterven' (Dutch language right to die society) and the 'Association pour le droit de mourir dans la dignité' (French language right to die society) in Belgium, 'Dying with dignity' in Canada, 'Derecho a Morir Dignamente' in Spain and the Japan society for dying with dignity. After the Second World War, however, the right to die movement was tremendously damaged by the discovery of the Nazi 'Euthanasia' programme through which thousands of physically and mentally disabled people were murdered. After WWII, the movement experienced a fall of its potential. Until today, the Nazi use of the term 'euthanasia' continues to haunt proponents of euthanasia and assisted suicide (Cohen et al., 2006; McInerney, 2000; Atwood Gailey, 2003).

4.1. The right to die, euthanasia and assisted suicide

In the 1960's, the right to die movement re-emerged in its contemporary form as a new social movement (McInerney, 2000: 140) and has been in its heydays for the last three decades. In its contemporary appearance, the right to die or requested death movement focuses on the right of individuals to determine both the timing and manner of their own deaths (Green & Javis, 2008). The requested death movement, like many other new social movements, is concerned with the re-definition of individuals' identities as well as their relationship with and control over their bodies (McInerney, 2000: 139). Concretely, the right to die movement proposes a new model of dying that allows the sick, especially those experiencing pain and suffering, to end their life (in the case of physician assisted suicide) or to have them ended (in the case of physician-performed euthanasia).

The main obstruction the right to die movement - and the legalisation of euthanasia and/or medical suicide it advocates - faces today is the Hippocratic Oath[38]. One of the ethical principles physicians subscribe to by taking the oath is to refrain from 'killing' their patients. Deliberately bring about patients' deaths at those patients' invitation at the very least requires an overcoming of Hippocratic's opposition against 'killing' (McInerney, 2000: 138). It was not until recently that the ending of a patient's life at his/her own request has become more and more accepted as a part of the doctor's professional activities. In a number of countries, this acceptance has resulted in a legalisation of euthanasia and/or assisted suicide. The Netherlands was the first country to legalise euthanasia in 2001 for legally capable individuals of 16 years and older whose suffering is hopeless and unbearable. Belgium followed in 2002 with the legalisation of euthanasia for legally competent majors whose suffering is hopeless and unbearable. One of the most important requirements in both countries is that *"the request for euthanasia must be voluntary, well considered, durable and persistent"* (Bilsen, 2005: 12), which reflects the importance of the ideal of a death under the patient's control. In

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[38] The Hippocratic Oath is an oath taken by physicians, by which they agree to uphold a number of ethical and deontological rules and principles.

2009, the euthanasia bill passed in Luxemburg as well, much resembling the Dutch law. In Switzerland and a limited number of states in the US (including Oregon, Washington and Vermont), medical assisted dying is legally regulated. The most recent accomplishment of the right to die movement is situated in Belgium, where intense debates resulted in the legalisation of euthanasia for competent minors. The new law triggered fierce reactions, both on a national and on an international level, which illustrates the way the right to die movement is still very much embedded in a political space of conflict and antagonism, much more – so it seems – than the hospice movement.

The difference between the right to die movement and the hospice movement in terms of their political embeddedness becomes nicely illustrated with a simple query on Google Images. These are the first images to pop up when searching on respectively the terms 'hospice' and 'right to die':

Picture 1: hospice on google images (http://www.lutheranhospice.org/)

Picture 2: the right to die on google images (http://www.huffingtonpost.ca/2014/01/16/supreme-court-right-to-die-bc-assisted-suicide_n_4609946.html)

5. Autonomy and dignity in the right to die discourse

The political demands of the right to die movement draw on a particular articulation of autonomy and dignity. An articulation, as mentioned earlier, that differs from a hospice articulation on a number of levels.

At the core of the right to die discourse are a number of signifiers that are inherent to a liberal and ratio-personal discourse of autonomy, including self-determination, choice and independence. In articulating autonomy with these signifiers, the right to die discourse tends to oppose more communitarian approaches on autonomy that focus on relationships of dependence between the patient and his social and medical environment (his 'community of care'). In the right to die discourse, the right of patients (as long as they meet the criteria formulated in the law) not to take into account the desires and preferences of the social and/or medical environment when it comes to making the own decisions at the end-of-life, is supported. Hence, it stresses the individual's 'right to die'.

While the right to die movement acknowledges the importance of (palliative) care, the right to die discourse simultaneously suggests that care from other people is not always enough to overcome the dying person's suffering. As Seale (1995; 1998: 190) argues, the right to die discourse uses a different articulation of some of the core values of revivalism; a request for euthanasia can be seen as a statement that care (in its traditional sense) has its limits and may not be sufficient to cope with suffering, or that a different form of care is necessary (in the form of medical assistance with dying).

While a liberal autonomy concept, as articulated with the 'right to die', is a central to the right to die discourse, there are a number of ways in which the right to die is limited and restricted in concrete end of life situations. Existing euthanasia and/or assisted suicide laws, which can be seen as materialisations of the right to die discourse, often install a number of (due diligence) requirements. First, only patients that are considered competent of autonomous decision-making are qualified to request for euthanasia. This often excludes patients suffering from dementia and, in some countries, minors. Second, the medical situation of the patient should be 'hopeless' and his (physical or mental) suffering should be 'unbearable'. In practice, this often means that it is much more difficult for people who suffer mentally to obtain euthanasia, for mental suffering (and its hopelessness) is indeed hard to measure and is generally perceived as more subjective than physical suffering. While, through the legalisation of euthanasia and/or assisted suicide, the patient has achieved the right to control the time of his own death, he still shares this power with the medical and legal system. Indeed, in societies where death and dying have become increasingly insititutionalised, medicalised categorisations of the patient (and his body) as for instance 'terminally ill' and 'suffering unbearable' label specific categories of patients as (not) qualified to request for euthanasia. The 'right to die', then, should best be interpreted as the right to die of a strictly defined group of patients. The scope of this group of course varies across countries, pointing to the varieties of the extent to which a right to die discourse is accepted as well as to variations within the different national variants of the right to die movement – illustrating that the right to die movement (just like the hospice movement (see earlier)) is no homogenous movement.

As a signifier, dignity is at the core of the right to die discourse. The names of almost all right to die organisations throughout the world bear witness of the centrality of dignity in the right to die discourse: 'vzw Recht op Waardig sterven' and the 'Association pour le droit de mourir dans la dignité' in Belgium, 'Dying with dignity' in Canada, 'Derecho a Morir Dignamente' in Spain and the Japan society for dying with dignity. It seems that dignity is articulated here in (extrinsic) terms of 'actively determining the timing of your own death' when 'a dignified existence' is no longer possible and when the individual's quality of life (often very much defined in terms of independence and self-reliance) is considered insufficient. Behind this view lay two additional assumptions, which are – as is the case for every discourse – potentially disciplining and compelling. First, the right to die discourse (implicitly) builds on the idea that the deterioration of the body and the self affect the 'dignity of the identity' of the dying person. A good and dignified death, in the right to die discourse, implies maintaining one's independence and mental and physical abilities (including the capability to enjoy life) until the last moments of one's life. Advocates of extending existing euthanasia laws to patients with dementia often echo arguments that build on a suchlike articulation of dignity. The case of euthanasia and dementia is particularly interesting, indeed, as it represents a space of conflict where an emphasis on dignity in terms of independence and 'authenticity' of body and mind clashes with an emphasis on autonomy and competence as legal conditions (see earlier).

Chapter IX: Identifying normative stances towards the visibility of death and dying in the media

In a final theoretical chapter, we shift from a focus on discourses on (the good) death towards a focus on discourses on death and dying *in the media*. While the previous chapters provide theoretical support for the analysis of the construction of the good death in media representations of the end of life and audiences' receptions of these representations, this last chapter of the theoretical framework supports the discourse-theoretical exploration of the way normative constructions of good journalism are anchored in media representations of the end of life and audiences' receptions of these representations. Identifying discourses that normatively evaluate the visibility of death in the media is not only necessary as theoretical support for the empirical analysis, it also quite naturally flows from the observation made earlier that the revival of death shows itself in the great amount of media depictions of death and dying we encounter today (see chapter V).

In this chapter, I identify discourses that normatively evaluate the visibility of death in the media and that, either implicitly or explicitly, deploy concepts and signifiers inherent to normative theories on media and journalism and hold particular ideas about the influence and effects of media representations of death and suffering on audiences. In more concrete terms, I appeal to three thematic bodies of literature in the research area of death in the media; violent death (disaster, war, conflict, suicide), terminal illness, and grief and mourning[39].

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[39] Only a limited number of thanatology studies have examined media representations of death and dying, and classic authored books, including Kearl's "Endings" (1989) and Howarth's "Death and Dying: a sociological overview" tend to deal with death in the media in discrete chapters. Media studies, from their part, have - with the exception of research on death in the context of war coverage - shown relatively little interest in the study of death in the media. Research on death in the media is often subtly spread across a variety of disciplines, amongst which sociology (of death, health and illness), psychology and communication studies. This diffusion makes it not easy to get a hold on

Existing literature on death in the media agrees on the idea that "*much of what we know about death comes through the media*" (Hanusch, 2010: 3). There is hardly any consensus, however, when it comes to the way portrayals of death and dying in the media are evaluated. The reason why this is the case can be found at the intersection between discourses on the role of media and journalism in society with discourses on death and dying. Concretely, there are multiple normative frameworks that construct the role of media and journalism in society in sometimes radically different ways, and a series of concepts and dimensions constitutive of these frameworks, such as 'objective/subjective', 'private/public' and 'emotional/rational', intersect with discourses on death, the result of which is a multitude of normative stances towards the visibility of death in the media.

A careful reading of the three bodies of literature identified earlier points in the direction of seven discourses that evaluate media portrayals and coverage of death and dying in specific ways. Roughly speaking, four of these discourses evaluate media representations of death and dying negatively: 'media and the pornography of death', 'media and the spectacle of death', 'biased media coverage of death', and 'stigmatising media coverage of death', while three discourses a stress the potential emancipatory nature of media portrayals of death and dying: 'Engaging media coverage of death', 'media coverage of death and social cohesion' and '"learning" media representations of death and dying'. The list of seven discursive approaches is established by means of a discourse-theoretical reading consisting of three phases that are closely intermingled, and not always chronologically performed. First, I identify the nodal points around which research on death in the media is, be it explicitly or implicitly, structured. Second, I look into the way these key signifiers become articulated, how

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existing research, but a focus on the intersection between death studies and media studies allows me to capture the different normative approaches towards the visibility of death and dying in the media in an exhaustive way.

they are meaningfully combined with other concepts in specific ways. Third, I attempt to identify the broader theoretical frames on which these approaches draw.

1. The construction of media representations of death and dying as harmful

A first set of discourses evaluates the visibility of death and dying in a rather negative way, pointing to its potential harmful effects. These four discursive approaches include: 'media and the pornography of death', 'media and the spectacle of death', 'biased media coverage of death', and 'stigmatising media coverage of death'. It is notable that discourses are articulated with more 'traditional' discourses of the role of media and journalism in society and/or with pessimistic stances towards mass media in general. Below, each of the negative stances towards death in the media is discussed in detail.

1.1. Media and the pornography of death

A first discourse on death in the media has 'emotion', 'taboo', and 'de-sensitivity' as its nodal points and cannot be seen in isolation from a death-denial discourse (see chapter II). The roots of the pornography of death discourse originate in Gorer's (1955) sociological account of what he refers to as the 'pornography of death'. The central argument of Gorer's thesis goes that because death is a great taboo in modern society, *"a diet of violent films fuelled a fascination with its depiction"* (Seale, 1998: 125). The danger of this, according to Gorer, is that death is portrayed in media as stripped from any emotional content, which would numb viewers' sensitivity to interpersonal violence. Inspired by Gorer, Giddens (1991: 204) and Mellor and Shilling (1993: 422) claim that contemporary talk about death rarely deals with its subjective and existential aspects. According to Gorer and Mellor and Shilling, when something as significant as death becomes a taboo, its portrayal goes 'underground' rather than disappears; it re-appears as pornography (Walter et al. 1995). And this, for Gorer, is exactly what happened in the twentieth century:

> "While natural death became more and more smothered in prudery, violent death has played an ever-growing part in the fantasies offered to mass audiences – detective stories, thrillers, westerns, war stories, spy stories, science fiction, and eventually horror comics" (1965: 173).

A notable feature of the cinematic representation of violent death, for Gorer, is that death is present, but distanced from the audience as it bears little resemblance to the everyday experience of dying. Although the deaths depicted are violent, they are accompanied by little or no *'dying'* and they are not the sorts of deaths that happen to *'us'*. The deaths depicted in media indeed tend not to follow after long periods of illness, and they hardly happen to people with we can identify, but rather to cartoon characters, criminals and gangsters, people from distant pasts or from non-Western cultures. Death, in this sense, is 'othered' (Howarth, 2007: 104). The mechanism of 'othering' death is sometimes present in cinematic representations of war, detaching the audience from the death of the 'other' by, for instance, justifying the act of killing by reference to the notion of a 'just war' (Howarth, 2007: 105).

The pornography of death thesis tends to refer exclusively to cinematic representations of violent death. Yet, the argument that media de-sensitise people to death has inspired scholars studying factual representations of violent death. A number of studies on news coverage of conflict and disaster, for instance, draw on a pornography of death discourse when arguing that this coverage, and particular visual coverage, de-sensitises the spectator to death and detaches him from the 'suffering other' (Sontag, 1977; 2003, Moeller, 1999, Zelizer, 1998; 2010). In her book 'Regarding the pain of others', Sontag (2003) unmistakably builds on a pornography of death discourse, pointing to the voyeuristic similarities between looking at a dying body and a naked body. Sontag continues to draw comparisons between the pornography of death and the pornography of sex by referring to the gendered nature of visual depictions of war. She uses the example of the photojournalism of Roger

Fenton (1855), who represents war as an *"all-male-outing"*, avoiding all evidence of slaughter.

The argument that portrayals of violent death in the context of war and conflict are highly unethical because they desensitise the public to death is captured in a compassion fatigue thesis. This thesis is for instance articulated by Margareth Somerville (2001: 110), who argues that the great majority of media representations of death erodes our sensitivity to death and that especially children are desensitised through their exposure to violence in mass media. Lilie Chaouliaraki (2008), who points to the 'comfort zone' from which the spectator watches the distant sufferer, echoes a similar argument. News coverage, for Chaouliaraki, often[40] facilitates responses of compassion fatigue because of the way it 'packs' news about death and disaster; minimally narrating the suffering, providing little context, refusing to humanise and personalise sufferers, and interrupting emotion vis à vis distant suffering.

Also Susan Sontag – at least in her early work – strongly subscribes to a compassion fatigue thesis, arguing that graphic representations of death have *"the potential to freeze public emotions"*, because they crystallise a particular moment and can be looked at over and over again" (Quoted in Hanusch, 2010: 105). She goes on to argue that media, through depicting misery and injustice in a very frequent way, make the horrible seem ordinary and familiar (Sontag, 1977; 20-21). Moeller (1999: 32) also connects compassion fatigue to the familiarity and reciprocity of images of death and suffering, which she in turn connects to processes of commercialisation and increasing competition between media:

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[40] Chaouliaraki also stresses the possiblity of news coverage of death and dying to be engaging, but states that only a minority of news accounts can be labelled as such.

> "As always, newspapers, newsmagazines and television don't want to get beat by the competition – either in the stories they cover or in the packaging they come in. As a result, much of the media looks alike. The same news, the same pictures. What's the inevitable result much of the time? Compassion fatigue".

Arguments like those formulated by Somerville, Moeller and Sontag reflect concerns about the corruption of public morality by mass media. Media, following a pornography of death discourse, deal with death in a highly unethical way by blunting the public's empathy with the suffering of the other. Implicitly drawing on a social responsibility of the press model, which points to the task of media in offering comprehensive and intelligent accounts in a contexutalising manner (Hutchins, 1947; Nordenstreng, 1984), Sontag argues that images of war should best be presented in newspapers, rather than in magazines, where they can be presented in a contextualised way, "*surrounded by words*" (Sontag, 2003: 32). Sontag further points to the failed social responsibility of media when stating that media have made us very skilful in transforming a harsh and intolerable reality into fiction, making us believe that we are watching an action movie rather than 'real' suffering and death. Moeller (1999: 40) links this failed social responsibility to processes of commercialisation, which turn suffering into a 'commodity', making it easy to leave the troubles of others behind, to *"turn the page, as the Save the Children advertisement cautions us against"* (Moeller, 1999: 40).

1.2. Media and the spectacle of death

A second discourse constructs media representations of death and dying in terms of sensationalism and spectacle. Here, similar arguments than those found in the pornography of death thesis can be traced. Like the pornography of death discourse, the 'spectacle of death' discourse has emotion as a nodal point, but simultaneously presents an alternative analysis when it comes to the way emotion is, or is not, involved in media portrayals of death and dying. Rather than arguing that media representations of violent death are detached from human emotion – as the pornography of death discourse holds, a sensationalist media discourse articulates them as permeated by emotion. As Walter et al. (1995: 19) argue in their article "Death in the news – the public invigilation of private emotion": *"far from being averse to portraying the humanity of those killed and the emotions of those who grieve, reporters actually home in on emotions like flies to a glowing light"*.

The 'spectacle of death' discourse, where representations of death in the media are regarded as being surrounded by spectacle, takes shape at the intersection between thanatology and media studies. More specifically, media representations of death and dying are evaluated using concepts like sensationalism and infotainment, which have been formulated in critiques on popular media and journalism.

A number of studies on media representations of war and conflict articulate the spectacle of death discourse in blaming media for being sensationalist and evoking and facilitating audiences' responses of 'schadenfreude'[41] vis à vis the dead and the bereaved. News coverage has a certain 'feel-good' factor, according to Thussu (2003: 129), who describes media representations of war and conflict as forms of infotainment that fail in providing economical and political context that help explain the why of conflicts in the world. Also Moeller (1999: 34) argues along similar lines, stating that watching and reading about suffering, in particular suffering that takes place somewhere else, has become a form of entertainment. Critiques like those formulated by Thussu and Moeller build on a normative framework on media and journalism where processes of commercialisation are argued to focus on the spectacular and the sensationalist because this is deemed newsworthy (see for instance Sparks, 2000; Allan, 2010). Central to this discourse on media and journalism is the argument that the sensational has supplanted the public interest (Franklin, 2008: 13) media and journalism should serve. Infotainment, it is argued, trivialises news because it does little in providing proper information about issues of high significance (Cunningham and Miller, 1994; Hallin, 1994). These arguments are in line with Bell's

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[41] Schadenfreude is the German word for malicious pleasure

(1991: 156) statement that, in addition to death itself, concepts such as damage, injury and deviance are the common building blocks of news portrayals.

Research on suicide in the media sometimes draws on a similar normative framework, criticising media for depicting suicide as a sensational 'spectacle'. In particular research on celebrity suicide in the media (see for instance Cheng et al. 2004; Yip et al. 2006) echoes arguments about spectacle and sensationalism. According to Van den Bulck and Claessens (2013), for instance, a celebrity suicide is often an occasion for intruding into the celebrity's private life, emphasising the scandalous. Other scholars, whose work is more situated in a media-effects paradigm, link between media's attention to celebrity suicide, processes of sensationalisation, and national suicide rates (see for instance Chen et al. 2010; Niederkrotenthaler et al. 2009; Niederkrotenthaler et al. 2012). Arguments about the sensational invasion of the private sphere can finally be traced in research on terminal illness in the media. According to Seale (2002, 2002), media coverage of (terminal) illness provides a "spectacle of ordinary people" who become 'ordinary heroes'. Building on arguments of sensationalism, the coverage of British big brother star Jade Goody has been described as being surrounded by a *"baroque emotionality"* (Walter, 2009). Critics on media representations of terminal illness are sometimes grounded in a health-education perspective, where media are supposed to bring objective information about illness, rather than irrelevant facts about – for instance – the lives of celebrities who have cancer (Kilgore, 1996). Media, in a health-education model, are supposed to inform the audience objectively and quantitatively correct about health and illness rather than *"irrationally alarming the public at large"* (Williamson et al. 2011: 549) or, by reporting on scientific developments in the treatment of cancer that emphasises the 'amazing miracle' (Kilgore, 1996: 249), falsely raising hope with coverage that is deemed newsworthy. Health education perspectives thus draw on a view on journalism that focuses on the necessity of 'objective' and 'neutral' information. Henderson and Kitzinger (1999: 570), for instance, criticise the 'soft' coverage of breast cancer and invoke a health educator's complaint about inaccuracy, stressing the negative implications *"for those seeking to promote public understanding of cancer"*.

Criticising media coverage of (celebrity) suicide and illness, the studies discussed above seemingly draw on more encompassing critiques on process of initmisation, where the latter is often described in terms of "*dumbing down*" (Dahlgren 1992: 7), and where a media coverage that focuses on the private and the intimate is accused for substituting *"emotion for analysis"* (Macdonald, 2000, 251). Grounded in a modernist rationality-emotionality dichotomy, these critiques seem to identify with a 'traditional' articulation that describes journalism in terms of the rational transfer of socially and politically useful information rather than in terms of emotionality and dialogue (Meijer, 2001: 193). Media that thrive on intimate and emotional stories, it is argued along these lines, have the tendency to mask deep and complex problems, *"the things that journalists should be exposing"* (Harrington, 2008: 14).

A final set of arguments that is relevant in a discourse of the spectacle of death is one that points out the very *impossibility* of capturing the reality of death and suffering with media representations that always in a way prey on the suffering of others. Kearl (1989: 379) for instance argues that media portrayals of 'real' death and 'real' grief are rare, because the emotions and fears such portrayals provoke *"are too great, their exhibition too 'real' for the comfort of their escapist viewers go garner the viewer rating required to subsidise their production"*. With this, Kearl expresses the argument that media are in fact not capable of grasping the overwhelming emotions death and mourning evoke. The link between death and the media, so Kearl suggests, often simply is a failed one. A similar argument about the impossibility of representation can be traced in reflections about the representation of the Holocaust. After the release of 'Schindler's list' (1993), debates about the visualisation of the holocaust became the subject of debate between filmmakers, when Lanzmann – the maker of the Holocaust movie 'Shoah' (1985) – blamed Spielberg, driven by the rules of melodrama, for distorting reality (Kearney, 2002: 28). The argument of the impossibility of representation has also been echoed by academics. Lang (2000) for instance argues that any representation of the Holocaust in media, literature or art cannot ever convey the reality of its lived experience. Also Adorno has written about the representation of the Holocaust, and he brings the notion of Schadenfreude back into the picture, arguing that representing the holocaust in film always contains *"the possibility that pleasure can be squeezed from it"* (1997: 252).

1.3. Biased media coverage of death

A third discourse on death in the media has 'bias' as its nodal point, and evaluates coverage of illness and death against the journalistic ideals of objectivity, neutrality and accuracy as embedded in an 'information model' (Schudson, 1978). Research on death in mass media makes mention of bias in different ways, and a careful reading of this literature points in the direction of two types of bias reported on: bias in the form of an unrealistic coverage and coverage that is ideologically biased.

As for bias in the sense of unrealism, we may begin by quoting Clive Seale (2002: 45), who states that media, when reporting on death and its causes, are 'producers of unreality':

> "media images of death acquire a particular importance as sources of information about what causes death and what it might be like to die. It is therefore disturbing to see that death in media representations is not at all realistic and, further, that this really does seem to influence audiences into mistaken beliefs".

Along these lines, a number of scholars have pointed to the way media depict death and its causes in a misleading way, over-representing unusual deaths of unusual people. Walter et al. (1995) for instance report that the deaths reported in the media typically occur in a public place, while Seale (2004) notes that newspapers tend to place negative emphasis on deaths of people who die alone. Combs and Slovic (1979) found that newspapers over-emphasise homicides, accidents, and disasters while underemphasising ‘natural’ death causes. And in their study of illness causing death as depicted in the media, Williamson et al. (2011) determine an over-representation of certain types of cancer, flu/pneumonia and dementia and an under-representation of certain infectious diseases.

Critiques on the unrealistic reporting on death and its causes are seemingly formulated from a health-education perspective (see earlier), which pleads for an accurate and neutral representation. Starting from a health-education perspective, the argument goes that a biased coverage contributes to a “*culture of fear*” (Seale, 2002: 83). Over-reporting breast cancer and reporting on celebrities with breast cancer, for instance, is argued to result in an exaggeration of risk and an increased anxiety (Boudioni et al. 1998). Other studies, embedded within a similar media-effects paradigm, point in the direction of a myth of immortality rather than a culture of fear in relation to coverage of breast cancer. Elliott and Decker (2011) argue that by distributing narratives of success and shiny images of young, attractive survivors, media create the myth that people don’t die from breast cancer anymore. Seale (2002: 43) argues in similar vein, stating that portrayals of cancer are biased towards stories about people who conquer the disease.

While disagreeing on the ‘direction’ of the bias, the studies discussed above link inaccuracy in coverage to media’s hunger for sensation and spectacle, which is believed to threaten the ‘truth-speaking’ task of journalism. A similar traditional interpretation that defines journalism in terms of factual accuracy also underlies the study of Rietjens et al. (2013) about euthanasia in the media. The authors conclude that Dutch newspapers often use the term euthanasia for practices that are outside the scope of the Dutch euthanasia law, referring to practices such as the ending of life without a request of the patient, the forgoing of potentially life prolonging treatments, and assisted suicide by non-physicians. In criticising inaccuracy in newspaper coverage of euthanasia, Rietjens and her colleagues (2013) subscribe to a health-education perspective that, as stated earlier, is grounded in a traditional articulation of journalistic values such as objectivity and accuracy. As they echo in their concluding discussion:

> "Because newspapers are generally considered to be an important source of health information, this kind of definitional variability is likely to feed misunderstanding and confusion in public debates."

A second type of bias that is reported in research on death in the media criticises the ideological partiality of portrayals and coverage of death and dying. First, a number of scholars have focussed on the reproduction of dominant ideologies in news coverage of violent death. In his examination of killers and victims on US television programs, Gebner (1980) for instance argued that women and minorities were more likely to be represented as victims than others, hence reproducing a dominant gender ideology. Other scholars argued along similar lines; Moeller (1999) examines news reporting of death and concluded that mothers and their children were more often depicted as victims, while Seronson et al. (1998) found that women, children, and elderly victims of homicide were more likely the receive news coverage than other victims (Hanusch, 2010).

While there are quite some studies focussing on the reproduction of dominant ideologies through death-related news, like those mentioned above, I found few analyses studying 'death-ideologies' themselves in media representations. These rare studies I found focus on the representation of euthanasia and assisted suicide, which comes a no surprise knowing that these issues are very much linked to particular political ideologies. Publications that examine the interface between euthanasia and the media often report a bias in favour of euthanasia, which is exemplified by referring to a *"neo-liberal spirit"* (Birenbaum-Carmeli et al. 2006: 2154) a *"pro-choice world view"* (Somerville, 2001: 292) or *"a stereotype of the independent individual"* (Hausmann, 2004: 8) where a pro-choice position on euthanasia has become *"politically* *correct"* (Somerville, 2001: 295). According to Somerville (2001: 295), media professionals often endorse a liberal ideology that comes with a focus on personal autonomy and the right to self-determination, and, *"any infringement on these rights – especially prohibiting access to something, such as euthanasia, that they believe pertains only to the individual – is unacceptable to them"*. Studies that point to an ideological bias towards a pro-euthanasia position in the media sometimes make the link to broader normative frameworks where the media's hunger for sensation and drama is criticised. For Somerville (1997, 2001), it is the media's need to personalise and dramatise stories in order to capture a reader's or a viewer's attention that results in a pro-euthanasia coverage. Anti-euthanasia arguments, especially those based on potential harm to society in present and future, she argues, do not make dramatic and compelling television. Fran McInerney argues along similar lines, albeit from a more constructivist point of view, stating that Australian media portrayals of physician-assisted suicide often come with a dramatic representation of terminally ill people requesting for assisted suicide as *"victims in need of rescue from two malevolent enemies who would seek to thwart their request for death, namely medical professionals and politicians"* (2006: 659). Such a mode of representation, according to McInerney, potentially strengthens the justification of calls for requested death (p. 658).

1.4. Stigmatising media coverage of death

Closely related to the 'biased media coverage' discourse is 'stigmatising coverage' discourse. While critics towards bias in the media are often structured around concepts like objectivity, impartiality, and accuracy; research dealing with stigma in media representations of death and dying has the notion of 'fairness' as an underlying ideal. Not so much bias is criticised as the presence of stigmatising images, i.e. images that attribute a deeply discrediting label to a group that is considered 'different' from normal by society (Goffman, 1963), in media coverage. Although not dealing with media portrayals, the following quote from Moremen (Quoted in Bryant, 2003: 402) nicely illustrates the idea of stigmatising the ill and dying:

> "In them we see our own failure to beat back death. In their wasting bodies, we see the reflection of our own mortality. And because we reject this vision, we often reject them. It is from these origins that stigmas are born. We differentiate ourselves from their experience – they are the dying and we are the living. We are not like them."

In order to elaborate the 'stigmatising media' discourse, we must turn our attention to the field of the sociology of health and illness. In addition to research that looks into stigmatising media representations of a series of health-related problems and issues (such as mental illness, obesity, and infertility) that would diverts us too far from the focus on death and dying, there are a number of studies on media representations of chronic and terminal illness that contain reflections about the stigmatising nature of media representations. In particular research on the depiction of HIV/AIDS and cancer is worth dwelling upon here.

Research on the representation of AIDS in the media was mainly conducted in the 1980's and 1990's. Scholars (see for instance Herzlich and Pierret, 1989 and Watney, 1997) came to similar results, arguing that the media coverage of the disease stigmatised AIDS patients and the homosexual community by extension by describing the disease as a 'gay plague', 'homosexual pneumonia', or 'gay cancer'. In a more recent publication, Lupton (2010: 65) points to the stigmatising nature of the way media coverage of aids and other immune diseases suggests the 'deficient' immune system of patients: *"People whose immune systems are 'inferior' become members of a new stigmatised and victimised underclass".*

Media coverage of cancer has also been described as highly stigmatising. In 'Illness as metaphor', Susan Sontag (1991) argues that the recurrent use of metaphors referring to cancer as the ‘killer disease’, as ‘invasive’ and as ‘setting up outposts’ that ‘colonise’ the body create an image of cancer as the ‘dread disease’ (Patterson, 1989). In similar vein, Meira Weiss (1997) points to the negative discrimination against cancer and the stigma’s associated with cancer patients with the use of metaphors which represent the illness as transforming patient into an ‘other’ who becomes socially isolated. A number of scholars have observed the use of military metaphors in media representations of cancer, which entail the image of the ‘heroic’ cancer fighter who never gives in to the disease (Clarke & Everest, 2006: 2597), but stays optimistic, cheerful and strong and demonstrates a ‘coping attitude’ in facing the disease (Lupton, 2003: 72). The ‘winning the battle against cancer’ metaphor has also been criticised because it could result in the patient being held culpable for not being ‘strong’ and ‘positive’ enough to conquer the disease. In this context, Sontag suggests that the common tendency to view cancer as the result of internalised and bottled-up stress and anger constitutes *“a powerful means of placing the blame on the ill; patients who are instructed that they have, unwittingly, caused their disease are also made to feel that they have deserved it”* (1989: 57).

Critiques on the stigmatising nature of media representations of illness can, as suggested earlier, be linked to the ideal of ‘fair’ representation. Fair representation is one of the criteria for media to be socially responsible formulated by the Hutchins Commission (1947) (see earlier). Following a social responsibility of the press model, media are required to project a representative picture of the different groups in society (Severin and Tankard, 1992: 37). This means that racial, social and cultural groups should be represented without stereotypes. Social responsibility, thus, requires an affirmative role for the media in building positive images. Traditionally, the social responsibility of the press in avoiding stereotypical (and stigmatising) images refers to the representation of class, ethnicity and gender. However, a same social responsibility argument might be applied to the representation of the ill and the dying as well, emphasising the media’s responsibility of avoiding stereotypical and stigmatising representations which might contribute to a social isolation of these groups.

2. The construction of representations of death in the media as emancipating

Four discursive approaches that provide a rather pessimistic analysis and reading of media representations of death and dying have been identified above. It has been shown that these approaches draw on more traditional interpretations of what 'good' journalism should be and on more pessimistic evaluations of processes that are argued to mark contemporary media landscapes such as tabloidisation and intimisation. In addition to these four pessimistic discourses towards death in the media, a number of alternative discourses can be traced when linking existing literature on death in the media to normative evaluatory frameworks on media and journalism: engaging and mobilising media coverage of death, 'binding' media coverage of death, and 'learning' media coverage of death. These discourses stress the potentially productive, emancipatory and empowering nature of media representations of death and dying.

2.1. Engaging and mobilising coverage of death

A first discourse that stresses the potential emancipatory and empowering nature of media portrayals of death and dying is one that emphasises the engaging power of these portrayals and in so doing offers a radically different interpretation of the signifier of 'emotion'. In research on war and conflict in the media, Barbie Zeliser's work is illustrative of this articulatory logic. With her book 'About to Die', Zeliser (2010) argues that images picturing death or impeding death engage people with what they see. These images, she argues, cannot be understood 'rationally'; they do not 'objectively' inform us about a news event, but they speak to our emotions. Lilie Chouliaraki (2008) equally stresses the engaging potential of news accounts of death and suffering, albeit under specific circumstances that are often not present in media representations. She states that news depictions of suffering actively engage the spectator with the distant sufferer when including verbally and visually rich narratives as well as aesthetically complex and contexualising presentations. Patching and Hirst (2014: 188) do not formulate verbal context as a criteria for engagement. Countering a compassion fatigue thesis, they state:

> "Such emotion-charged pictures put a human face on tragedy and have moved nations to action – over political issues, over famines in developing countries, over examples of cruelty in times of conflict – and they have also led to soul-searching by the public".

Rather than articulating media images of war and death in terms of de-sensitisation, then, their political potential is stressed. This is also voiced by Howarth (2007: 105), who argues that cinematic portrayals of war as *"immoral games of the ruling elite"* can contribute to the formation of 'communities of resistance'.

Focussing on the representation of requested death, Fran McInerney argues along similar lines. According to her, social movements - such as the requested death movement - increase their chances of mobilising people when they court the media's attention. McInerney, and others who stress the mobilising nature of media representations of (politicalised) death-related issues (such as requested death, war and conflict) draw on a broader theoretical framework on media and political agency/mobilisation. McInerney for instance quotes Klandermans (1988: 174) who states that media, by picking up a certain issue, often trigger an increase of public awareness about it and – by making the issue more 'real' – stimulate mobilisation. McInerney goes on to argue that (popular) media's tendency to personalise news, and the issue of requested death in particular, facilitates and encourages mobilisation. An individual, via his or her representation in the media, represents a broader social and public concern (Scritchfield, 1995: 131). McInerney is seemingly inspired by the arguments of Gamson (1995), who argues that mobilisation is facilitated when media adopt a frame of injustice that provokes emotional responses such as compassion and anger by transforming impersonal and abstract forces of unfairness into concrete human actors that do injustice to individuals and groups we can identify with. From this perspective, emotion and more specifically the display of emotion in the media that is often criticised, is revaluated by stressing its potential mobilising and democratic force (Harrington, 2008).

2.2. Media coverage of death and social cohesion

Closely related to the discourse that stresses the engaging and mobilising potential of media people is one that highlights the potential of these representations to enhance social cohesion. In particular research that is embedded within a more culturalist tradition tends to make note of the binding potential of media representations of death and dying. Walter et al. (1995), for instance, focus on news coverage of disasters, which is argued to bring people together on the basis of their mere humanity; affirming the (Western) value of human attempts at rational control over nature through technology or, when the death of children is at stake, the value about the importance of children's lives. Walter (2006: 275) further argues that news media represent the evil, threatening and disturbing nature of death and disaster, but at the same time offer an affirmation of the *"ordinary, and sometimes extraordinary, goodness of the local community"*. Other studies, which constitute a fairly well established research tradition, link media coverage of death to the construction of national identities.

According to Seale (2002: 122), the coverage of the deaths of national leaders offers occasions for the enforcement of national feelings. He gives the example of the ritualisation of the death of Lincoln, where newspapers converted him into a sacred symbol that triggers and furthers national sentiments. Similarly, a number of scholars analysed the death of princess Diana (see for instance Turnock, 2000; Walter, 1999), whose funeral became a media event that constructed and enforced national identity through public mourning rituals (Hanusch, 2010, Pantti & Sumiala, 2009; Turnock, 2000). Not only the death of national leaders are reported as occasions for the mobilisation of national feelings. A number of authors (Walter et al. 1995; Pantti & Sumiala, 2004) have looked into tragedies that involved the death of either a substantial number of victims or victims with exceptional symbolic value to the community and argue that media coverage of these tragedies equally provokes feelings of national unity through describing the collective experience of shock and grief, which is sometimes accompanied by symbolic actions such as putting up flags at half mast (Pantti & sumiala, 2009).

Research describing the way coverage of death and dying 'joins' people together often draws on a theoretical framework on media and ritual, existing at the intersection between ritual studies and media-and communication studies. This theoretical framework argues that ritual is deeply affected by the media – that rituals are 'mediated' (Cottle, 2006; Couldry, 2005). The concept of the mediated ritual refers to the way media not only report rituals, but "performatively enact" them. Studies on media and mourning rituals often combine the concept of the mediated ritual with the more sociological thanatological argument that death deeply disturbs the social order by destroying the faith society has in itself and that bereavement rituals serve to repair the damaged social order (see e.g. Kearl, 2009; Howarth, 2007). Also for van Gennep (1960: 147), mourning is a transitional healing period for survivors.

Research where the binding nature of representations of death either implicitly or explicitly prevails, comes – like in the articulatory logic of 'engaging' media coverage - with an alternative evaluation of a focus on emotion and the intimate. Rather than arguing that the visibility of death and rituals relating to death, such as funerals and memorial services, are to be regarded as a perverse voyeurism, this visibility is approached as having a potential democratising force, *"promoting social and cultural inclusion"* (Harrington, 2008: 15).

2.3. ‘Learning’ media coverage of illness and mourning

A final discourse that can be traced through a meta-reading of existing literature on death in the media is one that puts the emphasis on (popular) media coverage of death as a ‘learning’ device that, mainly through the focus on personal experiences, distributes (popular) forms of knowledge. Like the ‘biased media coverage’ discourse, it has ‘information’ as a nodal point, but rather than relating the concept to traditional journalistic values such as objectivity, impartiality and factuality, it interprets the notion of information through alternative perspectives on the public sphere.

A first research area where a ‘learning media’ articulation appears is that of terminal illness in the media, where Clive Seale’s formulates critiques on the arguments of Lupton and others about the stigmatising nature of cancer representations (see earlier). Studying media accounts of cancer, Seale (2001, 2002) sates that the use of ‘fighting’ metaphors (such as the ‘struggle’ or ‘battle’ against cancer) in media depictions of people with cancer allows the illness to be portrayed as a psychological and spiritual journey, even when death awaits at the end. Seale speaks of a ‘psychological discourse’ on illness that has the capacity of inspiring patients who ‘learn’ how others experience the disease through the media. McKay and Bonner (1999) argue along similar lines, stating that personal stories about breast cancer in the media, in particular those focusing on ordinary people help women to deal with the experience of illness. Celebrity stories of cancer, on the other hand, would often fail in inspiration and moral help. Jade Goody’s mediatised cancer, according to Ashton’s reception analysis (2014), are regarded as “*distant and unidentifiable*” (p. 131) compared to personal experiences.

Unlike a health-education perspective, accounts like those of Seale and McKay and Bonner highlight the emancipatory potential of media, seeing personal stories on cancer in the media as places where ‘alternative’ forms of knowledge are distributed – containing not so much scientific knowledge as knowledge that entails a therapeutic potential through the personal stories that offer existential and moral help. Such a perspective draws on a more encompassing normative framework on popular media and journalism that, rather than seeing a focus on emotion and the intimate as a form of 'dumbing down' of the serious news agenda, applauds the presence of often silenced voices and thus endorses the view that such intimate coverage approaches audiences as human beings rather than as citizens (Gripsrud, 2008: 44). Stories about the tragedies, but also *"triumphs and achievements of ordinary people"* (Gripsrud, 2008: 43) can, following such a perspective, be understood as contributing to an 'alternative' public sphere, were *"different people debate different issues in different ways"* (Ornebring and Jonsson, 2008: 25). These stories, so the argument goes, can be regarded as legitimate forms of knowledge (Machin and Papatheoderou, 2002: 46). In this approach, 'traditional' journalistic values of neutrality and factuality are not considered priority. Rather, dealing with people's personal *"lives, joys, tragedies"* (Graber, 1994: 212), it embraces the subjective and the authentic – two values central to 'new journalism' (Wolfe, 1973) and 'human interest' journalism (Harrington, 1997, Meijer, 2001).

A similar revaluation of the emotional, the private and the subjective seems to underlie the analysis of Walter et al. (2007) on the portrayal of grief and mourning in the media. According to Walter et al., news coverage that is often described as 'sensationalist' and 'intruding into the relatives' grief, allows people to make sense of death and dying in an area where grieving rituals have become de-traditionalised. Walter at al. (2007) formulate three hypotheses about the way media representations of grieving and mourning after disaster function in a 'learning' way. A first hypothesis is that, with the demise of Victorian mourning rituals, (Western) people no longer know how to behave both as griever and towards those who grief. As a consequence, people show intense interest in media accounts depicting mourning that learn them how their fellow citizens cope with loss and bereavement. A second hypothesis is that there is a culturally accepted norm of proper grief, one that on the one hand encourages people to express their feelings and on the other hand is boundd them by the cultural ideal of self-control and stoicism. Media representations of grief and mourning that show how others pull off this delicate task thus act as useful learning resources. A third, and closely related, hypothesis refers to the ideal of expressivism that is often endorsed by experts on bereavement advising us to 'express our feelings'. Walter et al. argue that while expressivism - stating that 'letting out our grief' is only natural - has become increasingly 'trendy', it remains true that the public display of grief is strongly governed by socially constructed rules. Expressivism does not say anything about those rules and as a consequence leaves *"millions of would-be expressivists rather confused"* (Walter et al. 2007:24). People thus turn to media representations of grief and mourning to be offered guidelines as to which situations are appropriate for expressing grief. In hypotheses two and three which Walter et al. believe to be more likely than hypothesis one, media *"instruct audiences in the acceptable ways of dealing with grief"* (2010: 125).

A similar analysis is offered by Pantti and Sumiala (2009), who studied media coverage of seven national tragedies in Finland and argue that this coverage disseminates cultural 'norms' of proper grief and mourning. They also point to the role of the representation of 'ordinary people', who are often key actors in media coverage of grief and mourning. Their role, for Pantti and Sumiala, is to set an example for the appropriate public display of emotions, whether it is in private grief, in the semi-public setting of funerals, or in more active and public mourning (like bringing flowers and candles to accident sites). This argument about ordinary people can, again, be linked to a broader normative stance that applauds the presence of the experiences of ordinary people in media accounts, for these experiences then gain public relevance, "*granting them (possible) political relevance*" (Livingstone and Lunt, 1996: 102). Stories that centralise (ordinary) people's experiences can thus be seen as *"serving the public good"* (Ornebring and Jonsson, 2004: 284) because they help people thinking about existential matters, like loss and bereavement, that individuals and groups encounter in their everyday life (Gripsrud, 2008: 42).

PART C: DEVELOPING A METHODOLOGICAL FRAMEWORK FOR THE DTA OF MEDIA REPRESENTATIONS OF THE MEDICAL DEATH AND THEIR AUDIENCE RECEPTIONS

“Like theories, methodologies cannot be true or false, only more or less useful” (Silverman, 2009 110)

Research, as Hammersley and Atkinson (1994: 23) rightfully argue, is *"a practical activity requiring the exercise of judgement in context"*, and *"is not a matter of simply following methodological rules"*. In somewhat similar vein, Andersen (2003) warns against methodological purism, focussing exclusively on 'how' questions rather than on 'what' and 'why' questions. Andersen goes on to emphasise the importance of adopting a reflexive *research strategy*, calling for an awareness of the researcher in terms of the implications of his choices; realising that a particular choice could be made differently with different implications. While Andersen is right in drawing attention to the way methodological choices are inevitably embedded in philosophical presuppositions, it is at the same time important not to lapse into an extreme relativist position resulting in the disposal of methodology all together. It is indeed important to note that while the socially and culturally embedded nature of scientific knowledge cannot be denied or neglected, conducting research systematically on the basis of a specific set of rules provides a way to deal with the contingency that marks the nature of every type of knowledge production. Investing in the development of a proper methodological framework helps making the research scientifically legitimate, and distinguishes it from other types of knowledge (see chapter I).

This dissertation draws on Silverman's (2001: 3) definition of methodology as *"a general approach to studying research topics"*, which allows us to construct a methodological framework (in a flexible way) that is above *useful* to study the phenomenon under analysis. In this case, this means that the development of a methodological framework should provide useful support to explore the 'putting into practice' of discourses in a specific meaning-making environment: that of Belgian media representations of the end of life and audiences' receptions of these representations. That Silverman's definition allows for the construction of a useful methodological framework where the researcher borrows concepts from and shops within different approaches does not imply however that 'anything does'. It is indeed crucial that the methodological framework is compatible with the premises of discourse theory; in this way, the methodological framework ensures coherence between the different parts of the dissertation. Coherence, in turn, adds to the validity of the research (see part A).

The development of a methodological framework is crucial, finally, for the simple reason that tracing down discourses in textual material is not an easy task. A well thought-out methodological framework needs to assure that the analysis surpasses a *"kind of retelling of the materials themselves"* (Barker, 2003: 331), and that the analysis is fact becomes an analysis of the interplay between discourses, the way they are operationalised in media articles and the way audiences identify with them in producing talk about these articles (in the setting of the qualitative interview).
The development of a methodological framework for the analysis of both media contents and audiences' receptions of these representations occurs in different phases. In chapter X, discourse-theoretical analysis (DTA) is first situated in the field of discourse analysis by discussing the approach taken on both text and context - as it is indeed a text-context dimension that runs through the broad field of discourse analysis and taking position on the text-context axes comes with a set of premises underlying the analysis. The chapter goes on to describe discourse-theoretical analysis as a macro-textual and macro-contextual approach, and then elaborates on how this perspective is operationalised in the two analytical phases central to this research. Chapter XI works towards the development of a 'workable' methodological framework; one that overcomes the 'methodological deficit' inherent to discourse theory and that allows for the discourse-theoretical analysis of the construction of the good death in both media articles about the end of life and receptions of these articles. Integrating the procedures of qualitative-interpretative analysis into a DTA does exactly this.

Note, finally, that this part of the dissertation deals with the development of a methodological framework that translates discourse theory into discourse-theoretical analysis. The more practical issues of corpus-construction are discussed in parts D and

E, which respectively with the discourse-theoretical analysis of media representations of the good death and audiences receptions of these representations.

Chapter X: Discourse-theoretical analysis and the text – context dimension

Discourse analysis, according to Teun Van Dijk (1997: 3), concerns the study of "*talk and text in context*". This definition, however, hides a great diversity of approaches that marks the field of discourse studies. This diversity can be understood in terms of different approaches to both 'text' and 'context'. Roughly speaking, we can distinguish micro-textual and micro-contextual approaches to the analysis of discourse from macro-textual and macro-contextual approaches (Carpentier & De Cleen, 2007). A discourse-theoretical analysis adopts both a macro-textual and a macro-contextual approach to the analysis of textual material. These approaches, as will become clear, have concrete implications for the way both the contents of media articles and their audiences' receptions are analysed.

1. Text and context

In micro-textual approaches to the analysis of discourse, the notion of text basically refers to spoken language. This narrow approach to text is for instance adopted in socio-linguistic rhetoric analysis and in conversation analysis. Sometimes the definition of language is broadened, when also written documents and audio-visual material are defined in terms of discourse. Such a broader definition of language is for instance adopted in the tradition of Critical Discourse Analysis, where a text refers to language in use (Fairclough, 2003: 3). A macro-textual approach, which marks an analysis based on and guided by discourse theory, defines not only language in its narrow or broad sense as text; but any materialisation of meaning; written and spoken words, images, sounds, gestures, as well as physical architectures, institutions, organisations, practices etc. (Carpentier & De Cleen, 2007, Howarth, 2000); all materialities that carry meaning and that people make meaning from (McKee, 2003: 4). An empirical study grounded in discourse-theory, therefore, may include an analysis of texts as diverse as those mentioned above. A macro-textual approach comes with an interest in meanings, i.e.; representations, ideologies, belief-systems, rather than in pure linguistic aspects. This particular analysis looks at two sets of texts: media articles and audiences' talk about these articles. At this point, the question may arise as to why this sort of empirical material, i.e. written and spoken texts, was chosen, considering the above-elaborated macro-textual approach. A macro-textual approach of course does not exclude written and spoken texts from the range of discourse-theoretical analysis. Important, however, is that within the logics of discourse theory, the aim of an analysis is to draw conclusions that transcend the individual text and that make the connection to more encompassing discourses. We could argue, then, that media articles and talk about media articles provide specific entry points for the analysis of discourses circulating in society.

A text under analysis is always contextually embedded. For Blommaert (2005: 39), context – for discourse analysts – concerns the question about the way in which the discourses under analysis *"become part of, get integrated in, or become constitutive of larger activities in the social world*". The question of context, according to Goodwin and Duranti (1992: 3), is basically a matter of the *"use of background information"*. Different approaches to discourse analysis hold different views on what this background information encompasses and to what extend it should be incorporated into the analysis. In discourse analysis, context is generally understood as the way in which the discourses under analysis (Blommaert, 2005: 39). Depending on the view being taken to discourse, scholars either lean towards a focus on macro contextual aspects like social categorisations and structures of social life or towards micro levels of social interaction. It is in this respect that Carpentier and De Cleen (2007) claim for distinguishing between macro and micro approaches to context. Micro-contextual approaches, while not neglecting or denying the significance of broader social categorisations and structures, generally take on board only limited aspects of context, for instance the specific social setting of a conversation. In the macro-contextual tradition of discourse theory, context refers not only to conventions related to a genre of text, but also to the broader environment in which the text is situated, and which enhances understanding of that text. Indeed, the meanings produced in a text can only be understood within a broader societal context within which individuals produce meaning. A macro-contexutal perspective, it should at the same time be noted, does not imply that 'all' aspects of contexts *should* be taken on board when conducting a discourse-theoretical analysis. Indeed, as context is not finite in any sense, and cannot be described exhaustively (Verschueren, 2012: 58), some aspects of context – those that are actualised in the texts under analysis – may be deemed more relevant. The above brings us to a second, related, dimension; that of structure-agency. This thesis, as already became clear, holds a position that balances between an emphasis on the importance of discursive structures and an approach that stresses individual agency. The dissertation subscribes to the view that individuals are shaped by social structures and dominant discourses, while at the same time these discourses are contingent and depend for their reproduction on the agency of individuals. Concretely: the meanings that are inscribed in the texts under analysis reflect existing discourses and structures, but they are not 'mere' representations of them; they are 'mediated' by human thought and interpretation. Indeed, discourses themselves do not act or speak; they are given a voice through human agents.

2. Text and context in the analytical flows

What does the above-elaborated approach towards text/context (and structure/agency) imply for the analysis of media contents and their audiences' receptions in very concrete terms? More specifically: how are the texts under analysis contextually embedded; what aspects of context are taken on board during the analysis and how? To answer this question, we turn our attention to the three flows of meaning-making and signification that structure this discourse-theoretical analysis: operationalisation, interpretation and identification. On the basis of the discussion below, a more elaborated version of the visualisation of the three research flows can be presented; one that adds contextual aspects as well as the actors involved in the signification processes.

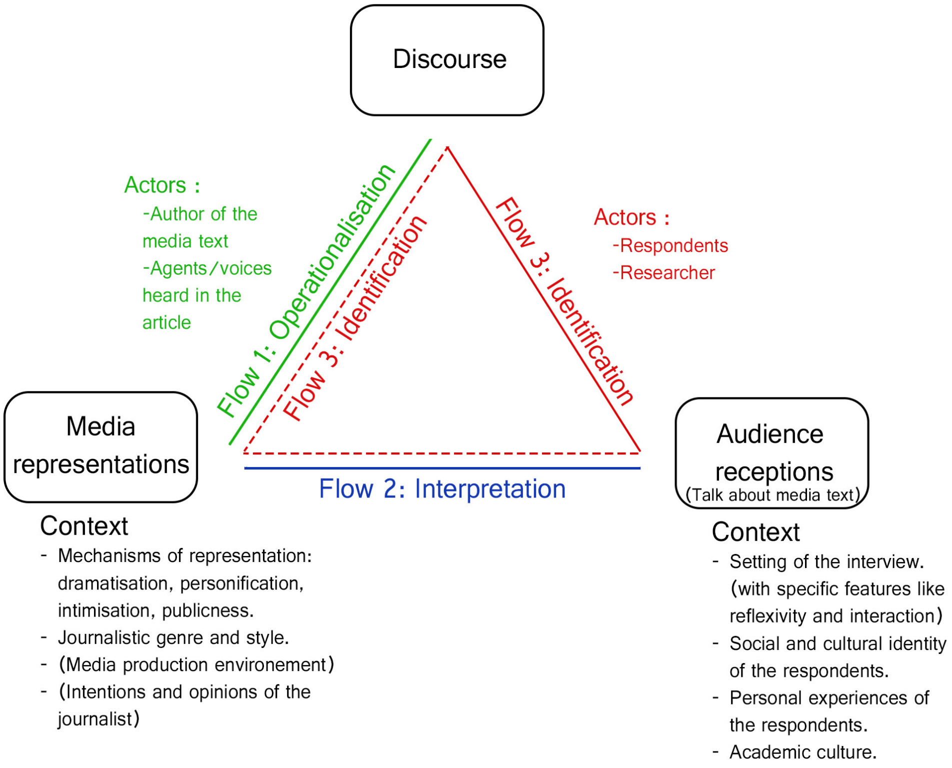

Figure 5: text-context-actors

2.1. Flow I: Operationalisation

The aim of the representation analysis is to gain insight into the way discourses and systems of meaning are operationalised in the contents of media articles about the end of life. The analysis is guided by two research questions:

- **How, and following what media-specific logics of representation, does the Belgian print media coverage of the medicalised death operationalise particular discourses on death and the good death (with their respective nodal points)?**
- **What are the normative stances or discourses on good journalism (in covering the end of life) that are operationalised in media representations of the medicalised death?**

The notion of text, in the representation analysis, refers to a selection of Belgian print-media articles. Drawing on the macro-textual approach to discourse, however, it is the aim to draw conclusions on a supra-textual level. This objective is theoretically supported by the concept of operationalisation (see chapter III), which refers to the way discourses are put into practice in media representations and manifested in the 'materiality' of the media article. This operationalisation, as explained earlier in this thesis, follows media-specific logics of representation, such as dramatisation and personification (see chapter III). If we want to achieve an in-depth understanding of the media articles under analysis and way meanings are inscribed into them, we must take on board these logics as contextual information. Also the journalistic genre to which the article belongs - so called quality journalism on the one hand and popular journalism with its frequent reliance on techniques of 'human-interest' journalism on the other - potentially enhances the knowledge of the texts under analysis, and is therefore taken on board as context. Throughout the DT representation analysis, I will be attentive for the way media-specific logics of representation and their connection to specific media genres and journalistic styles facilitate or hamper particular constructions of the good death. Doing this allows us to avoid a discursive reductionism, where texts are merely the 'effects' of deep-rooted discursive structures (Howarth, 2005), and to hold an approach that sees media contents as materialities that operationalise discourses in *specific* ways; in ways, that is, that are potentially different from the operationalisation of discourses in other textual genres.

In addition to media-specific logics of representation that are manifested and actualised in the texts under analysis, there are other contextual aspects that make media-texts specific and different from other types of texts. A representation analysis does not give access to all of these aspects, however. We know, for instance, that media-economic aspects, regulatory frameworks regarding media and journalism, journalistic routines and so on impact on the media product. While it is acknowledged that these aspects of context constitute a particular discursive structure that limits the freedom (the agency) of producers and authors of media contents, it is outside the scope of this thesis' focus on meaning to elaborate and take on board these contextual aspects. It can be expected, moreover, that these contextual aspects impact on the eventual media product, but not in a way that affects the way taken for granted systems of meanings that circulate in society become subtly materialised in media contents. Finally, there are the individual intentions and opinions of the authors of the articles, to which the chosen method does not give (direct) access. As should be clear by now, meanings inscribed in media texts are viewed here as transcending the intentions and opinions of the individual journalist. The author of a media article inevitably draws on existing discourses that circulate in society; discourses that provide him with meanings and subject positions that in turn allow him to 'speak'.
Yet, in order to deal with the fact that we have no access to the intentions of the authors of the media texts, the analysis is based on multiple textual features, which prevents it from taking textual ingredients that are inserted on purpose by the journalist for ideological aspects.

Next to the above-discussed dynamics of structure/agency operating on the level of the production of the media article, the media article itself is marked by dynamics of structure and agency. With this, I refer to the voices present in the article, which include not only the voice of the author but also the voices of a variety of other actors who are represented and 'heard' in the article. Discourses are often materialised in the media article via subjects who 'give a voice' to these discourses (as mentioned earlier, discourses themselves do not 'speak') – media articles thus contain representations of actors engaging in discourse, and these representations can be more direct (for instance when actors are interviewed, or quoted), or less direct (when they are for instance paraphrased). The focus on meanings and discourses inscribed in media text makes it in a way less 'important' who expresses a particular argument. At the same time, it is crucial to be transparent about which type of actor (a medial professional, an academic, a patient, …) expresses an argument in the text – for discourses cannot be isolated from the fields in which they circulate. At the same time, it is crucial to note that actors, in the DT representation analysis, are not threated differently in terms of 'hierarchy'. The voice of a patient, the voice of reader, the voice of a doctor, the voice of a professor etc. are seen as equivalent in the sense that they articulate elements of discourses rather than 'the truth'. Different types of actors can of course appeal to different types of 'knowledge' (including medical knowledge, emotional experiences, and so on), which results in a particular usage of discourses.

2.2. Flows II and III: Interpretation and identification

A DT-inspired reception analysis is used to look into the signification flows of interpretation and identification. By drawing on the theoretically elaborated assumptions about the active audience (chapter III), it studies the way people attribute meaning to media articles about the end of life and end-of-life decision-making (flow II) and in so doing use and identify with discourses and subject positions (flow III). The following research questions are answered by means of a DT reception analysis:

- **How do audiences interpret the Belgian print media coverage of the medicalised death and in so doing identify with more encompassing discourses on death and the good death?**
- **What discourses on 'good journalism' are inscribed in the audiences' interpretations of the media coverage of the medicalised death, i.e. with which discourses on good journalism do they identify?"**

To analyse audiences' practices of interpretation and identification, the method of qualitative interviewing is adopted. During these interviews, respondents generate talk - talk, that is, *about* media texts. Talk, here, refers to the ensemble of concrete utterances through which the audience members participating in the interviews interpret the media articles under discussion and identify with discourses. The notion of talk is borrowed from conversation analysis; a discourse-analytical tradition that studies talk in interaction (Sacks, 1972; Goffman, 1967; Psathas, 1995). In this research, talk as such is not the primarily object of interest. Rather, talk is approached as a discursive device, where one can retrace utterances to more encompassing discourses by looking at markers of identification and dis-identification voiced by the audience members who partake in the interviews. Talk about media text, then, is analysed here as a text that contains materialisations of discourses.

In analysing talk as text, a number of contextual factors are taken into account. First, there is the aspect of social context; respondents occupy certain social positions, which give them access to certain types of knowledge they bring into their encounter with media contents. In the case as hand, the interpretation and identification practices of three main audience categories are studied, including members of the general public, medical professionals, and relatives of deceased persons. An underlying assumption is that these groups uphold different types of knowledge about, and have different experiences with the end of life - which potentially impacts on the way they receive media representations of the end of life. At the same time, it should be noted that tracking down whether, how and to what extent different interpretation and identification practices can be linked to particular experiential, social, cultural, professional and/or socio-demographic contexts is difficult and potentially tricky. With this in mind, I well set out a discourse-theoretical argumentation for the selection of three categories of audiences later in this thesis (see chapter XIV).

A second key contextual factor is the interview setting as such. Interpretation is a social process, as we indeed often engage with media texts in social settings (Fairclough, 2003; Croteau & Hoynes, 2014: 263). Also the 'staged' setting of the qualitative interview constitutes a particular social context in which interpretation takes place; it functions as a discursive structure in which the production of meaning takes place. Key characteristics of the setting of the qualitative interview are interaction and reflexivity. I will extensively elaborate on these characteristics later (see chapter XIV). Important to note at this point is that the setting of the qualitative interview, with its distinctive features, to some extent has a determining influence on the talk produced by the respondents – even only through the posing of questions that are, inevitably, always framed and formulated in particular ways. This, in turn, boils back to the role of the researcher in the process of qualitative interviewing, who conducts the interview from a specific academic (as well as personal) background. Again, I will discuss the discursive activity of 'asking questions' in the qualitative interview later in this thesis (see chapter XIV). Not only the two aspects of context discussed above limit the agency of the interview respondents. Like authors of media articles, audiences are embedded within a certain discursive formation; in engaging in the production of talk, they draw on existing discourses circulating in society. These discourses provide individuals with the subject positions they can (dis-)identify with and that allow them to speak. Audiences bring to their encounter with media contents personal experiences and knowledge, which are shaped by these more encompassing discourses that they internalise by what they read and hear in the media, by what the learn at school and so on. At the same time, and as will become clear throughout the reportage of the analysis that follows later, audiences are creative in combining elements of different discourses; they are capable of negotiating discourses and of resisting them as well.

Chapter XI: Towards a DTA methodology

Now that it has become clear what exactly is analysed - both in terms of text and context - we can turn our attention to the development of a workable analytical framework grounded in discourse theory. In order to come to such a framework, this chapter begins by discussing the so-called 'methodological deficit' inherent to discourse theory (Torfing, 1999; Zienkowski, 2012; Howarth, 2005; Glynos & Howarth, 2007). Building on Siverman's (2001: 3) definition of methodology as a general approach to studying research topics, the chapter goes on to integrate the analytical procedures of qualitative-interpretative content, i.e. the procedures of coding data on the basis of a number of sensitizing concepts, into a DTA. The qualitative-interpretative approach indeed provides us with a number of relatively stable analytical procedures that can nonetheless be combined with the methodological principle of openness and the research-strategy of theory-supported investigation that was set forth in part A of the thesis. In a last part, finally, the chapter discusses how DTA of media articles and their receptions works – as a method - in practice, and the way – more concretely – the coding process relies on a number of clusters of sensitizing concepts.

1. Overcoming the methodological deficit

A widely spread critique discourse theory (still) faces, concerns its lack of engagement with methodology. Throughout the years, several scholars (including discourse theorists themselves) have pointed to the lack of methodological operationalisation under the banner of the methodological deficit. Howarth (1998: 288) has recognised this methodological deficit with the argument that the discourse-theoretical rejection of essentialism makes the development of a methodology particularly difficult. Torfing (2005: 25), in similar vein, has argued discourse theorists *"have thrown the methodological baby out with the epistemological bath water"*. In recent years, discourse theorists themselves have responded to this methodological deficit. In "Applying Discourse Theory", Howarth (2005: 317) clarifies the way discourse theorists often shy away from detailed methodological and analytical questions by distinguishing discourse theory from discourse analysis. Discourse theory, Howarth (2005: 318) argues, is *"not just a toolkit designed to analyze 'language in use'"*. At the same time, Howarth (2005: 318) leaves room for an integration of discourse theory and discourse analysis when he acknowledges that the various tools of discourse analysis can provide the researcher with a set of techniques that help him/her interpreting and explaining empirical phenomena. In 'Logics of Critical Explanation in Social and Political Theory', Glynos and Howarth (2007) go on to bridge between discourse theory and more linguistic approaches of discourse analysis by stressing the importance of paying attention to the languages and vocabularies by which subjects articulate themselves. Also in 2007, Carpentier and De Cleen published an article where discourse theory is brought into media analysis, also answering to the methodological deficit in discourse theory. Carpentier (2010) goes on to provide media scholars with guidelines for the operationalisation of discourse theory into discourse-theoretical analysis (of media material).

Despite the responses and attempts to operationalise discourse theory, methodological guidelines and tools for the application of discourse theory remain fairly vague. Torfing (2004: 25) acknowledges that a main challenge of discourse theorists today indeed concerns the issue of method. As he puts it:

> "We should not surrender to the positivist obsession with method that is founded on the belief that the observation of a set of methodological rules somehow guarantees the truth of the research results. However, we need to reflect, openly and critically, upon the many methodical choices that we make in the analysis of specific discursive formations".

The development of a practical research design begins with the observation that DTA should not be seen as a clearly defined method, but rather as a analytical frame informed by the assumptions of discourse theory, in which a variety of methods, techniques, procedures, and concepts can be integrated – on the condition that they are made compatible with DT's assumptions. In the development of an empirically usable research design, there first of all is a need for analytical procedures. The study of both media articles and audiences' talk about these articles relies on the analytical principles set forth in the literature on qualitative-interpretative content analysis and more specifically adopts the analytical procedure of coding data on the basis of a number of sensitizing concepts. It is important to note at this point that the procedures of qualitative-interpretative content analysis are adopted both in the analysis of media contents and in the analysis of audiences' receptions of these representations. The notion of content analysis, in other words, refers to the analysis of contents of *any* textual material (including for instance talk produced in the setting of the qualitative interview), not only to the analysis of media contents.

2. Analytical procedures of qualitative-interpretative content analysis

Qualitative content analysis (QCA) (Altheide, 1987; Strauss & Corbin, 1998; Wester, 1995) is not tied to any specific conceptual or theoretical framework and can therefore be adopted in an empirical research regardless of any concrete approach to discourse. Consequentially, QCA can quite easily be integrated in a methodological framework based on the assumptions of discourse-theory. This would be much harder in the case of, for instance, semiotics, narrative analysis or framing analysis – which are approaches that (unlike QCA) subscribe to a specific approach to discourse that is not always commensurable with DT. The relative independence of QCA from any conceptual framework does not imply that 'anything goes', however. Unlike the notion of textual analysis that refers to a very diverse range of methods for analysing texts both quantitatively and qualitatively, QCA proscribes well-developed procedures for the systematic qualitative analysis of a large corpus of texts.

The qualitative-interpretative variant of content analysis was developed in response to the dominance of quantitative content analysis, which is *"a summarizing quantitative analysis of messages that relies on the scientific method (including attention to objectivity-intersubjectivity, a priori design, reliability, validity, generalizability, replicablity, and hypothesis testing) […]"* (Neuendorf, 2002: 20). Qualitative content analysis, similar to the quantifying variant of content analysis, works with categorisation (Hseih & Shannon, 2005; 1278); sorting pieces of data and linking them to each other. This is done through the process of coding, through which links between the data and particular (theoretical) categories are established. In contrast to quantitative content analysis, qualitative content analysis moves iteratively from more open categories to (Strauss & Corbin, 1998) – emerging through a process of open coding, to a refined categorisation system – established through a process of axial coding - that allows for the formulation of answers to the research questions.

In QCA, the process of coding comes about through a systematic, yet interpretative reading of the data, where - as opposed to quantitative analysis' attempts to objectify the analysis and to limit the subjectivity of the researcher - the subjectivity of the researcher is acknowledged (Altheide, 1987: 65; Wester, 1995: 137). Whereas quantitative content analysis limits itself to manifest contents, QCA is above all interested in latent contents (including what is not there), which implies that content cannot simply be read in the data; content has open qualities and that what is not present in the data is also of interest (Kohlbacker, 2006; Wester, 1995). In addition, the contents of a text are always situated within a broader context, which is another point where QCA distinguishes itself from quantitative content analysis – where scholars indeed generally pay less importance to context (Titscher et al. 2000: 67). A last main difference between qualitative and quantitative content analysis concerns the research process. Whereas quantitative content analysis relies on a pre-defined codebook listing all categories, qualitative content analysis follows an iterative research logic where concepts emerge and become refined throughout the analytical process (Altheide, 1996: 15-16; Wester, 1995). QCA, in short, is clearly different from quantitative content analysis on a number of levels, and the difference between both forms of content analysis goes beyond the mere fact that qualitative analysis does not involve counting.

Despite these main characteristics qualitative approaches to content analysis share, qualitative content analytical approaches differ significantly on a number of aspects. The most well documented aspect where QCA approaches differ from one another is that of the hierarchy between theory and data. Two main approaches are generally distinguished here: the inductive approach and the deductive approach. The inductive approach is guided by the ambition to 'discover' theory (Dey, 2004: 90): "*patterns, themes, and categories come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis*" (Patton, 1980: 306). In deduction, the researcher starts with a (fixed) theoretical framework, makes an empirical observation and deducts conclusions (Dey, 2004: 91). Dey (2004: 90) rightfully remarks that it is easier to reject deduction in theory than to dismiss it in practice. While the research conducted here is not directly aimed at formulating theory, but rather at increasing understanding about a phenomenon using a series of concepts and hence is more theory-supported that inductive approaches, it remains important not to be blinded by theory and to give the data the opportunity to speak for themselves. Abduction (and retroduction, see chapter I) - where the researcher interprets the data under investigation by adopting some (to a more or lesser degree developed) theoretical frame of reference that can offer new insights that help to increase understanding of the data (Dey, 2004: 91) - may be suggested here as an alternative for both inductive and deductive approaches. Following Danermark et al. (1997: 91), abduction is a mode of reasoning where the researcher describes, interprets or explains empirical observations from *within* a theoretical framework rather than by *imposing* that framework *upon* the data.

When the procedures of CQA are used to interpret and explain the texts under analysis within the framework of discourse-theory, it is crucial that this interpretation is coherent with and not disconnected from the discourse-theoretical framework. In order to ascertain the latter, a discourse-theoretical analysis benefits from the use of sensitizing concepts, derived from a general DT-framework as well as a DT-reading of other theoretical fields. Indeed, the notion of the sensitizing concept protects "*the balance between the need for theoretical foundation and the need to avoid a dominant theoretical framework that mutes the voices being analysed*" (Carpentier, 2010: 259).

The term of sensitizing concepts originates with Blumer (1954), who distinguished definitive concepts with sensitizing concepts:

> "A definitive concept refers precisely to what is common to a class of objects, by the aid of a clear definition in terms of attributes or fixed bench marks […] A sensitizing concept lacks such specification of attributes of banc marks and consequently it does not enable the user to move directly to the instance and its relevant content".

Instead, Blumer (1954: 7) goes on to argue, the sensitizing concept gives the researcher a general sense of guidance in analysing empirical material and suggests the direction along which to look. Sensitizing concepts can hence be regarded as "background ideas" informing the analysis (Charmaz, 2003: 259). Following an abductive logic of analysis, the role of sensitizing concepts is to deepen and increase understanding from within a particular theoretical framework, without turning them into ending points that elude rather than support and build the analysis (Blumer, 1969; Chamaz, 2003). While the DTA conducted here does not want to treat sensitizing concepts as ending points, it does follow a more directive approach than some qualitative methodologies that employ a completely open approach towards the selection of sensitizing concepts. Indeed, the analytical framework comes with a pre-set of sensitizing concepts. Grounded in discourse-theory, discourse (as defined in DT) becomes a primary sensitizing concept, strengthened by the more specific discourse-theoretical concepts of *articulation*, *nodal points, subject position* and *discursive struggle* (Carpentier, 2010). In addition to the lists of primary and secondary sensitizing concepts that can be found in DT, a series of tertiary sensitizing concepts can be developed – which comes about through a discourse-theoretical reading of specific concepts and theories. Concretely, part B of the dissertation - where existing literature produced in a variety of academic fields (amongst others thanatology, sociology and media studies) was read through the lens of discourse theory - allows us to arrive at a number of additional sensitizing concepts that guide the discourse-theoretical analysis in practice.

3. The DTA in practice

The analyses of the selected texts (including media articles and talk about these articles) deploy the analytical procedures of qualitative content analysis, where the text is coded on the basis of a number of sensitizing concepts. In the case at hand, the primary and secondary sensitizing concepts inherent to DTA are complemented with sets of tertiary sensitizing concepts. A first set of tertiary sensitizing concepts is derived from chapters IV to VIII, which provide insight into the discursive field of the good death. This discursive field, with its different dimensions, can be visualised schematically. The scheme presented below captures the building blocs of the late modern good death:

<table>
<tr><th colspan="2">**Medical-Revivalism**</th></tr>
<tr><td>Discourses on death and dying

Openness, Awareness, Control

(Chapter V)</td><td>Discourses on Medicine

Quality of life, Patient autonomy

(Chapter V)</td></tr>
</table>

The good death

<table>
<tr><th colspan="2">**Autonomy (Chapter VI)**</th><th colspan="2">**Dignity (Chapter VII)**</th></tr>
<tr><td>Ratio-personalism

Right to make own end-of-life decisions</td><td>Communitarianism

Focus on care</td><td>Innate human dignity

Every human life is dignified</td><td>Extrinsic human dignity

Dignity as moral conduct: self-control in dying; accepting the imminent death

Dignity as self-identity: avoiding the messy death (independence of care and ‘the civilised body’); avoiding social death</td></tr>
<tr><td colspan="2">(Chapter VIII)

Right to die: choosing own moment of death (euthanasia/assisted suicide)

Hospice: autonomy in deciding over circumstances of death; right to (palliative) care; natural death (nature decides)</td><td colspan="2">(Chapter VIII)

Right to die: dying before loosing (too much) independence; maintaining control over mind and body (= quality of life)

Hospice: accepting the imminent death (and dying peacefully); surrounded by good care; avoiding social death (= quality of life)</td></tr>
</table>

Table 1: the building blocks of the late modern good death

The following sensitizing concepts can thus be identified:

- Main tertiary sensitizing concepts death and dying: openness, awareness, control, quality of life, patient autonomy, autonomy (and self-determination, independence,…), dignity, care.

An second set of tertiary sensitizing concepts is derived from chapter IX, which identified existing normative frameworks regarding death in the media. This gives:

- Main tertiary sensitizing concept death in the media: emotion, spectacle, sensation, information, bias, objectivity, engagement, mobilisation.

These sets of sensitizing concepts facilitate the identification of (the use of) the theoretically elaborated discourses in the empirical material. Given that discourse theory is not connected to any particular method, we are allowed to add to these sensitizing concepts a number of other concepts. Arguably, the malleability of a DTA allows the researcher to 'shop' and borrow concepts from a variety of other methods – on the condition that they are made compatible with the DT's perspective on meaning. At this point, then, a number of analytical concepts taken from Critical Discourse Analysis (CDA) (these concepts are of course not exclusive to CDA, they are for instance deployed by pragmatics and in narrative analysis as well), are useful in helping to draw attention to which discourses are being imported in the texts under analysis where they are used, negotiated and contested in specific ways. These concepts, in other words, draw attention to the *"means and forms of realisation"* (Wodak et al. 2009: 35) of discourses. The combination of a broad perspective on meaning-making with these more linguistic concept adds to the validity of the analysis in terms of "*solidness*", which means that the analysis of a text is best based on more than one feature of the text (Jorgensen & Phillips, 2002: 173). Verschueren (2013: 27) refers to this in terms of "*vertical variation*". He states that an analysis of texts should best be based on one textual feature because of the risk to *"be stuck to a level that happens to be carefully monitored, thus distorting the picture of ingredients of ideology that, in this case, may only look like they are taken for granted and get carried along in the discourse while in* *fact they are inserted purposefully"*. The concepts CDA provides us with also make explicit what many scholars who adopt a qualitative content analysis tend not to define or leave implicit. Defining the 'means and forms' of discursive realisation also adds to the validity of the analysis.

In first instance, it is useful to look at the vocabulary or lexis adopted in the texts under analysis. Discourses provide actors with a wide range of words that, when used and combined in particular ways, actualise and realise them. Discourses, as has been mentioned several times in this thesis, do not lead an abstract existence. Rather, they provide the signifiers to 'word' or 'lexicalise' the world in particular ways (Fairclough, 2003: 129). The choice for a particular word *"carries along in its shade the sense of potential alternatives"* (Verschueren, 2012: 135). There are a number of aspects on the level of vocabulary that derive special attention in the context of this research. First, it is of interest to pay attention to the words used to name and label people, institutions, events, practices, and relationships. It is of interest to be attentive for the use of metaphors and similes, for they often reflect shared ideas and values among a particular social group and represent abstract thoughts and belief systems, deeply embedded in culture (Gibbs, 2003). Also the more grammatical question of whether actors are linguistically represented actively or passively, personally or impersonally, specifically or generically is a useful one to address in this context.

Discourses often use the same vocabulary. Both right to die and hospice discourses, for instance, use the words of autonomy and dignity, but they use them differently. Second, then, we need to look at semantic relations, for it is through focusing upon semantic relations "*that one can identify these differences*" (Fairclough, 2003: 129). The main question here is how relations of difference and equivalence are constructed in the analysed texts. Attention can be paid here to how conjunctions such as 'but', 'instead of', and adverbials like 'however' indicate contrastive relationships of differences. Elaborative relationships, in contrast, can be identified by looking at lists making entities equivalent and the use hyponymy, which refers to a relation of meaning inclusion whereby one identity, object, etc. is seen as part of a broader phenomenon or class of things (Fairclough 2003: 101).

In third instance, it is of interest to look at a number of implicit linguistic carriers of meaning, for they tell us something about the way actors, events, activities, decisions etc. become evaluated; i.e. which characteristics are silently ascribed to. Indeed, the discourses deployed, drawn on, negotiated and contested are not only identifiable on the level of the explicit, but also – and perhaps foremost – on the level of the implicit. It is thus asking the question as to what meanings are concealed behind more explicit utterances, that opens the possibility of gaining access to the discourses actualised in the texts under analysis. There are a number of carriers of implicit meaning that can be identified. First, there are presuppositions and assumptions that contain information about the taken for granted; what is assumed about what exists (existential assumptions), about what is, can, or will be the case (propositional assumptions), and about what is good and desirable (Fairclough, 2003; Wodak, 2009; Verschueren, 2012). Assumptions and presuppositions can be identified by paying attention to allocations, where *"the person who alludes on something counts on the general preparedness of resonance of the audience"* (Wodak, 2007: 212), as well as to the use of definite reference (the, this, that, those,…), evaluative verbs (for instance helping) and modal verbs. In additions, there are a number of other devices that tell us something about the way aspects of the social world are evaluated and consequentially about the discourses drawn from and identified with, including the use of irony, rhetorical questions, overstatements and understatements (Verschueren, 2012: 178).

Another way of identifying discourses in texts, which is particularly relevant for the analysis of audiences' interpretation practices, is by focussing on modalities. Modality refers to *"the ways in which language is used to encode meanings such as degrees of certainly and commitment, or alternatively vagueness and lack of commitment, personal beliefs versus generally or taken for granted knowledge"* (Wodak & Krzyzanowski, 2008: 41). Attention can be paid here to linguistic forms that function as hedges (used to modify an expressed proposition) and boosters (emphasising commitment to a proposition): modal verbs (seems, should, can), a variety of adjectives, nouns and adverbs that express degrees of commitment, and adverbial expressions (such as ‘in truth’) (Verschueren, 2012: 122; 152; Zienkowski, 2012: 523). Modalities not only point in the direction of how people identify with particular discourses and particular discursive elements (nodal points and other signifiers, subject positions), but also of reflexivity that marks interview-interaction; they may indicate how respondents position themselves vis à vis questions raised by the researcher and responses of other participants, which in themselves operationalise discourses. Other linguistic forms and figures that help focussing on reflexivity and disagreement/conflict are verbs of feeling and thinking, interruptions, pauses, silences, particular conjunctions such as ‘but’ and ‘however’, and all sorts of repair mechanisms.

Although the sensitizing concepts employed here are theoretically well-developed, they do not assume any fixed attributes to appear in the data. For instance, the main discursive elements of the ratio-personal autonomy discourse have been elaborated in the theoretical framework and the way these elements become articulated in Belgian print media has been analysed, but this does not imply that no new elements can emerge out of the data, nor that these elements cannot be combined (perhaps even with elements from competing discourses) in alternative ways. In second instance, and related to the former, it has to be noted that the sensitizing concepts listed above are not necessary exhaustive; it is always possible that discourses that have not yet been identified emerge out of the data, and/or that (in the analysis of audience receptions) alternative or more specified reading positions become demonstrated, or that relevant aspects of interview-interaction come to the fore. These two observations concerning the nature of sensitizing concepts aligns with the basic premise of DT that it is structurally impossible for discursive elements – including sensitizing concepts – *“to provide full closure, or to completely capture social reality”* (Carpentier, 2010: 259).

To ascertain the possibility of new aspects to emerge out of the data, a relatively open approach towards coding the media texts and the transcribed interviews is adopted, one that does not work with a fixed unit of analysis such as words, sentences, paragraphs, dialogues and so on. Rather, codes can be attributed to all of these entities, depending on their meaningfulness for answering the research questions. Moreover, only those parts of the transcript are coded that are relevant for answering the research questions, which implies that some parts are not coded. The reason behind this is that the texts are used to draw conclusions about the interpretation of media contents and the identification with discourses, rather than about the media-items and interview as such.

In the process of coding the analysed texts, the parts of the text that are meaningful for the analysis are marked, which inevitably involves a discursive fixation of contingency. In so doing, the above-identified sensitizing concepts, which are in turn the result of an iteration between a DT-reading of scientific literature and analysis, are deployed. In a first phase of open coding, i.e. *"the process of breaking down, examining, comparing, conceptualizing and categorizing data"* (Strauss & Corbin, 1990: 61), the clusters of sensitizing concepts identified above are already drawn on. Yet, it is during this first coding phase that it is crucial to be attentive for the possibility of new aspects emerging out of the data that are not captured by the sensitizing concepts. This is why the first coding phase may perhaps best be described as a very careful reading of the data, where 'reading' is regarded as a method in its own right (Carbo, 2001). In the open coding phase, I stay close to the texts and conduct a close and detailed inspection of the data, by Glaser (1978) referred to as 'line by line' coding[42]. During this first

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[42] The method of open coding finds its origins in work of Glaser and Strauss (1967) on grounded theory, where the process is described as asking a series of very general questions to the data without any mediation of prior theory. Arguably, open coding may seem somewhat incompatible with the use of sensitizing concepts guiding the analysis. Even in grounded theory, however, it is acknowledged that researchers should 'come to open coding without preconceptions, but not entirely without ideas' (Dey, 2004: 85). At the same time, it remains true that the analysis

coding phase, all that seems relevant in some way to answering the research questions, is coded – which means that at this point in the analysis, codes can still overlap and change (Wester, 1991).

In a second phase of the coding process, I aim to grasp the more latent meanings of the texts. With axial coding, I work towards a more abstract and refined category system by connecting categories and codes (Dey, 2004: 84). Axial coding puts *"an axis through the data"* (Strauss & Corbin, 1998) in order to connect the various categories and lower level codes identified in the open coding process (Jaccard & Jaccoby, 2009: 275). The codes arrived at this second stage of the coding process are more theoretical in nature and, as noted, capture the more latent meanings in the text. In this second stage of the coding process, meta-codes (Miles & Huberman, 1994: 57) are developed that group first-level codes into smaller groups of codes, which is the result of an axial coding (Glaser & Strauss, 1967), and later of a selective codding, defined as the "*process of integrating and refining the theory*" (Straus & Corbin, 1998: 161). The codes developed in these stages are further removed from the texts; they are more theoretically inspired and deal with the latent meanings in the text.

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conducted here is much more theory-supported than the grounded theory approach to qualitative research.

PART D: A DTA OF BELGIAN PRINT MEDIA REPRESENTATIONS OF THE MEDICALISED DEATH

> "Mario calls his dad. 'Dad', he says, 'get that fine bottle of wine'. A Chateau Lafife Rotschild of 1989. 'Nice, isn't it?' Mario asks, 'I'm going in style'" (Mario Verstraete in De Morgen, 28 December 2002)

Mass media, as explained in chapter III of the dissertation, operate as discursive machineries that operationalise discourses and in so doing bring meaning into (wide) circulation. Mass media are important social arenas where discourses on death and the good death become operationalised, where particular constructions of the good death are (temporary) crystallised, but also where the (political) struggle over the meaning of the good death takes place. This fourth part, then, focuses on what has been labelled throughout this dissertation as the 'operationalisation flow' and presents a detailed report of the discourse-theoretical representation analysis of media articles about the end of life, found in a selection of ten Belgian media products.

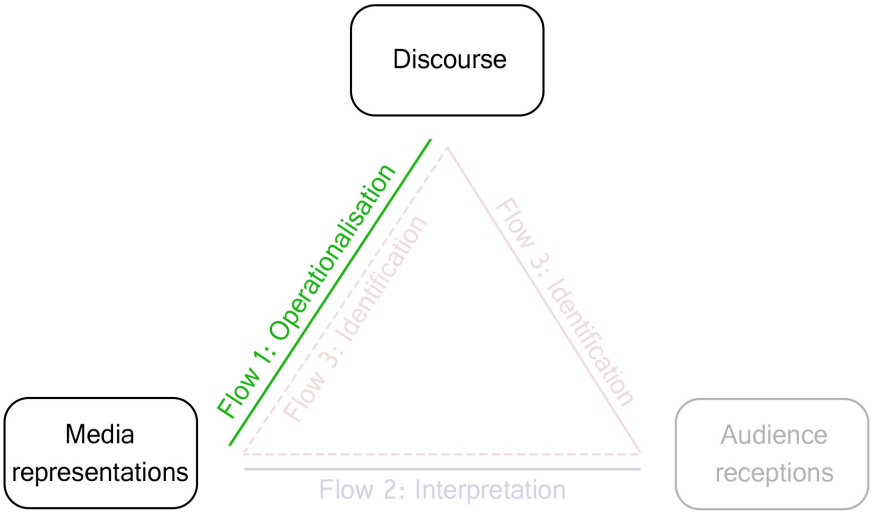

Figure 6: the analytical focus of part D

Part D of the dissertation encompasses two chapters. Chapter XII first presents a detailed account of the data-collection. In the light of assuring access to a variety of discourses circulating in the Belgian print media, it is indeed crucial that the corpus is composed in a well thought-out way. The chapter then goes on the map the corpus in by means of a basic quantitative analysis, which not only serves to pursue transparency about the corpus, but also to draw attention to notable features of the coverage that potentially are the result of specific logics of discursive construction. Chapter XIII, with its distinctive sections, zooms in on the discourse-theoretical analysis, reports the findings in detail and (re-)connects them to the theoretical categories developed in part B. This chapter is structured on the basis of the two research questions formulated earlier: “How, and following what media-specific logics of representation, does the Belgian print media coverage of the medicalised end of life construct the good death through operationalising particular discourses on death and the good death?” And “What are the normative stances or discourses on good journalism (in covering the medical end of life) that are operationalised in media representations of the medicalised death?”

Chapter XII: Constructing and mapping the corpus

Unlike as is the case for the analysis of audiences' receptions - where the corpus as such is produced (by means of qualitative interviews) - the corpus of the DT representation analysis is composed on the basis of already-existing material: articles about the end of life and end-of-life decision-making published in a selection of Belgian print media products. A number of actions need to be performed that narrow the compilation of exiting print media articles about the end of life down to a workable corpus. Of course, this inevitably implies that a lot of material does not get to be analysed, which is why these actions need to be well informed, thought-out and legitimised. A first section of this chapter discusses the construction of the corpus, which comes about through a threefold sampling procedure. A second section presents a basic quantitative mapping of the corpus and functions as a prelude to the actual discourse-theoretical analysis.

1. Sampling procedure

Constructing the corpus involves a number of choices and actions. A first action concerns the demarcation of a period, and I choose to select articles from the period 2000-2009. The reason for appointing the year 2000 as a start-point relates to the fierce debates about the possible legalisation of euthanasia that were going on in Belgium at that time[43], and the possibility of discursive struggle over the meaning of particular concepts such as autonomy and dignity these debates may entail. In 2008-2009, some euthanasia-cases (see further) revitalised the debates on end-of-life decision-making[44].

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[43] After the parliamentary majority submitted a draft of the euthanasia law in 1999, many parliamentary hearings followed in 2000.

[44] In 2013, we witnessed a similar revival with the legalisation of euthanasia for minors – but I was unable to include media articles published in that period because of pragmatic reasons of time limitation.

The procedure of constructing a corpus that gives us access to a variety of discourses involves two additional actions: the selection of media-products and the selection of relevant articles. As far as the choice for ten particular media products is concerned, I first of all decided to only take on board Dutch-language media. This is for the simple reason that a discourse-theoretical analysis is best conducted on material produced in the native tongue of the researcher, which excludes the possibility of misinterpretations due to a language barrier. Second, I opt to focus exclusively on written media products, because this choice allows us to include a number of niche media (targeting a religious community and medical professionals) that, in Belgium, do not have any audio-visual variant. Including these niche media is crucial, for this permits access to a wider variety of discourses.

Within the range of written media, a diversification is first made of mainstream media versus niche media. Next to a series of mainstream media, two niche medical newspapers and one explicitly religious newspaper are included in the study. Both the mainstream media and the niche media are part of the same Belgian (and Western) society; it can therefore be assumed that these media bring into circulation a number of shared meanings. At the same time, we can assume that mainstream media are more likely to operationalise the mainstream, i.e. dominant, discourses circulating in society. The medial newspapers and the religious newspaper, on the other hand, are more directly linked to specific fields and their respective communities: the medical field/community and the religious field/community. We may expect therefore, that the discourses they operationalise, as well as *the way* they do, differ from those operationalised in the mainstream media. More concretely, the assumption is that alternative and counter-dominant discourses find their way to the niche media more easily. Arguably, including both mainstream and specialised media allows to get a clear view on those systems of meaning that are shared by both - which gives an indication of their deep-rooted, taken for granted and hegemonic nature – while also providing insight into the differences between them – which gives an indication of the dynamics between dominant and alternative discourses circulating in the social.

The two medical newspaper that are selected, include:

- De Arstenkrant: a niche newspaper that appears twice a week and aims at medical professionals and health-care stakeholders. De Artsenkrant is published by UBM Medica and is freely distributed to medical professionals in Flanders.
- De Huisart: a weekly newspaper published by Roularta Medica. It is freely distributed amongst general practitioners and internists. De Huisarts is divided in three main segments: news, medicine and leisure.

In 2012, the publishers of De Artsenkrant and De Huisarts merged, and both newspapers are now published by Roularta. Note that all the data were gathered before the merger.

In addition to these medical newspapers, the religious Kerk en Leven (Church and Live), which is the weekly newspaper of the Flemish Church community and is published by Halewijn, is included in the study.

As for the mainstream media, I choose to include a number of so called 'quality' or 'elite' media and so called 'popular' media[45]. Part A (chapter III) of the dissertation explained how dramatisation, publicness, and personalisation can be understood as media-specific logics of representation. While it has been argued that these logics are not unique to human interest journalism, but also – albeit to a lesser degree – mark 'hard news', it can be assumed that the specificity of human interest journalism and new journalism in focussing on the dramatic and the personal potentially comes with a specific way of representing the end of life. And generally, personification and intimisation are linked to popular journalism, which is often opposed to 'quality journalism'. In recent decades, it has been argued that differences between popular and quality journalism are increasingly blurred. Critical views for instance assert that

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[45] Deploying the categories of 'quality/elite journalism' and 'popular journalism' does not mean that this dissertation subscribes to all the value judgements lying behind them. 'Quality journalism' is a discursive construction through and through, which can indeed by deconstructed and problematised.

the “serious” media are moving toward the news values of popular journalism and tabloid genres (Sparks, 2000: 2) but, at the same time, popular and elite journalism remain associated with different kinds of contents. Popular journalism often deals with human interest stories, or approaches an issue from a human-interest point of view, while elite/quality journalism frequently focuses on international news and stories about politics, ethics, social movements, and the like (Gripsrud, 2000: 293). These differences between popular media and ‘quality’ media, therefore, potentially result in different politics of operationalising discourses; privileging certain articulations of the good death over others.

The quality or elite media products selected for analysis include two newspapers and one magazine (De Bens, 2007):

- De Standaard: De Standaard, published by Corelio (formerly VUM), was traditionally a Christian-democratic newspaper, associated with the Flemish party. De Standaard is considered a quality newspaper and mainly aims at a high-educated public.
- De Morgen: De Morgen arose from a number of socialist newspapers and is now published by De Persgroep. De Morgen thinks of itself - and is generally perceived - as a quality newspaper. A high educated and young public mainly reads the newspaper.
- Knack: Knack is a weekly-published news-and opinion magazine. The magazine is published by Roularta and mainly aims at a culturally active and higher-educated public. Knack focuses on background information- and analysis on news from home and abroad and pays special attention to media and culture.

One popular newspaper and three popular magazines are included in the analysis (De Bens, 2007):

- Het Laatste Nieuws: Het Laatste Nieuws, which has liberal roots, is the most widely read newspaper in the Dutch speaking part of Belgium. De Persgroep publishes the newspaper. Het Laatste Nieuws is generally considered a ‘popular’ newspaper and is read by a broad audience.

- Dag Allemaal: Dag Allemaal is a weekly magazine published by De Persgroep and is often described as a tabloid magazine. It is the most widely read magazine in Flanders. De Persgroep defines Dag Allemaal in terms of *“bringing the true story of famous and less famous people”* and focuses on “involvement”, “emotion”, and “entertainment” (http://www.persgroepadvertising.be/nl/onze-merken/dag-allemaal#tabs-1)
- Flair: Flair is a women’s magazine published by Sanoma. It aims at women aged 25 to 45 (although in reality the magazine is mainly read by young (and above all childless) women aged 18-30). The magazine brings, in its own words, *“weekly entertainment and inspiration to women aged 25-45”* (http://www.sanoma.nl/merken/artikel/flair/print/merk-profiel/
- Onze Tijd/ Plus Magazine: In 2004, ‘Onze Tijd’, a monthly magazine for 50 + people, was renewed and named Plus Magazine. It is published by Senior Publications. Plus Magazine aims at the active senior and focuses on a wide range of topics including law, money, health, traveling, lifestyle and beauty.

The following scheme categorises the selected media products on the basis of the dimensions ‘popular versus elite’ and ‘mainstream versus niche’.

	Mainstream media		**Niche media**
	Mainstream media: newspaper	**Mainstream media: magazines**	**Niche media: newspapers**
Popular media	Het Laatste Nieuws (HLN)	Dag Allemaal, Flair Onze Tijd/Plus Magazine	De Huisarts (DH), De Artenkrant (DA), Kerk & Leven (K&L)
Elite media	De Standaard (DS), De Morgen (DM)	Knack	

Table 2: a selection of ten media products: mainstream and niche media; popular and elite media

The choice to include mainstream (including ‘popular’ and ‘quality’) media and niche media is not only based on the theoretically informed reasons mentioned above. It is also informed by a quality argument. It is indeed crucial that the selected data form a sufficient basis for answering the research questions. Setting out to investigate the construction of the good death in Belgian print media, and posting the ambition to link these constructions to more encompassing discourses means that it is insufficient to focus exclusively on one media genre. Verschueren (2013: 26) refers to this as horizontal variation (in accordance with vertical variation, see earlier).

It rapidly becomes clear that end-life-care and end-of-life decision making sparks plenty of media attention. Because it is infeasible to analyse all the articles on end-of-life decision-making in these media products during the period 2000-2009, a selection of two months per year is made. All relevant articles from the selected two months are included in the corpus. To include a spectrum as wide as possible, the two selected months vary from year to year. The content of newspapers often differs depending on the day of publishing. A newspaper can for example focus on sports on Monday and on media and culture on Friday. Especially in the case of magazines, the month of publishing also matters; during summer, the subjects of the articles are often lighter and more frivolous than during winter. Therefore, the same two months (that vary per year) are selected for each media product. A systematic stratified sample with a-select starting point is used to select the material. First, it is determined which two months would be selected for the year 2000. To reduce the complexity of the data-collection process, it was decided that the two months had to be consecutive. January and February are determined as 'starting months'. Again, to reduce the complexity of the data-collection process, March en April are selected for the year 2001, May and June are selected for the year 2002, and so forth. For the media products that do not appear once a day or once a week, but once a month, three months per year are selected. The choice to let the two months per year vary implies that it becomes difficult to compare the results per year. Making comparisons between the years of publication is not an objective of this analysis, however.

A last step of the data-collection includes the selection of the relevant articles. Three search methods can be distinguished: (1) the search for articles in the online database Mediargus, (2) the search for articles in online media-specific archives, and (3) the search for articles in paper archives. An online search for terms referring to end of life care results in a list of newspaper/magazine articles in which at least one of the following end of life care-related terms is included (see footnotes for the Dutch terms):

- End of life[46]
- End of life care[47]
- End-of-life decision(s)[48]
- End-of-life decision-making[49]
- Palliative care[50]
- Palliative/palliation[51]
- Euthanasia[52]
- Physician-assisted suicide/assisted suicide[53]

The result of the search is a total of 929 articles. The notion of articles refers not only to regular news articles. In order to take account of the official voices of the newspapers, that "*express an opinion, sum up the issues and make moral judgment or decision upon the issue*" (Lupton, 1992: 149) as well as a wide, but edited, variety of opinions from these newspapers' audiences, the corpus includes not only regular news items, but also letters to the editor (from readers), opinions (including those of the editors and others), and reportages (repo's) (which often use new journalism techniques to describe events or situations).

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[46] Levenseinde
[47] Levenseindezorg
[48] Levenseindebeslissing(en)
[49] Levenseindebesluitvorming
[50] Palliatieve zorg
[51] Palliatieve/palliatie
[52] Euthanasie
[53] Geassisteerde zelfmoord

2. Mapping the corpus by means of a quantitative analysis: What? How? Who?

As a prelude to the discourse-theoretical representation analysis, a quantitative content analysis is conducted. Given this entire research's embeddedness in an interpretative-qualitative epistemology (see chapter I) and a constructionist ontology (see chapter II), the question naturally arises as to whether integrating a quantitative analysis in this research does not create a paradigmatic conflict or irreconcilability. A number of authors have indeed pointed to the so-called 'paradigm war' between quantitative and qualitative research (see for instance Brannen, 1992; Bryman, 2004; Hammersley, 1992). This comes as no surprise, given that (as saw in chapter I of this dissertation) a positivist epistemology often embraces quantitative research methods, while qualitative research is the preferred research method adopted by scholars situated in a interpretative and subjectivist epistemological stance.

Great efforts have been made to reconcile quantitative and qualitative research, which has led to the emergence of a tradition of a mixed method approach (Kohlbracher, 2005). At the same time, when explicitly subscribing to a subjectivist epistemology and constructionist ontology, it remains crucial to reflect about the *integration* of a research method that embraces principles like objectivity and neutrality into a more encompassing research project that centralises (latent) meaning, the importance context and the interpretative role of the researcher. Bringing a quantitative analysis into a qualitative-interpretative research project does not mean reconciling with the paradigmatically assumptions that often lie behind a quantitative analysis, it rather means reconciling a quantitative analysis with the paradigmatic assumptions underlying a qualitative-interpretative research paradigm. One of the main assumptions of a quantitative research paradigm is that quantity matters a great deal. It is not denied here that quantity matters, but quantity matters because it can be a result or symptom of more latent discursive mechanisms. Quantitative observations thus always trigger questions relating to the unquantifiable; these are 'how' and 'why' questions and questions about what and who is silenced.

Integrating a quantitative analysis into a more encompassing discourse-theoretical analysis almost automatically gives the former a particular role and position. While the quantitative analysis has been published as a separate analytical entity[54], in the context of this research project it fulfils a preliminary and contexualising role. With its preliminary and contextualising function, the quantitative mapping more concretely serves a fivefold purpose: to create an overview of the basic features of the selected coverage (what is covered (which end-of-life decision, which illnesses? How or from what angle/point of view? who is heard?), to explore the differences regarding these features between the media genres (mainstream vs. niche and popular vs. quality), to select the sample for the DTA, to highlight potential relevant aspects requiring extra attention during the DTA, and to relate the findings of the DTA (zooming in on a part of the corpus) to the broader corpus.

In its preparatory or preliminary role, the quantitative analysis points in the direction of quantitative manifestations of underlying discursive logics and thus plays an indicative role. Taking on board notable features the quantitative mapping reveals during the DTA makes us attentive for the latent discursive logics underlying them. In distinguishing what is covered (i.e. which types of end-of-life decisions, which illnesses and conditions), how it is covered (i.e. from what angle (e.g. political discussion, ethical discussion, a personal case)), and who is heard (patients, medical professionals, politicians, …), the quantitative mapping also facilitates the sampling of the corpus for the DTA – for the mapping indeed allows ascertaining the representation of the different categories of coverage in the DTA. In its contextualising role, the quantitative analysis allows us to produce claims about the discursive construction of the good death in Belgian print media on a 'suitable' level. The quantitative mapping prevents the DTA, in other words, from drawing conclusions

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[54] The quantitative content analysis has been published in Van Brussel, L., Van Landeghem, P. (✝) & Cohen, J. (2013). Media coverage of medical decision-making at the end-of-life: a Belgian case study, Death Studies, 38 (2), 125- 135.

about the discursive logics of *'the'* Belgian print media coverage of the end of life when what we are talking about is in fact *a very particular segment* of this coverage – albeit an important one. This segment, as will become clear, above all includes coverage of personal end of life cases and coverage produced during moments of elevated political struggle – categories of coverage that contain discursively rich material indeed.

The quantitative analysis, although integrated in a more encompassing discourse-theoretical analysis, follows the general principles of quantitative content analysis, which Krippendorff (2004: 18) defines as *"a research technique for making replicable interferences from data in their context"*. Quantitative content analysis, described by Holsti (1969: 14) as *"any technique for making inferences by objectively and systematically identifying specified characteristics of messages",* is primarily summarising: *"a content analysis summarises rather that reports all details concerning a message set"* (Neuendorf, 2000: 15). With the term "*systematic-quantifying*", Wester (1995) stresses the often descriptive nature of quantitative content analysis and its focus on the different themes that occur in the analysed contents, the extent to which these themes occur, the question whether there is a change in time to be noted concerning these matters, whether there are differences between media to be noted concerning these matters etc.

The research interests that guide the quantitative analysis of the selected media texts indeed pursue a description or overview of its main features.

A first feature the analysis brings an overview of, relates to the types of end-of-life decisions that are addressed in the selected articles (and the differences in this regard between the different media genres). The objective here is to find out which types of end-of-life interventions are covered in the media, whether there is a dominance of particular types of decisions over others, and whether there is a difference to be noted on this matter between the different media genres (see further). Based on the Belgian legal framework[55], four types of end-of-life decisions can be distinguished: 1/ palliative care (decisions): (decisions to) discontinue life-prolonging treatments and/or to administer medication in order to control symptoms (including palliative sedation), 2/ euthanasia: decisions to administer life-ending medication at the explicit request of the patient, 3/ assisted suicide: provide or prescribe medicine to a patient, at his explicit request, in order to hasten his death, and 4/ non-voluntary euthanasia: administering medication without the patient's request in order to hasten his death.

A second feature the analysis brings an overview of relates to the visibility of certain illnesses and conditions leading to medical end-of-life interventions (and the differences in this regard between the different media genres). Certain illnesses have been reported to end in end-of-life decision-making practices more often (Smets et al. 2010) while others regularly result from dying processes taking place in a clinic or hospital (Cohen, 2007), which is likely to influence end-of-life decision-making (Cohen et al. 2007). Some illnesses and conditions, then again, are subject to discussions about the permissibility of human intervention in dying.

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[55] In Belgium, the withholding or withdrawing of treatment at the explicit request of a competent patient cannot be prosecuted, and possible life-shortening is considered an inevitable side effect of proper pain relief and, therefore, cannot be prosecuted because of the "justification of necessity" principle (Bilsen, 2005: 11). Until 2002, administering lethal drugs at the patient's explicit request (i.e., euthanasia) was considered murder. In September 2002, however, the Belgian euthanasia law was ratified and permitted a physician to administer lethal drugs under strict due care requirements. One of the most important requirements is that "the request for euthanasia must be voluntary, well considered, durable and persistent" (Bilsen, 2005: 12), which reflects the importance of the ideal of a death under the patient's control. Consequentially, non-voluntary euthanasia, including the administration of life-shortening drugs with the intention of hastening death, without the patient's explicit request, is prosecutable in Belgium. Physician assisted suicide, unlike the situation in the Netherlands, is not regulated by the euthanasia law, and under Belgian criminal law suicide is not a crime. However, if the act is interpreted as deliberate refusal to help a person in need, the physician can be punished for "neglecting to help a person in distress" (Bilsen, 2005: 12).

Third, the quantitative analysis gives an overview of the angles from which the issue of medical end-of-life decision-making is approached in the selected coverage (and of whether there is a difference to be noted in this regard between the different media genes). Possible angles from which the issue can be approach are: individual cases, political discussion, ethical discussion, juridical cases, (scientific) research, discussions on the legal framework, positions of institutions and social movements, critiques or reactions, charity, medical/technical discussions, and a cultural focus.

Fourth, the quantitative analysis gives an overview of the actors (individuals and/or institutions) heard in the selected articles (and of the differences in this regard between the different media genres). Besides those directly involved in medical end-of-life decision-making, i.e. patients, relatives of the patient (and by extension the general population), and representatives of the medical field, also other societal fields and their representatives are, at a macro level, involved in a medical end-of-life decision-making context. The political field and civic society field, but equally the religious field, the academic field, and the media/cultural field can be considered fields of struggle and conflict where the debates over (the permissibility of) medical end of life interventions are conducted.

2.1. Measurement Instrument

A system of categorisation is established to determine the following aspects: the journalistic genres of the articles (variable "Press genre"); the types of end-of-life decisions mentioned in the articles (variables "palliative care (decisions)," "euthanasia," "assisted suicide," and "non-voluntary euthanasia"); the illnesses referred to in the articles (variables "cancer," "Alzheimer's disease/dementia," "MS," "other musculo-neuro diseases," "heart diseases," "coma and locked in," "disability," "psychological diseases," "terminal illnesses without specification," "non-terminal illnesses without specification," and "other diseases/conditions"); the foci in the articles (variable “focus” with values “individual case”, “political discussion”, “ethical discussion”,” medical/technical discussion”, “legal discussion”,” juridical case”, “research”, “position civil society/movement/institution”, “media and culture”, “critique/reaction”, “charity”, “other”); and the actors heard in the articles (variables “actor1”… “actor9”) with the values: patient, relative, member political field, member medical field, member legal field, member of academic field, member religious field, member civil society, member of cultural field, member of general population, other. Note here that the codebook distinguishes nine actors per article. This number is based on an exploratory coding of 50 articles, which identified a maximum of nine actors (individuals or institutions) per article.

Because an article may deal with palliative care decisions as well as euthanasia and/or other types of end-of-life decisions, binary variables are created for each type of end-of-life decision, with two category options: yes and no. The same logic is applied to illnesses and conditions addressed in the articles; use of separate binary variables (e.g., CANCER/1=YES, 0=NO) makes it possible to indicate that the article deals with multiple illnesses, while the categories within the different variables remain mutually exclusive. For the variables “Press genre,” “Focus,” and “Actor1”… “Actor9” I do not use separate binary categories. The choice of one variable with different values implies that there is no possibility to allocate more than one focus to any one article or more than one sphere/field to any one actor. The disadvantage of this is that it is not possible to indicate, for instance, that one actor belongs to both the medical and the political fields. To reduce ambiguity in relation to this problem, the codebook gives detailed indications about the categorisation. At the same time, the use of one variable has some important benefits. Had it been possible to allocate multiple foci per article, many articles would be coded as ethical in focus *and* legal in focus, *and* personal in focus, *and* medical in focus, and so forth, which would have made it very difficult to comment on them. The aim is to code according to the *most prominent* focus of the article, and to code the actors heard in the articles according to the area to which the actor *most obviously* belongs or the capacity in which the actor *most obviously* acts. Allocation of the most prominent focus/the most important field required a qualitative evaluation of what is most prominent and most important, which potentially decreases the reliability of the measurement instrument. To determine the coding validity, an inter-coder reliability (ICR) test was conducted. This requires a minimum of one secondary coder. When all the articles had been coded, a second coder was trained and part of the material was re-coded by this secondary independent coder[56]. In order to determine the reliability of the coding system and instructions, the sample of re-coded material must represent the diversity of the data. A selected sample is drawn for every category and every type of medium (e.g., mainstream newspaper, mainstream magazine, niche media). The ICR sample consists of 115 articles. To measure the reliability of the ICR coding, the Cohen's Kappa coefficient of each variable is determined. Cohen's Kappa, unlike some other coefficients, takes account of the risk of coincidental similarities between coders (Den Boer et al. 1994: 141).

The ICR scores for the binary variables "palliative care (decisions)" (Kappa = 0.86), "euthanasia" (Kappa = 0.79), "assisted suicide" (Kappa = 0.96), and "non-voluntary euthanasia" (Kappa = 0.71) demonstrate that the coding of these variables is reliable. The binary variables that indicate illnesses often referred to explicitly (Kappa Cancer = 0.89, Kappa Alzheimer's disease/dementia = 0.90, Kappa Coma/locked in = 0.73, Kappa Heart diseases = 1.0, Kappa MS = 1.0, Kappa other neuro-diseases = 1.0) are reliable with the exception only of the variable Disability, which is moderately reliable (Kappa = 0.65). The variables for psychological diseases (Kappa = 0.90), terminal conditions (Kappa = 0.76), and non-terminal conditions (Kappa = 0.80) also are reliable. The ICR-scores of non-binary variables demonstrate high reliability of the press genres of articles (Kappa = 0.86), the foci of the articles (Kappa = 0.83), and the social contexts of the actors (Kappa Actor1 = 0.96, Kappa Actor2 = 0.93, Kappa Actor3 = 0.90, Kappa Actor4 = 0.95, Kappa Actor5 = 1.0, Kappa Actor6 = 1.0, Kappa Actor7 = 1.0, Kappa Actor8 = 1.0, Kappa Actor9 = 1.0).

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[56] Many thanks to Laurens Defo

2.2. Analysis

The statistics program SPSS is used to perform the analysis. First, in order to capture coverage of medical end-of-life decision-making in the 10 selected media products, overall number of references (frequencies and percentages) are calculated for each aspect of interest. Second, chi-squared tests are performed to test differences in the distribution among media genres. A p-value < 0.05 indicates statistically significant differences among media[57].

The data collection process, as mentioned earlier, yielded 929 articles on medical end-of-life decision-making. Most of the articles are from the three mainstream daily newspapers*:* *DS* (260 articles, 28% of the total number of articles), *HLN* (197 articles, 21.2% of the total number of articles), and *DM* (153 articles, 16.5% of the total number of articles). In the medical newspapers *DA* (published twice weekly) and *DH* (published weekly) respectively 103 (11.3%) and 71 (7.6%) articles are found. Next for number of articles is the quality magazine *Knack* with 69 (7.4%) articles. The religious newspaper *K&L* and the popular magazines *Dag Allemaal*, *OT*, and *Flair* yield the least articles; respectively 29 (3.1%), 24 (2.6%), 13 (1.4%), and 10 (1.1%) articles are found in these media.

Most of the articles (528 out of 929 articles or 56.8% of the articles) are regular articles: pieces written by a journalist without the explicit reproduction of his or her opinion. Letters to the Editor yield 136 (14.6%) articles. Ranked third are interviews, with 115 articles (12.4%), followed by 94 articles (10.2%) that include opinions, and reportages (49 articles, 5.3%).

In the share of articles per year, there is a peak in 2000, with 25.9% of the selected articles from this year. In addition, the years 2002 (14.4%) and 2006 (18.3%) yield a considerable number of articles. The fewest articles are found in 2003 (2.8%) and 2009 (1.6%).

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[57] I thank Joachim Cohen for his great and most welcome help with the statistical analysis.

2.2.1 Types of end-of-life decisions referred to in the coverage

The 929 articles contain a total of 1602 references to end-of-life decisions, with 789 (49.3%) referring to euthanasia. Of these 1602, 491 (30.6%) references to end-of-life decisions are related to palliative care decisions and 220 (13.7%) to non-voluntary euthanasia. Physician-assisted suicide is the least frequent decision in the articles (102 out of 1602 references; 6.4%).

In terms of differences among the selected media genres, the mainstream and niche genres report on euthanasia considerably more often than on other types of end-of-life decisions (see Table 3): almost half the references to end-of-life decision-making in both mainstream and niche media are references to euthanasia. When further comparing the mainstream media with the niche media, there is a similar proportion of references to palliative care decisions and to non-voluntary euthanasia in both media genres. The proportion of references to assisted suicide, however, is significantly higher in the niche than in the mainstream media (p=0.021), because of the high proportions in the two niche medical newspapers (9.6% of all references to end-of-life decisions in *DH* and 10.1% of all references to end-of-life decisions in *DA*).

The mainstream elite and mainstream popular media report on euthanasia more often than other end-of-life decisions (see Table 3). In all, 51.5% of all references made to end-of-life decisions in the elite media are to euthanasia. In the popular media, 44.4% of all references made to end-of-life decisions are to euthanasia. Although the proportion of references to euthanasia in popular media is significantly lower than in elite media (p=0.024) the proportion of references to palliative care interventions is significantly higher (p=0.003). This latter result is due to the women's magazine *Flair*, which frequently included articles on end-of-life interventions addressing palliative care (66.7%) rather than euthanasia (25%).

	Mainstream versus niche media				Popular versus elite media			
	Total	Mainstream	Niche	p-value*	Total	elite	popular	p-value*
Type of end-of-life decision covered:								
Euthanasia	789	610	179	0.745	610	450	160	**0.024**
	(49.3%)	(49.5%)	(48.5%)		(49.4%)	(51.5%)	(44.4%)	
Palliative care decisions	491	384	107	0.433	384	250	134	**0.003**
	(30.6%)	(31.1%)	(29.0%)		(31.1%)	(28.6%)	(37.2%)	
Non-voluntary euthanasia	220	170	50	0.907	170	118	52	0.662
	(13.7%)	(13.8%)	(13.6%)		(13.8%)	(13.5%)	(14.4%)	
Assisted suicide	102	69	33	**0.021**	69	55	14	0.095
	(6.4%)	(5.6%)	(8.9%)		(5.6%)	(6.3%)	(3.9%)	
Total	**1602**	**1233**	**369**		**1234**	**874**	**360**	

Total number of references to end-of-life decisions (and percentage within all references to end-of-life decisions).

* Pearson chi-square test, testing for statistically significant differences between mainstream and niche media and between elite and popular media in the proportion of the specific end-of-life decisions as compared to the other end-of-life decisions (df=1). Bold denotes a statistically significant difference (i.e., $p<0.05$). No cells had a count <5.

Table 3: Coverage of different end-of-life decisions in mainstream versus niche and elite versus popular Media

2.2.2 Illnesses referred to in the coverage of end-of-life decisions

The analysed articles on end-of-life decision-making refer predominantly to terminal conditions (22.2%). End-of-life decision-making is also frequently discussed in relation to non-terminal conditions (12.7%). When it comes to references to concrete illnesses, cancer (12.4%) and Alzheimer's disease/dementia (15.0%) and, to a lesser degree, psychological illnesses (11.9%) are most referred to. Heart diseases, multiple sclerosis, and other muscular-neurological diseases are the least referred to in the selected articles (see Table 4).

	Number of references	**Percentage**
Terminal conditions (general)	212	22.2
Alzheimer's disease/dementia	143	15.0
Non-terminal conditions (general)	121	12.7
Cancer	118	12.4
Psychological diseases	114	11.9
Disability	73	7.6
Coma/locked-in	61	6.4
Neuro-musco diseases (not MS)	19	2.0
MS	9	0.9
Heart diseases	9	0.9
Other	76	8.0
Total	**955**	**100**

Total number of references to specific illness or to an illness in general. Total number does not add up to the total numbers in Table 1 because not all references to end-of-life decisions referred to a specific illness or to an illness in general

Table 4: Illnesses referred to in the coverage of end-of-life decisions

Table 5 presents an overview per media genre, of the illnesses to which the articles refer. The variables included in the comparison are cancer, Alzheimer's disease/dementia, and non-terminal illnesses. Because of the large number of references to unspecified terminal conditions in *all* media, these references are not included in the comparison. Proportionally, mainstream media significantly more often than niche media refer to cancer (p=0.004). The popular magazines *Dag Allemaal* (70% of all references to illnesses) and *Flair* (33.3% of all references to illnesses) refer significantly more often to cancer than the other analysed media.

Mainstream media do not refer significantly more often to Alzheimer's disease/dementia than niche media, but elite media refer to this illness significantly more often than popular media (p<0.001). Finally, niche media significantly more often refer to non-terminal illnesses than mainstream media (p=0.002). Elite media discuss end-of-life decision-making in relation to non-terminal illnesses more often than popular media (p=0.022).

	Mainstream versus niche media				Popular versus elite media			
	Total	Mainstream	Niche	p-value*	Total	elite	popular	p-value*
Reference to cancer illnesses	118	103	15	**0.004**	104	63	41	0.098
	(12.7%)	(14.4%)	(6.9%)		(14.6%)	(13.1%)	(17.7%)	
Reference to other terminal illnesses	452	312	142	**<0.001**	408	257	151	**0.002**
	(48.7%)	(43.8%)	(65.7%)		(57.2%)	(53.3%)	(65.4%)	
Reference to Alzheimer disease	143	117	26	0.119	117	96	21	**<0.001**
	(15.4%)	(16.4%)	(12.0%)		(16.4%)	(19.9%)	(9.1%)	
Reference to other non-terminal illnesses	121	84	37	**0.002**	84	66	18	**0.022**
	(23.3%)	(25.4%)	(15.3%)		(11.8%)	(13.7%)	(7.8%)	
Total	929	713	216		713	482	231	

Total number of references to specific disease (and percentage within all references to diseases).
* Pearson chi-square test, testing for statistically significant differences between mainstream and niche media and between elite and popular media in the proportion of the specific diseases as compared to the others (df=1). Bold denotes a statistically significant difference (i.e., p<0.05). No cells had a count <5.

Table 5: references to cancer, Alzheimer's disease, and non-terminal diseases in the coverage of end-of-life decisions in different media genres: mainstream versus niche and elite versus popular media.

2.3.3 Foci of the articles

Of the 929 articles on medical end-of-life decision-making, 14.5% have a primarily political focus, 14.3% have a primarily ethical focus, and 13.8% centre on a critique and/or a reaction (see Table 6). Those articles that are primarily juridical in focus (12.3%) and articles that deal with the legal framework of end-of-life decision-making (12.2%) also appear frequently. Articles focusing on social movements and institutions, individual end of life cases, (scientific) research, and charity represent respectively 8.2%, 8.1%, 7.2%, and 3.1% of the 929 articles. Articles that focus on pure technical-medical matters (1.5%) and articles with a media/cultural focus (1.3%) are rare.

In terms of differences between mainstream and niche media, the latter significantly more often focus on ethical (p<0.001), legal (p<0.001), and research-based (p=0.011) aspects of end-of-life decision-making, and the former significantly more often focus on juridical (p<0.001) and/or individual cases of end-of-life decision-making (p<0.001) (see Table 6). There are significant differences between the foci in the mainstream elite media and the mainstream popular media. Elite media, like niche media, significantly more often focus on the political (p<0.001), ethical (p<0.001), and legal (p=0.025) aspects of end-of-life decision-making; the popular media tend to report more frequently on juridical end of life cases (p=0.002) and individual real patient cases (p<0.001).

	Mainstream versus niche media				**Popular versus elite media**			
	Total	**Mainstream**	**Niche**	**p-value***	**Total**	**Elite**	**popular**	**p-value***
Political	135 (14.5%)	102 (14.3%)	33 (15.3%)	0.722	102 (14.3%)	87 (18.0%)	15 (6.5%)	**<0.001**
Ethical	133 (14.3%)	84 (11.8%)	49 (22.7%)	**<0.001**	84 (11.8%)	71 (14.7%)	13 (5.6%)	**<0.001**
Critique/reaction	128 (13.8%)	105 (14.7%)	23 (10.6%)	0.128	105 (14.7%)	69 (14.3%)	36 (15.6%)	0.655
Juridical	114 (12.3%)	106 (14.9%)	8 (3.7%)	**<0.001**	106 (14.9%)	58 (12.0%)	48 (20.8%)	**0.002**
Legal	113 (12.2%)	65 (9.1%)	48 (22.2%)	**<0.001**	65 (9.1%)	52 (10.8%)	13 (5.6%)	**0.025**
Social movement	76 (8.2%)	61 (8.6%)	15 (6.9%)	0.449	61 (8.6%)	47 (9.8%)	14 (6.1%)	0.099
Individual Case	75 (8.1%)	71 (10.0%)	4 (1.9%)	**<0.001**	71 (10.0%)	30 (6.2%)	41 (17.7%)	**<0.001**
Research	67 (7.2%)	43 (6.0%)	24 (11.1%)	**0.011**	43 (6.0%)	33 (6.8%)	10 (4.3%)	0.186
Benefit	29 (3.1%)	29 (4.1%)	0 (0.0%)	**<0.001**	29 (4.1%)	3 (0.6%)	26 (11.3%)	**<0.001**
Media and Culture	14 (1.5%)	13 (1.8%)	1 (0.5%)	0.209	13 (1.8%)	12 (2.5%)	1 (0.4%)	0.055071
Medical discussion	12 (1.3%)	9 (1.3%)	3 (1.4%)	0.999	9 (1.3%)	9 (1.9%)	0 (0.0%)	**0.035**
Other	33 (3.6%)	25 (3.5%)	8 (3.7%)	0.891	25 (3.5%)	11 (2.3%)	14 (6.1%)	**0.010**
TOTAL	929	713	216		713	482	231	

Total number of articles (and percentage within all articles).

* Pearson chi-square test, testing for statistically significant differences between mainstream and niche media and between elite and popular media in the proportion of the specific focus as compared to the others (df=1). Bold denotes a statistically significant difference (i.e., p<0.05). For cell counts <5, Fisher Exact test was used.

Table 6: Main foci of the articles on medical end-of-life decision-making in mainstream versus niche and elite versus popular media

2.3.4 Actors heard in the articles

The selected articles are particularly dominated by political (27.8%), medical (24%), legal (10.3%), and academic (8.5%) actors. Least heard are patients (5.2%), patients' relatives (and the general population) (10.5%), civil society representatives (6.3%), religious actors (4.2%), and media/cultural actors (2.3%) (see Table 7). Mainstream media significantly more often than niche media report the views of legal actors ($p<0.001$). Niche media significantly more often than mainstream media give a voice to political ($p=0.004$) and medical ($p<0.001$) actors. Mainstream elite media significantly more often report the views of political actors ($p<0.001$) and medical actors than the mainstream popular media to ($p<0.001$); mainstream popular media more often report the opinions of medical actors and more often allow the voices of patients' relatives and the general population to be heard ($p=0.012$).

	Mainstream versus niche media				**Popular versus elite media**			
	TOTAL	Mainstream	Niche	p-value*	TOTAL	Elite	Popular	p-value*
Actors:								
Political	633 (27.8%)	464 (26.3%)	169 (32.9%)	**0.004**	464 (26.3%)	420 (32.3%)	44 (9.6%)	**<0.001**
Medical	546 (24.0%)	375 (21.3%)	171 (33.3%)	**<0.001**	375 (21.3%)	239 (18.4%)	136 (29.6%)	**<0.001**
Legal	235 (10.3%)	213 (12.1%)	22 (4.3%)	**<0.001**	213 (12.1%)	152 (11.7%)	61 (13.3%)	0.372
Academic	194 (8.5%)	130 (7.4%)	64 (12.5%)	0.290	130 (7.4%)	122 (9.4%)	8 (1.7%)	0.143
Civic	143 (6.3%)	121 (6.9%)	22 (4.3%)	0.593	121 (6.9%)	91 (7.0%)	30 (6.5%)	0.928
Patients	119 (5.2%)	110 (6.2%)	9 (1.8%)	0.357	110 (6.2%)	71 (5.5%)	39 (8.5%)	0.565
Relatives/population	238 (10.5%)	213 (12.1%)	25 (4.9%)	0.127	213 (12.1%)	114 (8.8%)	99 (21.5%)	**0.012**
Religious	95 (4.2%)	75 (4.3%)	20 (3.9%)	0.940	75 (4.3%)	53 (4.1%)	22 (4.8%)	0.894
Media & Culture	52 (2.3%)	40 (2.3%)	12 (2.3%)	0.990	40 (2.3%)	31 (2.4%)	9 (2.0%)	0.937
Other	20 (0.9%)	20 (1.1%)	0 (0.0%)	**0.012**	20 (1.1%)	8 (0.6%)	12 (2.6%)	0.712
Total	2275	1761	514		1761	1301	460	

Total number of references to a specific actor (and percentage within all references).

* Pearson chi-square test, testing for statistically significant differences between mainstream and niche media and between elite and popular media in the proportion of references to a specific actor as compared to other actors (df=1). Bold denotes a statistically significant difference (i.e., p<0.05). For cell counts <5, Fisher Exact test was used.

Table 7: Actors Mentioned in the Articles on Medical End-of-life decision-Making in Mainstream versus Niche and Elite versus Popular Media

2.3. Interpreting the results and defining the corpus in light of the DTA

The quantitative mapping of the selected articles revealed a number of basic features of the coverage, related to the main research interests of the mapping: the types of end of life interventions addressed in the coverage; the illnesses and conditions referred to in the coverage; the main foci of the coverage and the type of actors heard in the coverage. As mentioned, the main findings are taken on board during the discourse-theoretical analysis, as they can be helpful in drawing attention to particular logics of discursive construction underlying the material. It is therefore necessary to take a closer look at the main findings the quantitative analysis revealed and the way they are taken into consideration during the DTA.

In terms of the types of end of life interventions addressed in the selected media, first, a predominance of references to euthanasia compared to other types of end-of-life decisions has been found. Both mainstream and niche media, and mainstream elite and mainstream popular media, with the exception of the popular magazine *Flair*, more often refer to euthanasia than to other types of end of life interventions. The focus on euthanasia reduces the visibility of alternative end of life interventions. Palliative care interventions include a wide spectrum of end-of-life decisions and represent a much larger proportion of the decisions made at the end of life in Belgium. Euthanasia accounts for only 1.9% of all deaths in Belgium (Bilsen et al., 2009). The discourse-theoretical analysis takes note of this discrepancy in quantitative terms in shedding light on underlying discursive logics; it is of interest, then, to explore the discursive construction of particular end-of-life decisions as ‘good’ or ‘bad’ ways of dying and the logics of media representation that contribute to and/or strengthen this construction.

As for illnesses leading to medical end-of-life interventions, second, the analysis has shown that the selected media items most often refer to cancer, Alzheimer's disease, non-terminal conditions, and sometimes psychological illnesses. The relatively high number of articles related to (non-terminal) diseases, such as Alzheimer's disease and psychological disorders, might seem surprising given the small number of cases of these diseases resulting in euthanasia (Smets et al., 2010). However, it is precisely because these diseases are not terminal, but affect the patient's mental abilities that there is such intense discussion about the applicability of the euthanasia law to such cases. Again, the discourse-theoretical analysis will take the above into account by paying attention to the construction of (the subject position of) the patient suffering from Alzheimer's disease and the discourses underlying them.

Third, the analysis has demonstrated that the general focus in the selected articles is on political aspects of medical end-of-life decision-making. Especially in the niche media, this focus is at the expense of more personalised and individualised accounts about the end of life. The niche media, which rely less on mainstream news values, primarily bring debates on ethics and research related to the end of life. Closely related to the focus of the media items is the type of actors that are heard and given a voice. The most frequently heard are the opinions of representatives of the political, medical, legal, and academic fields, whose voices outnumber those of the patients.

Despite a general disappearance of the patient, there are some important differences among the personalised representations in mainstream media. Concretely, mainstream popular media report individual and juridical end of life cases more often than mainstream elite media. The political, ethical, and legal aspects of end-of-life decision-making are more often reported in elite than in popular media. While the focus in popular media on individual cases is related to a wider representation of patients, patients' relatives, and members of the general population, the elite media

focus on "harder" aspects of end-of-life decision-making is accompanied by a greater visibility of the political and ethical through discussions, for instance, about the applicability of the euthanasia law to people with Alzheimer's disease/dementia.
Again, the results of the quantitative analysis will be kept in mind when conducting the discourse-theoretical analysis. The differences between popular and elite media in terms of from what angle they approach the medical end-of-life will be taken into consideration, and this draws attention to the way quantitative differences may be accompanied by differences in terms of the discursive construction of the good death and the subject position of the dying patient. The findings reported above also bring in the question as to how coverage that focuses on the so-called harder aspects of the end-of-life, including political and ethical aspects, differs – in terms of the discursive construction of the good death - from coverage that brings personal stories about the end of life.

In order to be able to conduct an in-depth discourse-theoretical analysis, the corpus that has been analysed in quantitative terms needs to reduced – or better: the corpus needs to be redefined. It was noted earlier that one of the purposes of the quantitative mapping is to select the material for the discourse-theoretical analysis. Concretely, then, the quantitative mapping is used to selectively draw the sample for the DTA in such a way that every type of article (conventional, reportage, opinion piece and so on) and every substantive category (every type of end-of-life decision, every type of illness/condition, every angle, and every type of actor) is represented in the reduced sample. The easiest way to ascertain this presence is to define the corpus of the DTA on the basis of time-clusters, (proportionally) spread over the timeline this research takes into consideration: 2000, 2004 and 2007. Note that the selection of these three years only applies to the newspapers, where (given their daily distribution) most articles were found. This means that for the other media products, including the magazines and the specialised media, all the articles of the original corpus are taken along in the DTA.

While it is possible that the discourses surrounding the end of life evolve over this time-period, it is at the same time crucial to remark at this point that this discourse-theoretical analysis does not focus on discursive evolutions over time. This choice not to focus on a time-dimension is informed by two reasons. A first reason is pragmatic; an in-depth analysis (conducted in a delimited period of time) requires a clear-cut focus. A second reason is inspired by a more theoretical argument. Discourses, as we saw throughout the theoretical part of this dissertation, evolve slowly over time. A time period of seven years would probably not capture the complex, ambiguous and slow evolution of discourses surrounding the end of life. A medical-revivalist discourse and a patient-centred discourse have achieved dominance in Western societies long before the year 2000 – although of course, the process of hegemonisation is ongoing.

It can be assumed, moreover, that the most important discursive shifts surrounding the right to die occurred in Belgium before the year 2000, when euthanasia was already the object of political debate for a number of years. In other words, it was already possible in Belgium at that time to bring the issue of the legalisation to the table, and to merely talk about the possibility of a legalisation of euthanasia.

A first qualitative reading, which took place simultaneously with the quantitative coding, has drawn attention to the discursively rich nature of two types of media-coverage: coverage of the end of life during periods of elevated political struggle (mainly under the categories of 'political discussion' and 'ethical discussion'), and coverage of personalised and individual end of life cases (mainly under the categories 'individual case' and 'juridical case'). The discursive richness of these two types of coverage urges us to add two supplemental clusters to the above-discussed corpus (based on the selection of three time-clusters).

A first cluster includes coverage produced during and on the occasion of elevated political struggle and conflict about the end of life. The observation that coverage of the end of life during periods of elevated political struggle contains discursively rich material urged me to think of other periods of elevated struggle around the end of life that are not yet captured in the corpus. Going through the original corpus (of 929 articles) once again, attention was drawn to the debates about the possible extension of the euthanasia law to people with dementia, in 2005/2006. This coverage is added to the corpus, which makes that now two key moments of political struggle are included in the analysis; the coverage during the run-up to the euthanasia law in 2000, and the coverage of the discussions about the extension of the law to people with dementia in 2005 and 2006. The latter also allows us to explore the representation and construction of dementia, an illness that is in quantitative terms very present in the selected coverage (see earlier).

The discursive richness of personal end of life cases, second, urges us to add a cluster of additional personal end of life cases. A search on the online database Mediargus identified all the cases where the selected media-products spent significant attention on the medicalised death of a specific person because of illness. From these cases, only the Belgian ones are selected – a choice that is motivated by the very specific Belgian end of life context in which this research is embedded. The following cases were included in the corpus of the DTA (considering the significant media-attention these cases received, we from now on appoint them as 'prominent cases'):

- The euthanasia of Mario Verstraete, an employee working for the Flemish socialist party sp.a[58], who was relatively unknown before he publically proclaimed his wish to die and his request for euthanasia. Suffering from the non-terminal, but incurable neurological disease Multiple Scleroses, Verstraete became a key actor in the debates on the establishment of the euthanasia law in Belgium. He was the only patient ever heard on the topic in the Belgian federal parliament and eventually became the first patient 'legally' choosing for euthanasia in 2002, which caused serious societal upheaval in the country. The dying process and death of

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[58] The sp.a is the Flemish socialist party and has played a significant role in the legalisation of euthanasia in 2002.

Mario Verstraete was highly mediatised; not only was his struggle for his right to die highly appealing to media, Verstraete's also allowed the Flemish media to follow him during his illness and dying process.

- The euthanasia of Hugo Claus, a well-known Belgian writer/artist, caused considerable societal debates as Claus was not terminally ill, but requested death while suffering from an early form of Alzheimer's disease. Choosing for euthanasia in this stage of the disease was the only way Claus could meet the criteria of the euthanasia law. If he had waited longer, Claus would no longer qualify as legally competent. The euthanasia of Claus revitalised the debates about euthanasia for people suffering from dementia.
- The euthanasia of Marcel Engelborghs in 2008. Marcel Engelborhs was a local politician, but became known by a wide audience when – suffering from an incurable and terminal cancer (Kahler's disease) - he made his choice for euthanasia public. Engelborghs gave many interviews for a variety of media about his choice for euthanasia, and the Flemish commercial television followed him during his last weeks, including the day of the euthanasia.
- The euthanasia of Tuur Van Wallendael, a journalist and politician, in 2009. Van Wallendael suffered from an intestinal cancer, from which he initially cured. When the cancer came back and no further curative treatment was possible, Van Wallendael publically communicated he would choose for euthanasia. He gave many interviews about his experience with the illness and his choice for euthanasia.

The cases described above involve the death of public figures, and the public nature of their identity at last partly contributes to the significant media attention for the death of these people. Two other prominent cases revolve around the death of 'ordinary people'. Here, other features that fit dominant news values result in significant media attention.

- The euthanasia of Amelie Van Esbeen in 2009. The request of 93-year old Van Esbeen, who suffered from a wide variety of geriatric ailments but was not terminally ill, revitalised the debates around end-of-life decision-making and the (limits of) patient autonomy. Van Esbeen, whose request for euthanasia was rejected with the argument that she was neither incurably ill nor suffering unbearable, went on a hunger strike to protests against the decision, and eventually died after euthanasia. The (perceived) extra-ordinary struggle of an old woman has been particularly appealing to (mainstream) media.
- The palliative sedation of Bart Verbeeck in 2011. Suffering from a rare and aggressive form of cancer, the 21-year old Verbeeck chooses for palliative sedation; he is being brought into a profound sleep and dies two days later. In this case, the young age and the rareness of the disease add to the attractiveness of this case to (mainstream) media. The case Verbeeck is the only one not including active euthanasia (although, as will become clear, also palliative sedation allows to report on a 'concrete momentum', i.e. not the moment of death but the moment of the 'final injection' putting the patient to sleep before he dies hours or days later).

In sum, the corpus of the discourse-theoretical representation analysis is (re-)defined on the basis of three clusters, where the starting point is the original corpus of 929 articles. The eventual corpus of the DTA can be visualised as follows:

Cluster I: time cluster[59] (including all categories of coverage identified in the quantitative analysis)	**Cluster II: coverage during elevated political conflict**	**Cluster III: prominent personal cases**
- 2000 (all articles included in the main corpus) (241 articles) - 2004 (all articles included in the main corpus) (90 articles) - 2007 (all articles included in the main corpus) (72 articles) Total: 403 articles	Coverage of discussions about the extension of the euthanasia law to people with dementia (35 articles) Total: 35 articles[60]	Six prominent end of life cases[61] (249 articles) Total: 249 articles

Table 8: the corpus of the DT representation analysis

The eventual corpus thus consists of 687 articles. Not all the articles included in the corpus, however, are equally relevant to answering the research questions. More specifically, a first reading of the material shows that particularly articles from the categories 'medical/technical discussion', 'research', 'legal discussion', 'charity' and 'media and culture' often do not contain much relevant discursive material to answer

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[59] As mentioned, this time cluster does not apply to the mainstream magazines and the specialised media (given the smaller amount of articles found in them). All selected articles (2000-2009) found in these media products are included in the DTA. In Flair, 10 articles were found, in Dag Allemaal, 24 articles were found, in Knack 69 were found. In De Artsenkrant 103 articles were found, in De Huisarts 71 articles were found, and in Kerk and Leven 29 articles were found.

[60] These are the articles (n=35) dealing with the discussions about the legalisation of euthanasia to people with dementia found in the original corpus (including a selection of two months per year), which implies that not all articles produced on this issue in the Belgian press could be included.

[61] Note that few articles dealing with a prominent case were found in the specialised media (n=20). Personal cases indeed are especially appealing to mainstream media. Note that the search for articles dealing with these cases (for which both Mediargus and paper archives were consulted) sometimes led to articles that only refer to them indirectly. When these articles are considered relevant, they are included in the corpus.

to research questions[62]. Above all the coverage-categories of personal cases (including the prominent cases and those (non-prominent cases) included in the time-clusters) and of political and ethical discussion (during moments of elevated political struggle) contain the most relevant material in the light of answering the research questions. This does make us aware, however, of the fact that the conclusions that are drawn about the construction of the good death in the Belgian print media apply particularly to these categories. As became clear in the quantitative analysis also indicated, these categories form only part of the entire corpus.

A first reading of the eventual corpus helps identifying relevant categories of media coverage. These categories, each marked by specific discursive logics of constructing the good death following specific mechanisms of representation, guide the analysis and are used in the reportage presented in chapter XIII. The prominent-case coverage constitutes a first category and encompasses the six cases listed earlier. A second type of coverage is the coverage of 'non-prominent' end of life cases (included in the coverage of 2000, 2004 and 2007). This is coverage dealing with the end of life of an individual (or multiple individuals), thus approaching the end of life from a personalised angle. Unlike the prominent-case coverage, the cases dealt with in the non-prominent coverage did not receive significant media-attention, but appear in the selected media-products once or on a very limited amount of occasions. Third, there is the coverage of/embedded in political struggle; articles that approach the end of life mainly from a political or ethical angle and that are published on the occasion of the legalisation of euthanasia or the extension of the euthanasia law. In addition to these three categories, the categories of 'mainstream coverage' and 'specialised coverage' meaningfully guide the analysis – for they often construct the good death in different ways; i.e. by operationalising different discourses.

In sum, these categories guide the analysis on the basis of type of coverage:

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[62] In primarily bringing short articles with legal information, the articles published in Onze Tijd/Plus Magazine do not contain discursively rich material and were not considered useful in the light of the research questions. Also few articles published in Knack were shown relevant.

- Prominent case coverage
- Non-prominent case coverage
- Coverage of/during elevated political/discursive struggle

And these categories guide the analysis on the basis of media genre:

- Mainstream media coverage
- Specialised media coverage

It should finally be noted, before starting reporting the analysis, that the comprehensive nature of the corpus has made it possible to reach saturation, referring to the point when new data add little to nothing to the categories, concepts, and relations between them (Lindlof 1995: 241; Lindlof & Taylor 2002: 223-225; Strauss & Corbin 1998: 143). For the case at hand, this more concretely means that saturation is reached within as well as across the different types of media coverage.

Chapter XIII: Constructing the good death in Belgian media representations: a DTA

The aim of the above-identified corpus is to give access to a wide variety of discourses on the good death circulating in society. In presenting the discourse-theoretical analysis of the corpus discussed in the previous chapter, this chapter sheds light on the operationalisation of the discourses (iteratively) identified in part B of the dissertation, and on the politics of representation that lie behind them.

The first three sections of this chapter formulate answers to the research question inquiring the construction of the good death. These sections focus on the construction of the good death by looking into the way the discourse of revivalism, the discourse of patient-centeredness and discourse of the good death, with autonomy and dignity as nodal points, are operationalised in the selected media items. A first key section is labelled 'the basics of revivalism' and deals with the operationalisation of a (medical)-revivalist discourse on death and dying and a patient-centred discourse on medicine. The basics of revivalism form a hegemonic context within which the nodal points of autonomy and dignity are articulated. Sections two and three, then, respectively deal with the articulation of autonomy and dignity in the selected media items. It is crucial to remark, once again, that these nodal points are not theoretically imposed upon the analysed media material, but that they are derived from an iterative research process and consequentially at least partly come out of the analysis. In section two, the analysis demonstrates how a ratio-personal discourse is dominant in the articulation of autonomy. Through the operationalisation of a ratio-personal discourse of autonomy, the patient's right to make the own end-of-life decisions is accepted. Interestingly, it also becomes clear how the interplay between this ratio-personal discourse with other discourses and with media-specific logics of representations results in a very particular construction of the good death. Here, the analysis points in the direction of on the one hand a democratic and pluralistic representation of the good death in the non-prominent case coverage, where the individual's right to choose is emphasised, and on the other hand a disciplining representation in the prominent-case coverage, where euthanasia – the right to die - is constructed as *the only* good death (as opposed to the bad death). In addition to the operationalisation of a ratio-personal discourse (in either a pluralistic or a disciplining way), we also encounter an operationalisation of a communitarian discourse, through which the patient's autonomy and right to self-determination in deciding over the own death are denied and contested. In section three, the analysis reveals a series of articulations of dignity – demonstrating the complexity and multi-layeredness of dignity as a nodal point of a late modern discourse of the good death. Most dominant are articulations that, encouraged and triggered by specific mechanisms of representation, draw on the operationalisation of an extrinsic approach to dignity, and more specifically of a discourse of self-identity through which autonomy, independence of care and the deterioration of the mind are constructed as threats to a dignified existence and death. Counter-hegemonic is an articulation that builds on a discourse of innate human dignity.

In a fourth section, the construction of good journalism in covering the end of life is discussed. Based on a limited amount of material, this section is remarkably shorter than the three others. Indeed, not very much material relevant to answering the research question as to what normative constructions of good journalism are inscribed in the selected media-representations, was found. It has been explained earlier that the research interest in the construction of good journalism was formed in the reception analysis, where a significant part of the analysed talk indeed revolved around the question as to what 'good' journalistic coverage of the good death should look like. In the media texts themselves, much less such reflections were found. This quantitative observation, however, does not make the relatively few reflections about good journalism found in the analysed media representations any less interesting or less worth discussing.

A final note before turning our attention to the analysis concerns the use of citations. The discussion below indeed includes many citations[63], some of them more concise and some of them more extensive. The function of the use of citations is to support the analysis and provide the reader with a more concrete idea about how discourses are put into practice in the analysed media texts. With each quote, the necessary information about its origin (source and date) and about its author is given. Sometimes, parts of the quote are underlined to draw attention to aspects that particularly support the analysis and interpretation. The use of quotes should also be seen in the context of pursuing transparency; the reportage of the analysis includes *"enough raw narrative to convey a vivid picture and support each of the points they are making from the analysis"* (Fade, 2003: 144).

1. The Basics of revivalism

It was argued in chapter V of this dissertation that death is (re)-introduced as a familiar part of life in a late-modern 'revivalist' area, and that in a medicalised context, a medical-revivalist discourse triggers and encourages the emergence of a patient-centred discourse. This section first of all shows that *openness*, *control* and *acceptance*, as nodal points of a revivalist discourse, appear as being at the very basis of revivalism throughout the entire corpus, where they become articulated according to media-specific logics of operationalisation. The analysis reveals a dominance of emotionalist articulations of revivalism, which is sometimes contested by more rationalist articulations – not in the least in coverage of prominent cases.

Second, this section illustrates how also a patient-centred discourse is at the very basis of revivalism as it appears as a deeply permeated system of meaning in the analysed media texts. The analysis points in the direction of a number of sub-dimensions of patient-centeredness. A first dimension relates to the contestation of the medico-technical death, which is opposed to a humane way of dying with the patient – instead of technology – at the centre. A second dimension concerns the construction of

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[63] The citations given throughout the text are translations from the original Dutch citations.

the scope of medicine, which is mainly found in medical media and through the voice of medical professionals. The scope of medicine is constructed mainly through the signifier of care, which serves the construction of the scope of medicine as including care for the dying patient but excluding euthanasia. Third, the doctor-patient relationship appears as a dimension of a patient-centred discourse. The analysis reveals three different constructions of the doctor-patient relation in the corpus, each of them embedded in a patient-centred discourse but each of them articulating a patient-centred discourse with a number of other discourses in a way that results in a specific construction of the doctor-patient relationship.

Openness, control and acceptance as well as patient-centeredness, as suggested above, appear as very dominant and deeply permeated throughout the analysed coverage. This observation corresponds to the theoretical claims made in chapter V, where it has indeed been argued that the discursive step from a medical-rational towards a medical-revivalist discourse has been taken. While some rare contestations of a medical-revivalist discourse were found, the latter still appears as a dominant and deeply permeated system of meaning. Medical-revivalism, with openness, control and acceptance and patient-centeredness appearing as its foundations, sets the hegemonic context within which the nodal points of autonomy and dignity – still at the very core of this analysis - become articulated.

1.1. Openness, control and acceptance

The nodal points of the revivalist discourse of death, as discussed in chapter V, are openness, control and acceptance. In the selected media texts, these nodal points indeed emerge as being at the very core of a late modern good death; they are the binding elements of a revivalist discourse. The analysis shows that openness, control and acceptance are articulated in often emotionalist terms, while in some cases, we find a more rationalist articulation - not in the least in the coverage of prominent cases. This latter observation suggests the specific discursive dynamics inherent to the prominent case coverage, through which also the articulation of the nodal points of autonomy and dignity – discussed further in this chapter - becomes very specific and peculiar.

While the mere ‘visibility’ of death and the end of life in the media is in its own not an argument to support the ‘revival of death’ thesis, the many media items found about the end of life and end-of-life decision-making at least *suggest* a certain ‘openness’ surrounding death and dying. A detailed analysis of the articles confirms the ideal of openness in death and dying. With their focus on personal stories about the end of life - giving a voice to the patient or the relative - particularly coverage of personalised cases emphasises the ideal of a death/dying process that is openly experienced.

The focus on openness in the analysed coverage is recognisably embedded in a revivalist discourse on death and dying, where the concealed and hidden death is replaced by a death that is seen as familiar. The expression *“death is part of life”* often appears throughout the corpus, and functions as a linguistic materialisation of revivalism. The revivalist ideal of ‘openness’ is, for instance, nicely illustrated in this extract from an article where the farewell of Tuur Van Wallendaele is described:

> ‘Tuur wanted a farewell party, spending time with all the friends (…) because he thought that we had to learn to deal with death. There was so much sentiment, tenderness, and power, and everything felt just right” (19 November 2009, DM – political commentator).

An openly experienced dying process is, as this quote also suggests, often articulated in emotionalist terms. A ‘proper farewell’ is indeed marked by *“beautiful and intense moments”* (6 December 2005, Flair – relative). Particularly articles in popular magazines, with their focus on ‘human interest’, frequently provide a detailed emotionalist account of the ‘farewell’, often from the perspective of the dying person’s partner:

> "Ramona was lying in the living room in the couch, and everyone came to say goodbye. That was a very intense and emotional period, the real farewell (…). We cried a lot during that last week. The last weeks were horrific, but I'm glad they were there. I felt so close to Ramona during those weeks. We had such beautiful moments, and talked a lot" (3 April 2007, Flair – relative).

In the coverage of euthanasia, having certainty about a farewell that is experienced in full awareness is often constructed as part of good death[64], as the following extract for instance illustrates: *"I've always been afraid that she would die whilst I was not there […] But we knew: 21 April 2003. That's the day she would leave us, the day of the final goodbye. In that sense, I found it a beautiful end"* (2 October 2004, DS – relative).

The farewell is also constructed in terms of expressivism; expressing feelings of love and friendship and making sure that personal conflicts and unfinished business are resolved. This expressivist construction is encouraged by a human-interest tendency to stage the end of life-trajectory, making it into a public media event. The following quotes from articles published in the popular magazine Dag Allemaal bear witness of the expressivist construction of 'the farewell':

> "When I knew my mother was terminally ill, I realised that it was now or never to tell her I love her" (7 May 2002, Dag Allemaal – relative)
>
> and
>
> "I was present beside his dead bed. That was horrible. But I'm glad I was able to say goodbye. I was able to tell Emmanual that I love him and that I'm grateful that I knew him" (14 February 2006, Dag Allemaal - relative).

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[64] This way of representing euthanasia as a good death is closely related to the construction of dying autonomously and dying with dignity, where the dominance of a liberal concept of autonomy and of a discourse of independence entail an image of the self-chosen death as a brave and dignified way to die.

In another article, not having expressed feelings of love is represented as part of a 'bad' dying process: *"We never cried together, not once did I ask her whether she thought she would die and never did I say her that I would miss her terrible. I regret that so much"* (27 December 2005, Flair – relative).

An expressivist ideal appears also in another way, when openness towards the imminent death becomes articulated with the another nodal point of a revivalist discourse: control. Here, openness creates an opportunity for the dying individual to arrange the funeral service according to the own preferences and thus allows him to have (some) control over the course of events. The funeral service, in this way, becomes an opportunity for the dying individual to express his/her personality 'post mortem'. The extracts below illustrate how 'making the own arrangements for the funeral' draws on ideals of expressivism and individuality:

> "Together, we organised her funeral. She choose the music, we listened to every songs, choose the texts" (3 April 2007, Flair - relative),
>
> "I also visited the undertaker. We drank coffee and talked about the way I see my funeral" (20 March 2007, Dag Allemaal – dying patient)
>
> and
>
> "He knew the meadow where his ash will be scattered, the casta diva by Maria Callas that will be heard in the auditorium. He wrote his own farewell speech, he choose the picture that will shine on the obituary" (repo 18 September 2008, DM).

The expressivist and emotionalist articulation of the farewell is not uncontested, however. An alternative construction appears in the coverage of Mario Verstraete and

Marcel Engelborhs, where a revivalist emotionalism becomes replaced by a more rational approach to the end of life: *"I don't fancy sad emotions. And now that I'm sick, I dislike it even more when people kiss or hug me. I don't want people to show their emotions to me"* (repo 7 March 2008, HLN – dying patient), or elsewhere in that same article: *"He was no into tears and drama"*. A similar appreciation of rationalism appears in the coverage of Verstraete: *"He has no intentions of telling the date of the euthanasia to anyone, or to make any so called 'last visits'"* (7 March 2008, HLN). These contestations of emotionalism give a first indication of the specific discursive dynamics inherent to the coverage of prominent euthanasia cases; dynamics that, as will become clear in the elaborations that follow, are relevant to the construction of a good death at a variety of levels.

A second nodal point of a revivalist good death is acceptance. While acceptance of the imminent death lies at the basis of both a right to die discourse and a hospice discourse (see chapter VIII), the construction of acceptance as an ingredient of the good death in the selected coverage above all comes into being through the operationalisation of a hospice discourse. The latter is especially the case in emotionalist articulations of acceptance, which find their origins in Kübler-Ross's ideal of grieving (see chapter VIII) that is at the core of a hospice articulation of the good death. Here, a good death is a death that is accepted by the dying individual; he or she is at peace with the imminent death, he or she is "ready" (e.g. 20 March 2008, HLN). The revivalist focus on the process of coming to terms with the imminent death is operationalised both in specialised medical media and in mainstream media. In the medical media, first, the ideal of acceptance often appears in articles about palliative care. For instance: "*In the unit, people are given the opportunity to accept death, to prepare for the mourning process*" (January 2000, DH). In the mainstream media, acceptance above all functions as a central signifier in the coverage of the dying process of Bart Verbeeck. For instance:

> "He was at peace with his self-chosen end. It would happen at home. Surrounded with the love of his parents and brother." (Opinon 3 February 2009, DM).

As the very concept of 'accepting' suggests, death remains grievable. It is, for instance, described in terms of *"a destiny"* (repo 20 December 2010, DS). Accepting the imminent death is hence a difficult task, but also an enriching one, allowing for a 'meaningful' death:

> "The young man accepts his destiny. He launches a facebook page and a non-profit organisation with the name 'Bart's route'. He organises a family day and goes from school to school to inspire youngsters to live positive. The money he makes with his efforts goes to cancer research" (repo 20 December 2010, HLN).

The articulation of acceptance that is found in the coverage of Bart Verbeeck is very much in accord with a hospice discourse, where death is seen as an opportunity for personal 'growth'. Sometimes, the difficulty of accepting the imminent death comes with a particular logic of operationalisation, where the prominent case coverage's tendency of creating extra-ordinariness results in a construction of *the brave dying individual*. In an article about Bart Verbeeck, the way the dying individual deals with terminal illness and faces his imminent death is described in terms of *"an almost unreal sobriety"*(opinion 3 Feb, DM), which implicitly applauds the way the dying individual has conquered feelings of fear about death. In the coverage of Marcel Engelborghs, the association between acceptance and conquering fear goes a step further, and moves away from a hospice focus on the *process* of growth in accepting imminent death. More concretely, a focus on acceptance manifests itself in the form of a kind of admiration of the dying individual's rationality. For instance: *"A posthumous tribute to* *the man who appeared stunningly strong enough to accept his irreversible*[65] *destiny"* (repo 16 December 2008, HLN). The construction of a rational fearlessness comes with a construction of the dying individual, and his rational attitude, as 'beyond the ordinary' – which is accomplished through the use of dramatised and personalised story-telling inherent to a human interest journalism. As the following extract for instance illustrates:

> "Not one second does he think about the paralyzing idea of human mortality and he refuses to let his pleasure be ruined by the knowledge that he will not ever see the sunset again". 'Oh no', he says, 'because I have accepted my destiny a long time ago'" (6 March 2008, HLN).

Acceptance, in the coverage of Engelborghs, is in a way stripped from its emotional aspects, as it becomes articulated in terms of fearlessness. A repo on the death of Engelborghs for instance describes the dying individual's attitude in encountering the end of life as follows: *"No fears, no regrets, ready with everything"* (16 December 2008, HLN). In another repo, Engelborghs' fearlessness towards death is once again stressed, which contributes to the construction of a 'rational' revivalism:

> "He died the way he lived: happy and at peace with everything […] 'Am I relaxed or what?' He rethorically laughs. 'I am not afraid to die. I never feared death, and I am not fearing death right now'" (repo 20 March 2008, HLN).

A similar rationalism and fearlessness was found only once in the non-prominent case coverage; an article in the popular magazine Dag Allemaal (3 April 2001), stresses the fearlessness of the terminally ill person facing death as follows*: "The set deadline of*

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[65] The word 'irreversable' is also illustrative for the (dominance of) a Western discourse of death (see chapter IV)

three months has almost passed. And yet she remains stoic. Nothing gives away the ongoing pain. Nothing gives away the insecurity or fear".

Elsewhere in the corpus, we find a contestation of the 'acceptance-fearlessness' articulation, where the difficulty of accepting death is emphasised. One example can be found in a letter to the editor, which was sent to the newspaper in response to an article about the euthanasia of Marcel Engelborghs. As the reader testifies about the death of her partner: *"The realisation that you are dying is very painful. He wanted me stay near him when they gave him the injection. And believe me, this was extremely difficult for him, for me, and for the doctor performing the euthanasia"* (25 march 2008, HLN). Another illustration of this alternative way of articulating acceptance can be traced in the coverage of the euthanasia of Tuur Van Wallendael, where the dying individual himself expresses the difficulty of coming to terms with the imminent death: *" Tuur Van Wallendael is gradually prepared, for better or worse. But reconciling with death is too much to ask. 'I am no hero'"*(repo 12 September 2009, DS). This last example entails a certain visibility of the potential 'failure' of the ideal of accepting the imminent death – whether it be according to a hospice logic where acceptance is the final stage in a process of growth, or following a more rationalist articulation in terms of fearlessness.

1.2. Patient-centeredness

A medical-revivalist discourse of death and dying, as the theoretical part of this thesis explained, arose alongside and triggered the emergence and establishment of a patient-centred discourse of medicine. In the analysed coverage, a patient-centred concern with the patient and his wellbeing appears as a hegemonic discursive dimension throughout the entire corpus, where it is often articulated with a hospice discourse. The latter might come as no surprise given hospice's explicit engagement with the wellbeing of the patient (the right to die discourse is, as we saw, also very much engaged with the patient's quality of life. But whereas the right to die discourse focuses on the right to determine the moment of death, the hospice discourse puts the emphasis much more on the caring *process*).

It will become clear on the following pages that a patient-centred discourse is multi-layered and therefore complex. The analysis, indeed, points in the direction of three sub-dimensions of the operationalisation of patient-centeredness. In a first dimension, patient-centeredness is operationalised in the articulation of resistance against 'high-tech' dying, which is constructed in opposition to a human and dignified way of dying. In a second dimension, patient-centeredness serves the construction of the scope of medicine. This dimension has care as a central signifier, through which care for the dying patient is constructed as a significant aspect and task of medicine, while euthanasia – constructed as an act of 'non-care' and 'killing' – is excluded from the scope of good medicine. In the analysed coverage, the construction of the scope of medicine largely remains within the boundaries of the medical field, where medical actors engage with reflections about what practices good and ethical medicine should and should not include. In a third dimension, patient-centeredness is operationalised through the articulation of the doctor-patient relationship. Here, the analysis shows that a patient-centred discourse is not uniform and unambiguous. The discourse indeed not solely articulates the subject positions of the emancipated and autonomous patient and of the serving doctor, but also allows for a combination with a discourse of medical paternalism. This, in turn, shows that while concerns with the patient and his quality of life are very dominant, patient-centeredness sometimes - especially in the medical sphere - continues to be challenged by remnants of a paternalistic discourse, where these remnants more specifically contest the notion of absolute patient autonomy.

1.2.1 Contesting the medico-technical death

Criticism against a medico-technical approach to death, which builds on the Foucauldian argument of an objectifying and de-humanising medical gaze, often emerges throughout the corpus. These critiques implicitly draw on a notion of quality of life (identified in chapter V as a nodal point of a patient-centred discourse), which indeed also includes 'quality of dying'.

An approach that alternatively constructs the patient as a 'human being' is often endorsed, as for instance nicely illustrated in the following extract from an article in De Artsenkrant that clearly draws on a patient-centred discourse:

> "As a doctor, you do not want to unleash your quantitative, Cartesian, statistic vision on a patient, a human being who will then be saying: "That is about chances, not about me"' (11 September 2008, DA).

In the medical coverage, critiques against a medico-technical death are often embedded within a hospice discourse; stressing the importance of a human, qualitative and dignified rather than a ratio-medical approach to death and dying, and thereby reflecting the revivalist argument that death is a part of life and should be treated as such: *"Dying is part of life. It should not be the monopoly of the hospital where medical technology is the main conductor"* (25 February 2000, DA). A 'techno-medical' or 'high-tech' versus 'human' approach that is implicitly articulated here also emerges in more explicit terms. As for instance in an article in De Standaard, where an oncologist argues that *"Medication is one thing, the presence of a listening and understanding ear is something else"* (7 January 2000, DS). Hospice's focus on dying in a 'home-like' environment is also frequently articulated as part of a good dying process: *"The unit has the unique appearance that is noting like a regular hospital unit, but that has a rather homely nature"* (January 2000, DH). The hospice ideal of dying in a 'home-like' environment also appears in the mainstream coverage, for instance in an article about the palliative care unit of the Antwerp Middelheim hospital (27 January 2000, HLN).

Clearly building on a patient-centred discourse, a member of the palliative care team states:

> "We try to give our patients what they wish for. Creating a homely atmosphere is important. If they want to sleep until eleven, that's possible".

In the mainstream case coverage, critiques against a highly medicalised end of life appear in the capacity of the ideal of dying at home, where dying at home is indeed constructed as part of a good death. For instance: *'Death is part of life and living is something you do at home. I hope to I will be able to die in my room in this house"*(3 april 2001, Dag Allemaal). Elsewhere in the mainstream case coverage, critiques against the medicalisation of death, which would entail an 'objectivation' of the dying individual, appear in more explicit terms:

> "That body was no longer the body of my father. <u>He was only 'a heap', surrounded by a bunch of machines</u> […] I immediately told Chris: 'If something like that were to happen to me, <u>please make sure that I don't die in the hospital"</u> (20 December 2005, Dag Allemaal – relative).

In similar vein, an article about the death of Mario Verstraete represents dying in a medical setting as part of a 'bad death', opposing it to a good death, which involves dying at home: *"He wanted to go in style, not in a hospital, but at home"* (19 June 2002, DS). Simultaneously, it should be noted that contestations of a "high-tech" death do not include a contestation of medicalisation as such. Indeed, euthanasia is of course a medical way of dying, and it is through the construction of euthanasia as a "soft" death (2 April 2009, DM – Van Esbeen) or a "peaceful" death (5 March 2008, HLN – Engelborghs) that the shift from a medical-rationalist discourse to a patient-centred medical-revivalist discourse becomes illustrated. Sometimes, medicalisation even becomes constructed as a precondition for a good death in a very explicit way; as is the case in an article about the request for euthanasia of a woman with depression, where - by quoting the person in question – euthanasia as a good death is opposed to a de-medicalised suicide as a bad death: *"I hope I don't have to commit suicide […] I want a soft death under medical guidance"* (19 October 2004, Dag Allemaal).

1.2.2. Caring for the patient versus killing the patient: constructing the scope of medicine

A second dimension of patient-centeredness revolves around the construction of the scope of good and ethics medicine. The construction of the scope of medicine is a dimension of patient-centeredness that is encountered almost exclusively through the voice of medical professionals, which suggests a high degree of reflexivity within the medical field about what practices medicine should and should not engage with. In the construction of the scope of medicine, the signifier of care (for the dying patient) plays an important role. Good care, so it is assumed, should result in a dignified dying process in which quality of life – defined in terms of being free of pain and fears and being surrounded by good care - is guarded over. The notion of care derives its specific meaning as it becomes articulated with the ideal of a natural death and in opposition to euthanasia, where the latter is discursively constructed in terms of killing.

In articulating care with the ideal of the natural death, the notion is opposed to both therapeutic tenacity and euthanasia. The 'care versus therapeutic tenacity' opposition, comes about through the operationalisation and importation of a (hospice) ideal of a natural dying process, where the patient's quality of life is not diminished by pointless and potentially painful treatments. A natural death, which is a qualitative death (in the hospice discourse), is marked by a dying process where the patient is surrounded by 'good care', and is opposed to an 'unnatural' prolonging of life, where the patient becomes the 'object' of useless medical treatment. Take for instance the following extracts:

> "'Our medical ethics is merciful', Gastmans confirms, 'that ethics is not focused on stretching life for as long as possible. It is focused on good care" (31 January 2000, DS– medical professional)
>
> and
>
> "To prolong a lifetime as long as possible isn't the ultimate goal of the medical world, rather it is to make a lifetime as long as possible as good as possible. An adequate supportive and palliative care for the terminally ill is extremely important here" (15 January 2008, DA).

The 'care versus therapeutic tenacity' opposition is further accomplished by emphasising the doctor's ability to *"know his limits"*. Such arguments draw on a foundation of patient-centeredness, focussed on *"the comfort of the terminal patient"* *(*DA, 3 March 2000). For instance: *"Patients […] need talented medical counsellors, who preferably cure, but when this is no longer possible, are able to recognise that."*

The articulation of care in opposition to euthanasia draws on an ideal of the natural death as well, as an article in the religious Kerk&Leven for instance describes euthanasia as *"unnatural"* (30 April 2008 – about the euthanasia of Claus) or as the Flemish Cardinal for instance defines euthanasia as a '*chemical*' death (27 March 2008, HLN – about the euthanasia of Claus). Articulations of the natural death as opposed to euthanasia also appear in the coverage of Amelie Van Esbeen. Here, they appear as counter-hegemonic to the dominant support of the right to die that marks the coverage of Van Esbeen. Van Esbeen's doctor is given a voice in a number of articles, where he motivates his rejection of her request for euthanasia and presents palliative care as an alternative: *"on her request, there will be no more therapeutic and medical interventions. Nature has free rein"* (25 March 2009, HLN), *"Amelie will be able to die with dignity without euthanasia"* (24 March 2009, DS). The counter-hegemonic nature of the construction of the natural death death as ‘the’ good death becomes illustrated in this same article, where the doctor’s decision to continue with palliative care is explicitly described as a threat to Van Esbeen’s right to self-determination. Another example is found in an opinion of a political commentator De Morgen (25 April 2009), who deplores the doctor’s rejection of Van Esbeen’s right to die and in a somewhat mocking way, by using quotation marks, contests the association of a natural death with a good death: *“A woman wants to die but is not allowed to do so. ‘They’ allow ‘nature’ it’s course”*

A care versus euthanasia opposition - where care represents good medicine – further delegitimises euthanasia by constructing the latter as an unethical act of ‘killing’ that is outside the scope of ethical medicine. In other words, whereas care for the dying is defined as a main objective of medicine, euthanasia is – by defining it as ‘killing’ – discursively excluded from the scope of ‘ethical medicine’.

The construction of euthanasia in terms of killing starts with an articulation of euthanasia as being outside of revivalism, or even as a threat to a revivalist approach to death and dying. In an article in De Artsenkrant, euthanasia is for instance described as an expression of a culture that doesn’t come to terms with death and dying, and fears ‘care’: *“Did we lose any cosmic vision on matters of death and live? Is our people the most uninspired alive? The most fearful about death?” (*4 July 2003, DA – medical professional). In similar vein, an article published in Kerk&Leven describes euthanasia as a phenomenon that is symptomatic for a society that cannot accept the fact that *“nobody can defeat death”* (12 January 2000).

An antagonistic ‘care versus euthanasia’ opposition goes on to be accomplished by more explicitly disarticulating euthanasia from care and hence from the scope of ethical medicine. Representations of euthanasia as being outside an ethics of care appear regularly, especially when representatives of the medical field and the religious field are voiced:

> "A society that chooses for euthanasia, runs the risk of neglecting care" (opinion (Chris Gastmans[66])24 maart 2009, DS)
>
> and
>
> "Is it from a care-ethical perspective legitimate to consider suicide or euthanasia as the right answer to life fatigue? We don't think so" (Opinion president elderly care Hospital Leuven 24 maart 2009, DM – about the euthanasia of Amelie Van Esbeen).

The construction of an antagonistic 'care versus euthanasia' opposition creates a discursive entry point for the construction of euthanasia as 'killing', which is strengthened by referring to a more encompassing ethical principle that forbids killing (and on which the medico-ethical resistance towards euthanasia builds). Referring to the principle of 'thou shall not kill' above all appears as a legitimising strategy to problematise euthanasia in the debates during the run-up to the euthanasia law in 2000 (and 2001):

> "The norm 'thou shall not kill' continues to be unimpeachable and should be pursued as good as possible in emergency situations" (15 January 2000, DS – Advice Board of the Flemisch Church Community)
>
> and
>
> "It takes a lot of courage for a doctor these days to defend the universal principle 'thou shall not kill'" (Opinion head of palliative care department general hospital St Lucas, 25 March 2000, DA).

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[66] Chris Gastmans is a professor medical ethics at the Catholic University of Leuven, Belgium.

Similarly, articles in Kerk&Leven states that *"the universal law Thou shall not kill"* is put *"between brackets"* (25 April 2001) and that *"a universal prohibition crucial to maintain humanity and social order is now refuted"* (5 January 2000).

Elsewhere, euthanasia is described as 'unethical'; an *"ethically impermissible act"* or an *"ethical evil"* (23 February 2000, DM –medical professional). As an 'act of killing', then, euthanasia becomes more explicitly constructed as not being part of 'ethical' medicine - defined in terms of care. Euthanasia is for instance described as not *"part of the exercise of medicine as determined in the law 'practice of health professions'"* (18 April 2008, DA –medical professional). The following extract from a letter to the editor in De Artsenkrant, voicing a non-medical, nicely illustrates the construction of care versus euthanasia, which is accompanied by a construction of euthanasia as outside the scope of good or ethical medicine:

> "A strict division between <u>palliative and medical care on the one hand</u> and <u>euthanasia on the other hand</u> is needed. This provides clarity and avoids possible misunderstandings regarding this non-medical treatment. In this way, doctors can focus on that were they were trained for: curing and, if nothing else is possible, <u>providing people with the best care</u>" (18 April 2008, DA –medical professional).

In another article, the account of a palliative care doctor clearly draws on a palliative care versus euthanasia contradiction, which is in turn grounded in a construction of euthanasia as outside the scope of 'good' or 'ethical' medicine, which gives priority to the patient's quality of life: *"Believe me, in the seven years the palliative department exists, I have never felt the need for euthanasia. Because we <u>provide physical and mental comfort</u>. (…) There is a <u>big differe</u>nce between <u>elevating pain treatment</u> in a systematic and controlled way and <u>consciously and abruptly end someone's life</u>"* (7 January 2000, DS).

Antagonistic 'palliative care versus euthanasia' constructions appear elsewhere in the corpus as well, for instance in articles published on the occasion of the euthanasia of

Hugo Claus. An article in De Huisarts, written in response to Claus' euthanasia, uses an exclamation mark to suggest the incompatibility of euthanasia and medicine:

> "From ex-prime minister of Belgium to the first intellectual of Flanders, from liberator to medical (!) practitioner, his courageous act was glorified' (22 May 2008 – medical professional)

It is interesting how the issue of patient autonomy is almost completely absent from medical reflections about the scope of medicine – even though patient autonomy is at the very core of a patient centred discourse. The discussion above illustrates how it is often implicitly assumed that the doctor knows best what good medical care is, and that euthanasia can never be a form of medical care.

Sometimes, a care versus euthanasia opposition is contested and euthanasia is reconciled with, and even constructed as 'a form of care'. In an article published in De Artsenkrant in 2004, a physician specialised in palliative care for instance states:

> "'Palliative care is based on one philosophy', dr. Mully argues, 'the possibility to die "well". It is something that means a different thing to each individual patient, but euthanasia can be a part of it'".

In the other medical newspaper, De Huisarts, similar contestations appear. In an interview with a doctor about his experience with euthanasia for people with dementia, *"helping"* the patient to die is argued to sometimes be *"the best care"* that can be offered (9 February 2006 – medical professional).

Earlier, in the run-up to the euthanasia law, arguments like these already appear. The extract below from a repo on "doctors and euthanasia" in De Standaard (4 January 2000) operationalises a medical-revivalist discourse and patient-centred discourse and in so doing constructs euthanasia as part of the scope of a late-modern revivalist medicine. One of the doctors heard in the article states:

> "When a patient asks for that injection [euthanasia], I don't think I have failed. Medicine has its boundaries. You can act like the absolute protector of life, and lapse into medical short-sightedness. Or you can stand by the patient until the end, whatever that end is. I don't have any doubts. I am that last doctor. The patient is the most important"

Also non-medicals sometimes express similar arguments. In an editorial from the mainstream newspaper De Morgen (written on the occasion of the euthanasia of Mario Verstraete), euthanasia is discursively brought into the scope of medicine - stating that by performing euthanasia, doctors are *"helping people in need, by doing exactly that what the word 'euthanasia' refers to etymologically: providing a good death"* (28 September 2002, DM).

1.2.3. The doctor-patient relation

A third dimension of patient-centeredness relates to the doctor-patient relation. It was explained that under a patient-centred discourse, the power positions between the doctor and the patient are impacted upon. More and more, it was explained in chapter V, is the patient defined and positioned in and through an ethical framework of autonomy and empowerment, which comes with the construction of the subject position of the good doctor in terms of respecting the wishes of the patient and it terms of showing empathy for the patient.

The analysis demonstrates how the subject position of the good doctor as possessing of the capacity of expressing emotions is dominant in both specialised and mainstream media, which again reflects a broader societal resistance against a medico-rational gaze. In the mainstream coverage, the construction of the 'humane' doctor above all appears in articles dealing with a personalised end of life case, where the importation of a subject position of the sensitive and humane doctor is facilitated through a personalised and intimitised (human interest) type of storytelling. An article about Mario Verstraete for instance describes the euthanasia process as follows: *"Also the doctors who were standing around his bed were moved. They even had to leave for a few moments because they could not deal with it emotionally"* (28 December 2002, DM – relative). Similar constructions of the good doctor are found in the non-prominent case coverage, where the doctor is for instance represented in a non-paternalistic way – as an 'ally' of the patient: *"The oncologist was her best friend, because she knew he would be there for her when she needed him, and precisely that gave her strength"* (31 October 2008, HLN – relative). Also in the medical media, representations that construct the doctor as an emotional being - with fears and insecurities - appear:

> "Relief and satisfaction, but also loneliness and abandonment […] doctors performing euthanasia often struggle with different feelings" (28 November, DA - relative).

In the medical media and in articles published in the mainstream media where medical professionals are heard, the good doctor is constructed in terms of being both non-paternalistic and non-authoritarian, and of having good communication skills and having the obligation to inform the patient:

> "Not every doctor can and wants to perform euthanasia. But you have to be able to talk about it with your patient. A lot of doctors don't know how to do that"
>
> and
>
> "It is up to the doctor to assess medical hopelessness, but up to the patient to determine it. It is very important that the doctor informs the patient honestly, in order for the patient to know his options" (12 February 2000, DM).

While the construction of the good doctor builds on a general principle of patient-centeredness, multiple discursive varieties can be traced in the corpus – coming into being at the intersection between a patient-centred discourse with other discourses. Below, three main constructions of the doctor-patient relationship the analysis reveals are set forth. This elaboration appears useful for the further analysis as well, as representations of the doctor-patient relationship support and effectuate the construction of specific aspects of the good death – including the autonomous death and the dignified death, which will be discussed in the following chapters.

1.2.3.1. Serving the patient

In a first articulatory logic, the good doctor becomes constructed as a 'servant' of the patient. This construction emerges at the intersection between a discourse of patient-centeredness, a consumerist discourse, and a discourse of patient autonomy. The good doctor, then, respects the wishes of the (autonomous) dying patient:

> "You have to listen to the patient and sometimes his ultimate question is to end his decay at a given time" (18 March 2008, DA – medical professional).

While the quote above was found in an article published in De Artsenkrant, this type of articulation appears above all in the mainstream case coverage, where story-telling techniques of new journalism and human interest journalism support and facilitate the construction of the good doctor in terms of serving the patient and respecting his wishes. In the coverage of Marcel Engelborghs, the good doctor appears through the narrative category of 'the helper'; the doctor performs the euthanasia and in so doing helps the patient to die:

> "'It becomes a conversation [with the doctor] that brings even more relief that he'd expected. 'Cause I am allowed to die today', Marcel says" (6 March 2008, HLN).

Whereas the coverage of Engelborghs' euthanasia represent a non-conflicutal doctor-patient relation, letters to the editor - often dealing with personal experiences with the end of life of a relative and written in response to this coverage - entail a visibility of doctor-patient conflict, and in so doing implicitly construct the 'bad doctor', paternalistically neglecting the wishes of the patient. For instance:

> "Four days before she died, she was hospitalised in the palliative care service. She could do nothing more than shake her head. I informed the doctor about her wish. His response: that is not possible. She will have to ask me herself, and more than only once. If she wakes up and she is in pain, we will give her painkillers" (28 March 2008, HLN – relative).

Also in the coverage of the case Van Esbeen, the good doctor is constructed as the doctor who serves the patient, and becomes opposed to the 'bad doctor' who threatens the autonomy of the patient. The patient, here, sometimes becomes constructed in consumerist terms; when not providing the desired services, the patient and the family for instance go searching *"for a new doctor who is willing to meet her request"* (25 March 2009, DS – relative). Again, the 'bad doctor' appears in terms of paternalism, not respecting the autonomous wish of the patient:

> "No, she did no choose the day of her farewell. The doctors decided that it would happen yesterday. If it were up to her, it would have happened last week, or even last year" (2 April 2009, HLN - relative).

Also coverage of non-prominent cases sometimes implicitly constructs the bad doctor in terms of neglecting the wishes of the patient, thereby drawing on both a discourse of patient-centeredness and a discourse of patient autonomy:

> "Raymond Verbiest wrote it down clearly. He was tired, in pain, and wanted euthanasia. But the hospital doubted. Raymond died, not after euthanasia, but after being put to sleep by a strong painkiller….'They wanted to offer him comfort (angry), 'but that was not the comfort he wanted'" (28 June 2008, DM – relative).

Despite the construction of the good doctor as respecting the principle of patient autonomy, the representation of the doctor-patient relationship in the mainstream case coverage still reflects the medicalised nature of the end of life, which entails a relationship of dependence. It is indeed through the medical (and legal) system, that 'unbearable suffering' and the 'hopelessness' of the situation are set forth as conditions that make euthanasia permissible, determining whether or not the dying patient is *'allowed'* to die. After having given permission to die, it is indeed the doctor who helps the dying patient to die. Sometimes, the very (medical) act of euthanasia is described in terms of 'helping' the patient – which above all appears in articles about the right to die of vulnerable groups such as elderly (e.g. letter to the editor 26 March 2009, DS) and psychiatric patients (e.g. 15 October 2004, HLN).

Particularly the coverage of Van Esbeen and Verstraete reflect the tension-field between the patient's right to self-determination and his inevitable dependency on the medical and legal field. The medicalised and legalised categorisation of Van Esbeen as suffering *"from all sorts of geriatric ailments", "but not terminally ill"*, labels her as not qualifying for euthanasia: *"The doctors rejected Amelie's request for euthanasia, but it is legally determined that there has to be an 'unbearable suffering' as a result of a disease that is labelled as incurable"* (2 April 2009, HLN). In the coverage of the case Verstraete, the patient's dependency on the medical system is suggested by stressing the way the doctor's decision to approve Verstraete's request for euthanasia brings salvation and relief:

> "When we got the 'we go for it' from the doctors, Mario became
> another person', lights in the eyes, humour, even a tempered happiness" (28 September 2002, DM - relative).

1.2.3.2. The doctor-patient partnership

A second articulation of the doctor-patient relationship comes into being at the intersection of a patient-centred discourse and a hospice discourse, and appears above all in medical media and in the mainstream coverage where representatives of the medical field are heard. The following extract from an article in which a politician from the Flemish Catholic party is heard, offers a nice example of the construction of a doctor-patient 'partnership' and its embeddedness in a hospice discourse: *"Goutry wants more attention for an anticipative dying policy. 'The palliative home centre should <u>write the end of life story together</u> with the resident in order for the personnel and the relatives to know how the person involved wants to say goodbye"* (12 June 2008, DS). Also the focus on the informative role of the doctor towards the patient can be seen in terms of a partnership, where *"ideally, the role of the doctor is to inform the patient in understandable language"* (5 December 2009, DM).

The construction of the doctor-patient relation as a partnership often comes with critiques against a doctor-patient relation where the doctor 'serves' the patient. For instance: *"Even though the patient has the right to ask, he cannot claim that his demand is met. <u>Doctors cannot be obliged to practice euthanasia</u>, even though every legal condition is fulfilled"* (DA, 4 January 2008 – medical professional). A 'partnership' between doctor and patient is sometimes explicitly suggested as an alternative to a consumerist approach to the doctor-patient relation. As expressed here by the president of the West-Flemish order of physicians: *"the patient asks a service and the doctor delivers that service. For him [the chairman of the Belgian liberal party], the patient is a consumer who can* *make demands. While the doctor-patient relationship is something very different. <u>It is a partnership where doctor and patient decide together</u>"* (DA, 4 June 2002).

1.2.3.3. Medical paternalism

A third articulation, finally, emerges at the intersection of a discourse of patient-centeredness and a discourse of medical paternalism. At the intersection between these two at first sight contradictory discourses, a construction of the good doctor as a 'protector' of the patient emerges. This type of articulation was exclusively found in the medical media and in the religious Kerk&Leven. When it emerges, it often serves a de-legitimisation of euthanasia. The patient, following this articulatory logic, should above all be protected against any form of pressure that would lead them to ask for euthanasia: *"Some patients feel as if they are a burden to their family. Sometimes, the family gives that impression. The doctor has to prevent that these factors play a role" (*2002, DA – medical professional).

In one article, a medical-paternalist 'the doctor knows best' argumentation appears explicitly. Again, it emerges as a discursive strategy in the de-legitimisation of the legalisation of euthanasia. In this concrete case, the argument goes that the proposal to legalise euthanasia would saddle people with a *"crushing responsibility"*. And the article continues: *"Implicitly or explicitly, they are confronted with the questions: 'Do I want to live like this'? But letting euthanasia depend on the mere choice of the patient is dangerous. He is then receptive to pressures hidden in the social and physical dependence"* (18 January 2002, DA – medical professional). Another rather explicit articulation of medical paternalism is found in Kerk&Leven, where it not serves the de-legitimation of euthanasia, but the de-legitimation of the other pole of a 'non-natural' death: therapeutic obstinacy:

> "Some people believe that a medically futile treatment should only be discontinued at the request of the patient or his family. Others rightfully think that a doctor has the duty to stop such a treatment, when it is - according to the current state of affairs of medical science – understood as pointless. It makes no sense to wait for a request of the patient or the family. Besides, they are not trained to judge whether a treatment is pointless or not" (12 January 2000).

Medical-paternalism appears in another way as well, where not the autonomy of the medical professional vis à vis the patient is emphasised, but where the political and legislative world is represented as a threat to the medical professional's autonomy. This representation appears in articles published in the medical media during the run-up to the euthanasia law. Like an 'ethics of care', this construction of autonomy appears as a means of delegitimising euthanasia. More concretely, the legal and political regulation of 'matters of life and death' is seen as a threat to the autonomy of the medical professional, who is placed between *"evil and the deep sea" (*22 February 2000, DA – medical professional*).* In one article, it is for instance argued that the euthanasia law is not necessary because *"most doctors continue to take their responsibility like they have been doing since the oat of Hippocrates"* (1 May 2008, DH and 6 May 2008, DA – medical professional). The argument goes that the end of life concerns *"one of the most intimate life phases of a human being"* (18 February 2000, DA – medical professional), *"the essence of life*" (22 February 2000, DA – medical professional), and therefore cannot be captured by or reduced to juridical and political regulations. Take the following extract:

> 'The consequence is, so he [professor Thierry Vansweevelt, medical law] argues, that the most intimate, most place-and situation dependent sentimental issue is reduced to a series of juridical concepts, principles and procedures about which jurists claim to have the exclusive insight" (4 February 2000, DA – medical professional).

The underlying assumption here is that end-of-life decision-making should remain primarily a medical matter, and that the autonomy of the medical professional in making the necessary end-of-life decisions should be respected. Medical ethics, then, rather than politics and law, is constructed as the most qualified and best-suited instance to deal with the end of life:

> "Doctors should not let their ethics be determined by a law, medical ethics exists independently from legalisation" (4 June 2002, DA – medical professional)
>
> and
>
> "When the law conflicts with medical ethics, the doctor should do everything to change the law. The ethical duties take precedence over legal duties" (4 July 2003, DA – medical professional).

2. The construction of dying autonomously

The previous section already suggests the importance of autonomy as a nodal point in the construction of the good death in the selected media. It for instance became clear that actively being involved in the organisation of the own funeral service appears as an aspect of 'dying well' – which implicitly draws on an appreciation of autonomy and individuality. We also saw how the representation of the doctor-patient relationship in some cases builds on the ideal of patient autonomy. The representation of the doctor-patient relation at the same time suggests the 'political' and contested nature of dying autonomously, pointing to its embeddedness in social conflict, antagonism and discursive struggle. This section further zooms in on the discursive construction of 'dying autonomously', where the latter refers to the ideal of self-determination in making the own end-of-life decisions. Constructions of dying autonomously draw on two main discourses, which were elaborated in chapter VI of this thesis: a ratio-personal discourse, and a communitarian discourse. It is illustrated, in this section, how these discourses are imported into the analysed coverage. The analysis uncovers three main logics of operalionalisation. The first two logics operationalise a ratio-personal discourse, hence accepting the individual's right to self-determination. At the same time, both logics operationalise the ratio-personal concept of autonomy in (radically) different ways. A first logic is found in the mainstream coverage of personalised non-prominent end of life cases, where the individual's *right to choose* for a particular way of dying is suggested, and where the autonomy of the dying individual is linked to a variety of possible end-of-life decisions. In a first logic of operationalisation, put differently, the right to autonomy is in a more latent and implicit way suggested or assumed. This logic also appears, albeit in a slightly different way, in the coverage of Bart Verbeeck – where palliative sedation is described as an alternative to euthanasia; as an active and conscious choice for a particular (good) death.

In a second logic of operationalisation, a ratio-personal discourse of autonomy is articulated with a right to die discourse. This results in an explicit and intensive use of concepts like (the right to) self-determination, through which the concept of autonomy is claimed and linked (exclusively) to the right to die. The articulation of a ratio-personal discourse of autonomy with a right to die discourse becomes very specific in the coverage of prominent euthanasia cases, through the use of specific mechanisms of representation. A first mechanism of representation that is specific to the prominent-case coverage relates to the representation of the patient's social network and the medical field, through which the patient's right to die is emphasised and claimed. A second mechanism concerns the construction of euthanasia as *the* good death, which comes with the construction of palliative care as a passive way of dying opposed to euthanasia as brave way of dying.

A third logic of operationalisation, finally, opposes the individual's right to autonomy subscribed to in the first two logics of operationalisation. This logic emerges above all in representations of the end of life in the specialised media (including the two medical newspapers and the religious newspaper), but also in the mainstream media, where it (counter-hegemonically) appears in articles published in the run-up to the legalisation of euthanasia. Here, a radical contestation of the very (ratio-personal) notion of autonomy emerges and an alternative of care is foregrounded, mainly but not exclusively by drawing on an autonomy concept embedded in a communitarian discourse.

2.1. The right to choose: (implicitly) suggesting autonomy

In materialisating a ratio-personal discourse - with choice as a nodal point - a first logic of operationalision builds on an implicit acceptation of the individual's right to choose for a particular end of life trajectory. Articles from the non-prominent case coverage category often latently accept the patient's right to self-determination in taking the own end-of-life decisions. Instead of a more 'politicalised' right to die vocabulary, which is found in the coverage of prominent cases, the right to self-determination is presupposed here by the use of an 'agency-assuming' lexis and grammar – by using words such as 'deciding' and 'wanting' and active sentences. This logic of representation is encouraged by the use of an emotionalised type of storytelling. As the following extracts illustrate:

> "When also the last therapy stopped being effective, <u>she decided</u> to request for euthanasia. It was the first time she ever thought of herself" (2 October 2004, DS - relative)

> '

> "She was recommended to follow chemotherapy, but she received bad news after only a month: there were metastases on the liver. When we informed mama, she decided to stop the chemotherapy." (5 July 2002, Dag Allemaal - relative)

> and

> "[…] last Saturday we were told that chances to survive are almost zero. "The moment when Britt decided to stop fighting and to stop treatment" (14 April 2007, HLN - relative).

The extracts above refer to the decision of the patient to request for euthanasia or to stop treatment. But also pursuing the palliative care trajectory, including continuing certain treatments, is (implicitly) represented as an active choice of the dying individual. For instance: *"He uses palliative chemotherapy. Not hoping for a miracle, but to buy extra time with his family"* (7 June 2007, DM).

These implicit ways of assuming and suggesting the dying individual's right to choose are grounded in a ratio-personal discourse of autonomy, as they accept the right of the individual to act on the basis of the own preferences. At the same time, certain aspects of a communitarian discourse on autonomy are equally inscribed in these representations, which is achieved through an emphasis on the embeddedness of the dying individual within his/her social network – an emphasis that emerges above all in popular magazines. The relationship between the dying individual and his or her relatives for instance appears as an important motive that steers decision-making. Take for instance also this example:

> "Mama's will to survive was very strong. She wanted to try everything not to leave us alone"(22 November 2005, Flair - relative).

Sometimes, the individual's choice for a particular end of life trajectory explicitly appears a the choice not to choose for euthanasia, or the choice against euthanasia:

> "That is up to 'up above' [referring to God] to decide', he answered to my question whether he would consider euthanasia. Evidentially, I will respect that decision" (28 February 2006, Dag Allemaal - relative).

This choice *not to choose* for euthanasia emerges in the coverage of the palliative sedation of Bart Verbeeck as well, where the choice against euthanasia derives a more 'political' character, as palliative sedation becomes explicitly represented as alternative to euthanasia. This political loaded nature also shows through the use of a more explicit vocabulary referring to the self-determination of the individual. For instance: " *He did not want to determine the moment he would die. He wanted to leave that decision 'up to his body'*" (2 February 2011, DS). The representation of autonomy that we find in the coverage of Verbeeck in a way corresponds to what has been labelled as a procedural approach to autonomy (see chapter VI), where autonomy does not necessarily refer to particular values or ideals, such as self-determination, independence and freedom. The choice not to be autonomous, then, when taken in full consideration of the existing options, counts as an autonomous choice. In the coverage of the case Verbeeck, the individual's choice *not* to take a particular decision - i.e. the decision not to choose for euthanasia - is constructed as an active choice:

> "Bart Verbeeck has chosen for palliative sedation. A sleep you never wake up from, but that leaves it up to the body to decide when to let life go" (3 February 2011, DM).

This impacts on the construction of palliative care as a 'good death', where the metaphor of 'fading away' frequently appears: "*Seven years later, the pain has become unbearable and he chooses palliative sedation, allowing his body to fade away slowly*" (1 February 2011, DM). Palliative sedation, then, is sometimes implicitly constructed as a 'softer' way of dying than euthanasia. The borders between life and death are more blurred[67] and the moment of death is not strictly defined and decided upon:

> "He did not want euthanasia, but choose for palliative sedation, allowing him to fade away softy" (13 Decembers 2011, HLN).

A similar metaphor of 'fading away' also appears elsewhere in the corpus when a palliative care based death is described, illustrating its rootedness in a hospice construction of a good death – where the latter is much associated with 'good care':

> "Somewhere in the middle of September, Martine was hospitalised in the palliative section where, after very good care, she passed away peacefully. In fact, Martine was able to say goodbye in a way she had always hoped for " (17 November 2008, HLN).

The individual's right to choose is not only assumed through the representation of the dying individual and his/her choice for a particular end of life trajectory. The right to make the own end-of-life decisions is the underlying principle in representations of conflict between the patient and the doctor, which indeed implicitly draw on a (ratio-personal) autonomy ideal. Whilst not deploying a vocabulary that explicitly refers to notions of autonomy and self-determination, the patient's right to make the own end-of-life decisions is assumed. Often, a dramatised storytelling that puts the emphasis on doctor-patient conflict facilitates the importation of a patient autonomy ideal. Take the following example:

> "Raymond Verbiest clearly wrote it down. He was tired, in pain, wanted euthanasia. But the hospital doubted. Raymond died, not after euthanasia, but

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[67] It is indeed notable how the words 'death' and 'dying' appear very rarely in the coverage of Bart Verbeeck.

> after being put to sleep by a strong painkiller….'They wanted to offer him comfort (angry), 'but that was not the comfort he wanted'" (28 June 2008, DM - relative).

While the extract above refers to the choice for euthanasia and the choice not to continue life-prolonging treatment, other articles representing doctor-patient conflict (again, in a dramatised and staged fashion) refer to the patient's right to continue life-prolonging treatment, thereby emphasising the patient's 'right to live':

> "A judge has compelled the head of palliative care of the Saint-Mary hospital in Halle to treat a terminally ill patient […] 'For three years, mother has been fighting cancer', Salvatore Pelonero (34), son of the recently deceased Marie Corbeel says' […] Every patient has the right to life, albeit only for one extra day. That is what mother wanted" (9 June 2008, HLN).

In the same article, the dying process is described by the journalist as *"a brave struggle"* against a paternalistic doctor as well as against the own illness. By quoting the son of the dying individual, the 'braveness' of continuing to 'fight' is further emphasised:

> "There may be people who voluntary step out of life by means of euthanasia and for whom it can't be over quick enough. But my mother wasn't like that. For the doctors in Leuven it was already a miracle that she was three years further. She was a fighter; she wanted to live, even with a lot of pain".

Fighting for one's life (and against illness) is described in terms of braveness also in another article, where the individual suffering from cancer is described as *"bravely"* continuing to *"fight for his life"*(20 March 2007, Dag Allemaal).

The above-given examples of representing doctor-patient conflict reveal two discursive logics that, as will become clear later, are radically the opposite of the logics of representation inherent to the prominent-case coverage. A first logic is the privileging of life over death, even when life involves pain and suffering. A second logic relates to the construction of the choice to continue to 'fight for one's life' as part of a brave dying process, which in the prominent-case coverage is sometimes constructed as a 'passive' way of dying – opposed to a good death and a brave death.

2.2. The right to die: claiming autonomy

Of all three logics of operationalisation (parts 2.1, 2.2 and 2.3), this second one – where a ratio-personal or liberal discourse of autonomy is articulated with a right to die discourse - is the most complex and multi-layered one.

The construction of the right to die builds on the operationalisation of a ratio-personal discourse of autonomy to support the individual's right to self-determination. Support for the right to die is above all found in the (mainstream) coverage of euthanasia, both in personalised cases (where an intimitised and personalised storytelling often comes with a privileging of particular constructions such as euthanasia as the brave death) and in articles that centralise political and/or ethical discussion about euthanasia. It comes as no surprise that constructions of the right to die appear foremost in articles dealing with euthanasia, knowing that the pro-euthanasia movement often goes by the name of the *right to die* movement (the right to die is indeed the main item on the agenda of the movement). There is, in other words, a semantic overlap between 'euthanasia' and 'the right to die'. It is however remarkable, and this is where this logic of operationalisation becomes particularly complex, how support for the right to die comes with a particular construction of the good death – especially in the prominent-case coverage, where specific discursive dynamics come with a sometimes limiting and disciplining construction of what it means to die well. This type of construction is the result of a complex interplay between a ratio-personal discourse of autonomy, a right to die discourse and media-specific mechanisms of representation.

Given the highly complex nature of this interplay, parts 2.2.1 and 2.2.2 zoom in on the logics of representation specific to the prominent-case coverage.

Before focussing on the specific discursive dynamics inherent to the prominent case coverage, it is crucial to first look into the way a ratio-personal discourse of autonomy, emphasising the individual's right to self-determination, is imported in the coverage as supporting the right to die claim for autonomy. There are three 'places' in the corpus where a ratio-personal or liberal discourse functions as a key system of meaning, and each of these places corresponds to a concrete moment of elevated discursive struggle about the right to die in Belgium. An explicit ratio-personal discourse in first imported in articles published during the right to die debates in the year 2000. Here, the right to self-determination appears as the most important argument in favour of the legalisation of euthanasia. Look for instance at the following extracts:

> "Euthanasia should remain one of the most individual decisions" (19 January 2000, Knack – medical professional)
>
> and
>
> "People are required to make choices a whole lifetime. Why would they not be entitled to that last choice?" (4 January 2000, DS - relative).

A second political moment where a ratio-personal articulation of autonomy prevails, is during the discussions about the possible extension of the euthanasia law to people with dementia. In the coverage of these discussions, a ratio-personal discourse of autonomy comes with an emphasis on individuals' right - *"their choice, their decision"* (Letter to the editor, 28 December 2005, DS), *"their autonomous will"* (opinion, 27 December 2005, DM) - to determine in advance - while being in a state of full consciousness - to have their lives ended in case of dementia:

> "If someone makes a decision while being in full consciousness, one has to respect that" (28 February 2006, Dag Allemaal – politician of the liberal party),

> "I want to have the right to make out a declaration in which I request doctor to end my life when I live under certain conditions" (Letter to the editor, 27 December 2005, DS)

> and

> "It is only logical that the extension of the law becomes a reality. But again, always and only on the request of the one involved" (opinion editor in chief, 27 December 2005, DM).

At the same time, opponents of the extension of the euthanasia law to people with dementia draw on an acknowledgement of autonomy as well – pointing to the risk that people might change their minds about their request for euthanasia during their illness and hence, that the person involved might be *"killed without having asked for this"* (27 December, DS – interview with politician from the Flemish Catholic party). Such arguments against the extension of the euthanasia law disarticulate autonomy from a traditional modern (medical) definition of consciousness and deconstruct the superiority of the fully conscious individual above the person who no longer is 'himself', thereby empowering the latter. As a catholic doctor and an academic for instance ventilate in an opinion editorial: *"Who has priority, the person who once made out the declaration of will, or the person with dementia who now enjoys the visits of his children, even though he no longer knows their names"* (28 December 2005, DS).

Third, the coverage of prominent euthanasia-cases often strongly draws on a ratio-personal conception of autonomy, which illustrates the political nature and relevance of these personalised stories. The self-chosen death as an individual right frequently and explicitly appears, in regular news items as well as in letters to the editor:

> “Dying with dignity should indeed be and remain an individual right” (letter to the editor, 28 March 2008, HLN – Claus and Engelborghs),

and

> “A human being has the right to self-determination […] No one can decide for anyone else” (opinion political commentator 5 October 2002, DM - Verstraete).

The dying individual’s right to self-determination indeed appears as the central theme throughout the prominent-case coverage. The following extracts suggest how articles about the euthanasia of Verstraete, Claus, Engelborgsh and Van Esbeen are inscribed into a right to die project – explicitly connecting euthanasia to the patient’s right to self-determination:

> “But the most important thing remains that Mario used his right to self-determination” (2 April 2002, DM – Mario Verstraete),

> “Just like Hugo Claus, he decided not to relinquish the control over his life” (19 November 2009, DM – Van Wallendael),

and

> “She was done with life and eventually died on her own terms. As she formulated it herself: ‘I am in control of my own life. I say that it’s time to go’” (2 April 2009, DM - Van Esbeen)

In the coverage of Van Esbeen, the centrality of a ratio-personal articulation of autonomy is combined with an 'emancipation of the elderly' discourse, where the possibility of an autonomous and self-determining elderly is stressed, often implicitly but sometimes explicitly. As respectively articulated by a medical care taker in a letter to the editor and by two ethicists in an opinion piece:

> "What is so filthy about self-determination? […] Please acknowledge these elderly and understand their request" (letter to the editor 28 March 2009, DM – medical professional)

and

> "What dignity does an elderly have when some options are excluded in advance and when others decide for her/him about how to solve 'the problem'? "(26 March 2009, DS).

The way Van Esbeen is described in several articles as a *"full individual"* (Letter to editor, 27 March 2009, HLN), a *"determined lady"* and a *"competent individual"* (2 April 2009, DM) also fits within the same emancipatory discourse.

It is particularly the coverage of prominent euthanasia-cases that requires further elaboration. In operationalising a ratio-personal discourse of autonomy, this coverage comes with a series of very particular logics of representation. These logics come into being in reciprocity between story-telling techniques like personification and dramatisation and the articulation of a ratio-personal discourse of autonomy with a right to die discourse.

The articulation of a ratio-personal discourse of autonomy and a right to die discourse is first manifested in and through the representation of the social network of the patient and of the medical field (part 2.2.1). With a dramatised and personalised (human-interest) type of story-telling, the representation of the social network and the medical field serves the reinforcement of the right to die claim. Second, these same story-telling techniques interact with the articulation of a ratio-personal discourse and a right to die discourse in such a way that is results in a rather limiting and disciplining construction of what it means to die well (part 2.2.2). Here, the analysis uncovers a 'euthanasia versus palliative care' antagonism, where the former is associated with an autonomous, good and brave way of dying whilst the latter is associated with a passive and bad way of dying.

2.2.1. The patient's autonomy and right to die versus the social network and the medical field

A first logic of representation that makes the right to die operationalisation of a ratio-personal discourse in the prominent-case coverage specific, is related to the representation of the patient's social network and of the medical field. The right to die-demand of self-determination is, in the prominent-case coverage, indeed enforced and validated through the representation of the patient's social network of the patient and the medical field. In a dramatised and personalised story-telling, the autonomy of the patient vis à vis his social network and the medical field is emphasised.

In the prominent-case coverage, the focus on the dying individual as having the ultimate and final decision-right is anchored, first, in a specific representation of the social network of the dying individual. First, the independence of the dying individual from his social network is emphasised. Especially the coverage of Mario Verstraete comes with a very strong focus on the independence of the dying individual from his relatives:

> "Mario made it very clear that he did not involve his son or his parents in his decision. Only he had control over his own life" (25 September 2002, DS).

Often, it is the dying individual himself who expresses arguments that draw on a strong sense of independence:

> "There have been people who tried to change my mind, but I stay determined: I cannot live like this" (25 September 2002, DS – dying individual)
>
> and
>
> "Will he wait for them [his friends to return from holidays]? 'I only wait for one thing: the permission to go, and then nobody will stop me'" (28 September 2002, DM – dying individual).

The right to take decisions in an independent way is also expressed by relatives of the dying patient, where the concept of 'respecting' the choice to die becomes important. Again, albeit in more implicit terms, the independence of the dying individual from his social network is endorsed:

> " I respect his choice. Indeed, only he can judge to what extent his suffering was unbearable" (Letter to the editor, 3 October 2002, HLN – Verstraete - relative)
>
> and
>
> "If she feels that it has been enough, I need to respect that. She decides about her life" (24 March 2009, HLN – Van Esbeen - relative).

The above does *not* imply that the dying individual is represented as socially isolated. In many articles, the relation between the dying individual and his social network occupies a central place, which - again - cannot be isolated from the case coverage's human-interest focus on the private sphere. The revivalist ideal of dying surrounded by relatives continues to be present, and the painfulness of the farewell is sometimes stressed – as for instance one article quotes Verstraete: *"I notice how much my leaving touches them, we have become so close these weeks. That makes the farewell harder"* (28 September 2002, DM – dying individual). A similar emphasis appears in the coverage of Van Wallendael: *"He had more difficulties with saying farewell to the people he loved, he said to our newspaper early in September"* (19 November 2009, HLN). Nevertheless, the ratio-personal articulation of autonomy, where the dying individual retains the right to self-determination, remains untouched.

The ideal of dying autonomously, embedded in both a ratio-personal discourse of autonomy and a right to die discourse, sometimes clashes with a communitarian discourse. More concretely, a tension between autonomy – as a nodal point of the ratio-personal discourse – and care – as a nodal point of a communitarian discourse – is anchored in the representation of the relation between the dying individual and his social network. In some of these representations, relatives of the dying patient do not support the decision for euthanasia, but contest it by drawing on a communitarian discourse that centralises the importance of care. It is by giving a voice to relatives of the dying patient - who articulate a form of resistance against the choice for euthanasia – that the discursive alternative of care becomes visible. The coverage of the case Engelborghs illustrates this:

> "It's not nice that Marcel wants to leave without telling us something', she explains in tears', I think it cruel' […] <u>We've always taken care of him and we still want to do so</u>" (repo 7 March 2008, HLN – relative).

A similar logic is revealed in the coverage of the case Verstraete, where his parents are quoted:

> "We wanted to <u>take care of him</u>, for our whole lives" (28 December 2002, DM)

And later in the same article:

> "We had a clear goal in our minds: we would convince Mario not the choose for euthanasia. But even love could not change his mind".

The patient's right to die is not only enforced by and achieved through the representation of the patient's social network. Also representations of the medical field serve a legitimation of the patient's autonomous right to die in the prominent case coverage. This occurs, more specifically, by constructing the doctor either as 'the helper', supporting the patient's right to die, or the 'villain', corrupting the patient's right to die.

Especially articles about the euthanasia of Marcel Engelborhs represent the doctor as the helper of the dying patient. The quote below for instance illustrates how the helper makes the euthanasia possible:

> "It becomes a conversation that brings even more relief that he'd expected. 'Cause I am allowed to die today', Marcel says'" (6 March 2008, HLN).

As a result of the construction of the doctor as the helper of the patient, the relation between the patient and the doctor is not marked by conflict. In the (few) articles where the medical professional is mentioned, he is represented a companion of the dying individual. For instance:

> "What was the most beautiful moment of your life?' The doctor asks. Marcel does not even have to think about it, because there was no such thing as 'the best moment' in his life. 'There were so many great moments', he says, thrilled because he is still capable of giving the answer"(6 March 2008, HLN).

The coverage of Engelborghs as well as the coverage of Claus (where the medical field remains invisible) to a certain extent render the possibility of conflict between the patient and the doctor invisible. This invisibility cannot be isolated from the construction of Engelborghs and Claus as extra-ordinary, and of their death as a 'brave death' (see later), as this construction allows them to symbolically transcend the power of the medical system. One article, where oncologist Wim Distelmans (director of the Flemish Right to Die organisation) is quoted, re-introduces the visibility of potential conflict:

> "Wim Distelmans, co-manager of the VZW 'right to die with dignity', is shocked. 'They [the doctors] proposed to bring him [Engelborhgs] to sleep so that he would die after a week, palliative sedation in other words. He was upset, he didn't want that. He wanted euthanasia" (20 March 2008, DM).

Two letters to the editor also take up on the seemingly 'taken for granted' right to die of Claus and Engelborghs – implicitly criticising the invisibility of possible patient-doctor conflict at the end of life:

> "Both Engelborghs and Claus were able to realise their ultimate wish […] Lots of other stories prove that it is not that easy to have the wish for euthanasia respected for Average Joe" (28 March 2008, HLN)
>
> and
>
> "I am happy for Engelborghs that he was able to go as he wanted. Congratulations to his doctor. A half year ago my father found himself in the same situation. For him, it wasn't that easy to obtain euthanasia although everything was legally in order" (15 March 2008, HLN).

Opposed to the doctor as helper is subject positions of the doctor as a ‘villain’, which appears above all in the coverage of the euthanasia of Amelie Van Esbeen whose old age and bedridden situation facilitate the construction of Van Esbeen as a victim. This construction is, again, encouraged by a dramatised and conflict-driven mode of storytelling and by the urge to stage the end of life trajectory. For instance:

> “Deeply sad: there is no other way to describe the situation of Amelie Van Esbeen. The elderly resident of the home Sint-Bartholomeus tried to commit suicide last year and has been on a hunger strike ever since. And this because she has only one more wish in her life. ‘I want to die. And rather today than tomorrow’ Amelie entrusts us, hooked to the bed of her too small room” (23 March 2009, DS).

Instead of helping the patient to die, the villain forbids the patient to die:

> “She was already a week on a hunger strike after her request for euthanasia was refused. ’The doctor thinks that my health is too good to let me die” (2 April 2009, DM)
>
> and
>
> “Amelies grand son […] is chocked. ‘This decision was taken without consideration of the wishes of Amelie and us. That is beneath contempt’” (25 March 2009, HLN).

In the coverage of the case Verstraete, the doctor is, to a lesser degree, positioned as a villain. It is indeed the medical professional who decides not to go through with the euthanasia. Rather than this being the decision of the doctor himself however, it is the legal system that is responsible for the postponing of the euthanasia. The doctor, in this way, becomes a victim of the legal system*: ″’We will not do it, Mario’, they said, ‘not* *before the euthanasia is published in the Belgian statute book'* (28 September 2008, DM). The patient, then, has to wait until *"the small letters he can't even read any more', permit him to die"* (28 September 2008, DM).

2.2.2. Autonomy and the construction of euthanasia as *the* good death

A second logic of representation that is specific to the right to die operationalisation of ratio-personalism in the prominent-case coverage concerns the representation of the good death versus the bad death. Here, it is particularly the construction of euthanasia as *the only* good death and as a brave death that is particularly interesting, as it indeed renders a discourse that supports the freedom of choice into a limiting and disciplining discourse that knows only one way of dying well.

The construction of euthanasia as *the* good death has different dimensions. A first dimension is relatively 'innocent' and concerns the construction of controlling the own moment of death as desirable. In a second dimension, the construction of the 'bad death' makes its entrance, where the latter is associated with palliative care – a 'passive' way of dying associated with dependency. A third dimension relates to the construction of euthanasia as a 'brave' and 'extra-ordinary' way of dying, where the identity of 'dying individual' intersects with other identities; the hero, the rebel, the bon vivant. Let us look at these different dimensions in more detail.

Choosing the own moment of death is – in the prominent-case coverage - constructed as allowing the individual to die well (first dimension). More concretely, it is the use of a particular vocabulary that contributes to the construction of the self-chosen death as a good death. In an article about the euthanasia of Engelborghs, a friend of the dying individual for instance argues that he is "*happy*" Engelborghs *"could choose the moment of his death"* (19 November 2009, DS). An article about Claus, similarly, describes the choice for euthanasia as allowing the individual not to *"say goodbye"*, but to *"celebrate goodbye"* (31 March 2008, DM), and yet another article writes about the way Claus experienced a *“great sense of rest”* when he *“decided his time had come”* (31 March 2008, DM).

The construction of euthanasia as a good death is also accomplished by combining an emphasis on autonomy and self-determination with a particular (metaphorical) description of euthanasia as way of dying well. In the coverage of the euthanasia of Mario Verstraete, controlling the moment of death by choosing for euthanasia is for instance described as dying *“in style”* (28 September, DM), and euthanasia is described as “*the soft death”* (7 October 2002, DS). Or for instance:

> “Mario Verstraete will soon die, after euthanasia. ‘In beauty’, he says […] He knew when, where, and how” (27 September 2002, DM).

Likewise, in the coverage of Claus, euthanasia is equated to *“a dignified death”: “Hugo Claus choose the moment of his dignified death himself, just like he had always claimed the right to make his own decisions in life”* (20 March 2008, DM).

The construction of euthanasia as a good death is further accomplished by assuming the possibility of the self-chosen death to put an end to suffering, illness and deterioration on the own command. Death, then, is to be preferred over a life of in which the individual is, for instance, *“weak, ill and tired”*[68] (27 September 2002, DM - Verstraete).

In the coverage of Engelborghs, the construction of euthanasia as a ‘good death’ emerges through the voice of the dying individual, who expresses feelings of

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[68] The privileging of death over life is contested in the coverage of Bart Verbeeck, the only case dealing with palliative sedation instead of euthanasia. Here, a similar appreciation and appreciation of life can be found than in the non-prominent case coverage. As for instance articulated by Verbeeck himself: *“I am grateful for every extra day I’ve been given”* (3 November 2011, HLN).

"gratitude" for being *"allowed"* to choose the own moment of death (5 March 2008, HLN; 16 December 2008, HLN). Similar articulations of gratefulness appear in the coverage of Verstraete, where the dying individual is for instance described as *"shifting between impatience and gratefulness to be allowed to die. Thanks to the law. On the own command"* (27 September 2002, DM).

The construction of the self-chosen death as a good death cannot be seen in isolation from the construction the 'other', not self-chosen, death (second dimension). Indeed, by describing the self-chosen death as a good death – as *"the ultimate right to self-determination"* (Opinion journalist 4 October 2002, DM) - not choosing for euthanasia, but dying with palliative care becomes a form of 'bad death' - where above all dependency is constructed as an aspect of this bad death. There are different ways in which the construction of the bad death is achieved, which are tightly connected to the specificities of the different prominent case.

In the coverage of Engelborghs, the articulation of palliative care, dependency and the bad death appears in several articles. In a repo, for instance, Engelborghs' choice for euthanasia becomes constructed as a good death allowing the individual to maintain his independence, thereby implicitly problematising the state of dependency. The journalist describes Engelborghs' decision as follows:

> "He wanted to demonstrate how it gave him peace of mind, knowing he would be <u>allowed to die before becoming dependent of whomever</u>. Because <u>he disliked nothing more then deterioration</u>" (16 December 2008, HLN).

In another article, the problematisation of dependency is enshrined in a quote of Engelborghs himself, where dependency, palliative care, suffering, deterioration and becoming a burden are articulated together into a chain of equivalence: *"Then I can go to palliative care and be dependent, continue to suffer and deteriorate and be a burden to the whole society"* (3 July 2008, HLN).

In the coverage of Verstraete, the construction of a palliative care based death as part of a 'bad death' is achieved through emphasising the way such a dying process, which involves hospitalisation, threatens the autonomy of the individual. As the mother of Verstraete is quoted: *"He visited several palliative care services, and he returned nodding his head. He would not be able to play his music, friends could only visit during certain hours, he would not be able to eat what he wants, smoking a cigarette in his room wasn't allowed"* (28 December 2002, DM).

In the coverage of the euthanasia of Claus, a palliative care versus euthanasia antagonism – where the former is constructed as a bad death and the latter as a good death – manifests itself through the construction of the Catholic Church as the ultimate other. By delegitimising reactions of the Catholic Church against Claus' euthanasia, where palliative care is manifestly presented as an alternative to euthanasia, an equation is created of Catholicism with palliative care. Catholicism and palliative care, then, become radically opposed to liberalism and euthanasia. Opinion pieces written on the occasion of the euthanasia of Claus sometimes very explicitly envisage the Catholic Church, take for instance the following example: *"As if they did not realise - or at least refused to acknowledge - how the public opinion is torn from the Catholic church and chose for a much more individual approach to what is moral acceptable and what is not"* (31 March 2008, HLN). Other examples of such an antagonistic 'liberal versus Catholic' construction also appears elsewhere - as for instance in this letter to the editor, where an equation of the Catholic Church with palliative care is manifested:

> "They [the Catholics] may tell me what the value of this prolonged agony is […] I wonder whether cardinal Danneels will still choose for palliative care after twenty hours next to the bed of a relative" (28 March 2008, HLN)

The construction of euthanasia as a good death and of a palliative-care based death as a bad death implicitly builds on a differentiation between dying actively and dying passively, where the former is associated with actively (and bravely (see later)) ending a life of pain, deterioration and suffering and the latter with *"continue to be dependent"* (3 July 2008, HLN - Engelborghs) and *"being a burden to others"* (25 March 2008, HLN – Claus).

Sometimes, these discursive associations become more explicit, when they for instance become articulated together in one sentence:

> "I think he did not want to <u>await the bitter end</u>, and wanted to retain <u>control over his own life</u>" (20 March 2008, DS – Claus).

The discursive association of palliative care as a passive death is sometimes contested. A journalist formulates an argument against the antagonistic 'euthanasia versus palliative care' dichotomy, which is close to the emancipating contextualist alternative presented by Agich (2003) (see chapter VI):

> "Either you raise a toast on your death with apparent insouciance or you wait, sometimes in intolerable pain, for the releasing end. In the first scenario you are brave, in the second scenario passive. <u>But should it be so black and white in the face of death?</u>" (28 March 2008, HLN – Claus & Engelborghs).

A similar contestation of an antagonistic euthanasia versus palliative care opposition appears elsewhere in the corpus as well. One example is a reader's plea for a holistic and inclusive end of life policy – formulated in response to discussions about the euthanasia of Verstraete: *"I believe that both palliative care and a euthanasia law should be properly established, which allows people to opt for what they feel is the right decision"* (28 May 2002, HLN). Another contestation of the euthanasia versus palliative care opposition is found in an opinion of the president of the Flemish Right to Die Association, stating that *"I believe that people at the end their lives just want to be free of* *any avoidable pain and misery. A lot of people prefer palliative care, others a self-chosen end. The one is no better than the other"* (29 March 2008, DM).

It is notable that contestations of a euthanasia versus palliative care antagonism appear in meta-discussions about the coverage of prominent euthanasia cases. The absence of these contestations in the personalised coverage of prominent euthanasia cases again points to its very specific discursive dynamics, which seemingly leaves no room for the importation of a discourse of care and a hospice articulation of the good death. Palliative care and euthanasia do become reconciled in the coverage of *non*-prominent euthanasia cases, however. In an article in the popular magazine Flair (14 February 2006) where a woman testifies about her father's choice for euthanasia, for instance, (the choice for) euthanasia becomes constructed as being part of a broader end of life trajectory; as the end-point of a palliative care trajectory. The palliative care unit is described as *"homely and friendly", "giving the patients everything they want".*

The self-chosen death is, through the prominent-case coverage's tendency to create 'heroes', also constructed as an extra-ordinary and brave death (third dimension). The discursive construction of euthanasia as a brave death sometimes shows in an explicit way, when the 'courage' of the dying individual is emphasised. For instance:

> "He determined the way in which he would die himself […] that deserves praise and lots of respect" (letter to the editor, 20 November 2008, HLN – Van Wallendael)
>
> and
>
> "Goodbye, brave Marcel" (8 March 2008, HLN)

Sometimes euthanasia is described as an act of resistance against death, which suggests a certain 'braveness': *"Tuur performed to only possible act of resistance against death: he would decide where and when he would leave life. A last act of self-determination"*, and the article goes on *"Death made it, but under Tuur's conditions"* (Opinion chief editor 19 November 2009, DM – Van Wallendael). In the same section of the newspaper, dedicated to the dead of Van Wallendael, the widow of Hugo Claus argues in a similar way: *"I admire his courage. You cannot let yourself be defeated by death*". An often-used metaphor in the coverage of Verstraete, Claus and Engelborghs is describing the choice for euthanasia as choosing to be a 'director' of the own life and death, and also contributes to the image of the individual conquering death. As nicely illustrated with this quote from the editor in chief of Het Laatste Nieuws: "*The famous dying Fleming died a masterterfully directed death*" (28 december 2002, HLN). In the coverage of Van Esbeen, it is above all the struggle for the right to die that is frequently described as courageous and in terms of 'braveness' – albeit in the capacity of being an 'ordinary hero'. Fighting for her right to die against both the legal and medical system, Van Esbeen takes up a 'heroic' subject position, as she eventually succeeds in claiming her right to self-determination:

> "Eventually, Amelie went on a hunger strike and throw the media into the gear to accuse the gap in the legal system. Successfully: on April 1, this brave lady got the end that she deserved" (25 December 2009, HLN).

The construction of euthanasia as an extra-ordinary death - which is facilitated by the prominent case coverage's tendency to focus on the extra-ordinary – is, in the coverage of Van Esbeen, accomplished also in more implicit ways, where the identity construction of the dying individual plays a crucial role. When reporting on Van Esbeen's dying process, a sense of extraordinariness is created through an identity-construction of 'ordinary hero'; a *"brave lady"* (25 December 2009, HLN) struggling for her right to die against the medical and political system. But it is in the coverage of Claus, Engelborghs and Verstraete that the construction of extra-ordinariness appears most prominently. In the case of Hugo Claus, this exceptionality is created through the construction of an identity of 'rebelling artist'. For instance, by combining the sentence *"He has always made his own decisions, until the last goodbye"* (20 March 2008, HLN) with a praiseworthy description of Claus (*"A universal artist, painter, sculptor, director, and cineaste")*, autonomous end-of-life decision-making is not only constructed as desirable, but also as a great deed. Through Claus' celebrity, his autonomous choice for euthanasia becomes represented as unusual and not reserved for everybody, but for those who, *"Like Claus, choose for a death that reflects the way in which and the philosophy of life with which they lived"* (21 March 2008, DM – opinion editorial about the euthanasia of Claus). Euthanasia, then, requires the existence of *"an autonomous mind", "an example", "a master", "a rebel"* (31 March 2008, HLN; Opinion 21 March 2008, DM; repo 20 March 2008, DM).

In the cases of Mario Verstraete and Marcel Engelborghs, a sense of braveness and extraordinariness is created through articulating their dying identities with an identity of *"an epicure"* or a *"bon vivant"* (5 March 2008, HLN; Opinion 3 August 2008, HLN and Opinion 2 October 2002, HLN). Especially in the coverage of Engelborghs, this identity construction (which emerges through the importation of a discourse of hedonism (see later)) comes with the construction of euthanasia as a brave death. Always having enjoyed life, Engelborghs has the *"great courage"* (Letter to the editor 3 August 2008, HLN) to make the autonomous end-of-life decision which allows him to *"continue enjoying life until the very last moment"* (21 March 2008, HLN). The extra-ordinariness of Engelborgh's death is further strenghtend when he is described as the one who comforts his relatives, thus demonstrating an extra-ordinary capacity of accepting his imminent death:

> "His phone rings. Again. 'No you shouldn't cry', he tells a friend. […] He doesn't want to be the one to be comforted. No, Engelborghs wants to comfort the others" (6 March 2008, HLN)

and

> "'I would never be able to be as brave as you', Gerets says to Marcel. 'Incredibly courageous how you are accepting and dealing with the imminent death'" (8 March 2008, HLN).

The discussion above illustrates the media's tendency to create 'heroes' and to emphasise extra-ordinariness. Contestations of the construction of euthanasia as 'the' brave death do exist, however. The most radical and obvious contestation appears in articles where Catholics are heard. As the Belgian cardinal is for instance quoted in one article: *"to get around death is no act of braveness"* (HLN 8 March 2008).

Another contestation appears in a letter to the editor (written in response to the coverage of Engelborghs) where a relative writes about the illness of her partner. In so doing, she reconciles the articulation of braveness that was found in the coverage of non-prominent cases – where fighting for one's life is described in terms of braveness, with the articulation of braveness that exists in the prominent-case coverage – where the self-chosen death is the brave death:

> "A dignified end indeed. <u>Congratulations to a brave man</u>. My husband is 55 years old and has had a terminal cancer for 5 years now […] He's been parallised since 6 months and stayed on a palliative care unit for 3 months. He is back home now and at times suffers unbearably. But don't talk to him about dying. <u>His motto: fighting until the very last breath. My hat's off to him too"</u> (8 March 2008, HLN).

2.3. Contesting autonomy: the right to care

The two logics of operationalisation discussed in 2.1 and 2.2 both draw on a ratio-personal discourse of autonomy, which means that they both subscribe to the individual's right to autonomy – the right of the individual to make the own end-of-life decisions. While they differ significantly in terms of how a ratio-personal discourse of autonomy is operationalised, they still share this basic acceptance of autonomy. A third logic of operationalisation, however, builds on a contestation of autonomy and instead operationalises a communitarian discourse and its focus on (the ethics of) care.

The debates about the legalisation of euthanasia in 2000 and the euthanasia of prominent cases provoke the fiercest contestations of the right to die, which again demonstrates how media articles about such events can be seen as places of discursive struggle. Contestations of the right to die can be traced in both the mainstream and the specialised (medical and religious) coverage. Whereas contestations of the individual's right to die are counter-hegemonic in the mainstream media, they appear in a more prominent way in the specialised coverage where they are more accepted and shared (by the medical en religious communities). In other words, when zooming in on the niche of specialised media, the mainstream counter-hegemonic becomes dominant.

Resistance against euthanasia and the right to die sometimes emerges as grounded in religious arguments. Evidentially, a religious contestation of self-determination appears in the Catholic Kerk&Leven. In response to the mainstream media coverage of the dead of Hugo Claus, one article for instance writes that euthanasia is not a courageous act, but that 'true courage' appears when people *"gratefully return their live to their Creator"* (2 April 2008, K&L).

In the mainstream media, religious resistance against euthanasia also emerges, albeit in a less 'elaborated' and reflexive way as in articles that bring ethical or political reflection and discussion do. One example of religious resistance against euthanasia is found in an article published in the popular magazine Dag Allemaal, where the testimony of a relative goes: *"'That is up to 'up above' [referring to God] to decide', he answered to my question whether he would consider euthanasia"*. (28 February 2006). A religious contestation of euthanasia appears in more political terms as well – both in the coverage of the discussions about euthanasia and dementia, as in the coverage of Hugo Claus, where it challenges the hegemony of right to die support:

> "Life has been given to us, it needs be handled with extreme care" (27 December, DS – politician of the Flemish Catholic Party)
>
> and
>
> "God disposes in death, not men" (25 March 2008, HLN – The Flemish Cardinal about the euthanasia of Hugo Claus).

In the coverage of Claus, a religious contestation of the right to self-determination is often radically delegitimised, and the Catholic Church becomes constructed as the 'ultimate other' – representing values that radically oppose autonomy and the right to self-determination. For instance:

> "Just because the end of life choice isn't theirs, they again crawl beneath the paving and they vent their spleen. Celebrate the own moral superiority above the body of a dead beloved one is no feat. Mister Cardinal: shame on you' […]"'I had to react', Mortier explained after his hard words during the funeral. 'It was vulgar and impudent how some people, only a few days after Claus' death, questioned his choice" (31 March 2008, HLN).

In addition to concrete religious resistance against the right to die, a denial of autonomy is most often grounded in a more encompassing communitarian discourse (which embraces religious arguments) and its focus on care[69]. The communitarian discourse indeed draws on societal concerns about *care* for the ill and dying. A communitarian discourse stresses and values the relations (of dependency) between individuals rather than the individual's right to self-determination. Both in mainstream and specialised media, arguments opposing euthanasia often draw on a communitarian discourse. Medical professionals and members of the Catholic community most often build on communitarianism, which suggests a dominance of this value system in both the medical and the religious field. The following expressions of resistance against euthanasia, for instance, strongly correspond to a communitarian discourse - remember Campbell's argument that 'to be a creature is to be born of others, to know ourselves through them, to depend upon them and create dependency':

> "The request for euthanasia or the right to self-determination is not unlimited. <u>A human is relational being</u>: you are a father, a mother, a daughter, a son, a partner or a friend" (11 April 2008, DH)
>
> and
>
> "The proponents of euthanasia legitimise their attitude on the basis of the right to self-determination[…] This self-determination is to be rejected. <u>A human being does not accomplish him-or herself alone</u>" (11 February 2000, DS – medical professional).

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[69] We saw in chapter VI that there is a close link between religion and communitarianism, which is why it comes a no surprise that arguments drawing on a communitarian discourse are often expressed by religious actors.

In an article published in Kerk&Leven on the occasion of the euthanasia of Claus, the communitarian emphasis on the interconnectedness of the self with the broader community is nicely illustrated: *"I believe that it is about an absolutisation of the right to self-determination versus the determination right of the community" (16 April 2008).*

Drawing on a communitarian discourse, a decision-making model building on the 'self-inside-community' concept sometimes appears as an alternative to a ratio-personal self-determination right. For instance:

> "Let it be clear that I define the us-determination right broader than the husband-wife relationship. There is of course a hierarchy: there are often children. But even when there are no wife or children anymore, there is still the nursing staff" (1 April 2008, DA – medical professional)
>
> and
>
> "'For the VVI [The Flemish nework of care] the objective of medicine is to 'provide good care'. Rather than to merely satisfy the autonomous volition of the patient' […] The alliance points out that the proposal [to legalise euthanasia] builds on an isolated vision of humanity. 'Only if the patient wants it, relatives and nurses can be involved in the euthanasia talk. That is noting like a 'relational (palliative) care context in which trust, accompaniment and discussability are central'" (18 January 2000, DA).

The above quote (again) reproduces a 'palliative care versus euthanasia' dichotomy, articulating palliative care with the notions of trust, accompaniment and discussabilty and euthanasia (implicitly) with a 'hard and socially isolated self-determination and autonomy'. A similar articulation appears elsewhere in the corpus as well, not in the least in Kerk&Leven. Look for instance at the following extract from an article published on the occasion of the discussions about the legalisation of euthanasia in 2000:

> "The absolute right to self-determination seems to be the ultimate [pro-euthanasia] argument. It is evident that this conception is in line with the extremely far-reaching individualism: the others have got nothing to do with my life or death".

Similarly, an article in De Artsenkrant (published after the legalisation of the euthanasia law) describes euthanasia in terms of an *"ultra-individualistic right of self-determination"* (4 July 2003, DA), and an article in De Standaard quotes Caritas Flanders (a Catholic charity organisation): "The proposal turns the right to self-determination into an absolute principle, which makes the patient incredibly lonely" (11 January 2000, DS).

'Care' functions as a nodal point of the communitarian discourse of autonomy, where caring for the ill and dying is, as a way of dealing with death and dying, opposed to euthanasia. Care is a matter of solidarity with those who need it – and can thus be seen in the light of a particular construction of the 'moral' society. Especially in 2000, during the run-up to the legalisation of euthanasia, these articulations of care (as opposed to euthanasia) become expressed:

> "What we need is a rediscovery of 'the community', concerned with the fellow human being who needs care" (Letter to the editor 28 January 2000, DS),
>
> "The right to self-determination cannot be an absolute norm. The fundamental question is: how does our society wishes to deal with suffering and human weakness?" (Letter to the editor 14 February 2000, DS)
>
> and

> "Do our politicians realise that their proposal […] <u>makes caring shady and excavates solidarity</u>?" (January 2000, K&L).

A similar appreciation of care appears in the coverage of discussions about euthanasia and Alzheimer, as for instance expressed by a scholar from a Catholic graduate school: *"Maybe, as a society, we have the duty to care after these people [people with dementia] […] the most vulnerable individual – also the individual who no longer disposes of his mental capacities – needs to be protected"* (9 December 2005, DS). A 'duty to care' is sometimes expressed in the coverage of personal end of life cases as well. Take the following examples, extracted from articles where someone testifies about living with a partner suffering from dementia:

> "When you love someone, you own that to him or her. At least, that's how I feel about it" (7 May 2002, Dag Allemaal - relative)
>
> and
>
> "What I do now, caring for him, is my duty" (28 February 2006, Dag Allemaal – relative).

Another argument drawing on a communitarian discourse is that the request for the right to die is a 'symptom' of a lack of care and humanity in society. Again, then, an association between euthanasia as an 'anti-social' and 'individualistic' way of dying emerges. In response to an opinion written on the occasion of the euthanasia of Van Esbeen, where the journalist stands up for the right to die, a reader reacts: *"In the vision of your commentator it is cowardly when a patient is refused euthanasia. The individual prevails. The real question of the individual is not heard […] Caring for people, is that still possible?"* (26 March 2009, DM). A similar argument appears in an article where a man with Multiple Scleroses is heard and gives his opinion about Mario Verstraete's choice for euthanasia:

> "Paul never thinks about euthanasia. 'People who do that, have more problems than only their disease. Above all a lack of friendship and tenderness'"(18 October 2003, HLN).

In Kerk&Leven, an article describes euthanasia as a *"refusal"* of human relationships (5 January 2000). Euthanasia, in Kerk&Leven, is radically opposed to an end of life where the dying individual is lovingly surrounded. Good care and human proximity, so the argument goes, takes away the individual's wish to die:

> "For the very first time in his life, he feels well surrounded and capable of dealing with his suffering. The request for euthanasia is no longer necessary"
> "Deep-human proximity and understanding very often make the request for euthanasia otiose"

Then again, the construction of care as the absolute answer to euthanasia requests and of euthanasia as a threat to care are sometimes dis-articulated and contested. Indeed, counter-hegemonic articulations of autonomy, structured around care as a nodal point, provoke reactions from the dominant discourse of autonomy – forcing it to engage with a signifier - care - that is normally (largely) outside its range. Take for instance the following extract, where an acknowledgement of care is reconciled with a ratio-personal conception of autonomy:

> "If a patient feels his life is inferior, then that's the way it is and then I respect that. But I have had patients with dementia for whom euthanasia was never an option. I respectfully give those people the permanent care they need" (9 February 2006, DH - doctor about euthanasia for people with dementia).

In addition to these more ‘elaborated’ meta-reflections, there are a number of representations where care and the self-chosen death are reconciled in more implicit ways. More concretely, articles that deal with a non-prominent personalised end of life case sometimes bring care into the range of a ratio-personal discourse of autonomy. In the article *“Sandra’s father choose for euthanasia”*, published in the popular magazine Flair (14 February 2006), for instance, neither the evidence of caring nor the individual’s right to choose for euthanasia are questioned. Care and the right to euthanasia are reconciled through an emotionalised narratisation, emphasising the loving relation between a daughter and a father: *“When you love someone, you have to let him go”.* A similar reconciliation of care and the right to euthanasia appears in an article in De Standaard, where respecting a loved one’s wish to die implicitly becomes constructed as an act of love and care: *“As a family, we respected her wish to die, because we loved her. Sometimes, love means letting go*” (28 March).

3. The construction of dying with dignity

The notion of dignity occupies a central place in the analysed coverage, which bears witness of the way it functions as a nodal point of a late modern discourse of the good death. It the corpus, it emerges mainly (although not exclusively) in articles about euthanasia. This comes as no surprise, as the pro-euthanasia movement often goes by the name of the ‘dying with dignity’ movement. In the analysed coverage, dying with dignity, or the right to die with dignity, appears regularly as a synonym for euthanasia, particularly in the prominent-case coverage. For instance:

> “At last you obtained your right to die with dignity” (7 October 2002, HLN - Verstraete)

> and

> “Hugo Claus has determined the timing of his dignified death himself” (20 March 2008, DM – Claus).

The notion of dignity is used in a variety of other ways as well, taking up multiple meanings. Building on the theoretical elaboration of dignity as a nodal point of the late modern good death (see chapter VII), the analysis unravels the different articulations of ‘dignity’ that appear in the coverage and the way they contribute to a specific construction of the good death. The majority of these articulations build on a approach of extrinsic human dignity. A first articulation (3.1) is close to what has been labelled in chapter VII as a discourse of moral conduct. Here, dignity becomes articulated as a certain way of encountering the imminent death and handling the end of life. Other articulations of dignity (3.2, 3.3 and 3.4) operationalise a discourse of self-identity and consequentially very much engage with the notions of autonomy, independence, the body and the self. A final articulation (3.5) operationalises a discourse of innate human dignity. This articulation challenges hegemonic articulations that draw on an extrinsic dignity approach and more specifically opposes the idea that old age and illness, and the dependency that comes with these conditions, affect human dignity.

3.1. Handling the end of life with dignity

A first meaning that ‘dignity’ takes up in the analysed articles refers to the way the dying individual deals and comes to terms with the imminent death, and emerges in the shadow of the far more dominant articulations of dignity in terms of independence and self-reliance, in terms of maintaining an ‘authentic’ self, and in relation to the question of a valuable human life. Despite the fact that an ‘handing the end of life with dignity’ articulation appears only rarely (and only in coverage of prominent cases), it still merits further elaboration – precisely because it subtly operationalises the idea of dignity as a way of dealing with difficult situations in a self-controlled way (see chapter VII). Encountering the end of life with dignity derives its meaning through the articulation of a discourse of dignity as a moral conduct (where dignity is linked to self-control) and a hospice discourse's focus on acceptance. Accepting death, and doing so in a particular way - without losing self-control and without demonstrating and giving in to extreme emotions of fear and anger – emerges as the ideal. Take the following extract from a letter to the editor about the euthanasia of Engelborghs:

> "It makes me quiet to see how a man who suffered incredibly, arranged his own end with such dignity".

In another article, where a friend of Engelborghs is voiced, a 'civilisation' articulation of encountering the own death with dignity emerges even more explicitly and radically, and a revivalist emotionalism (see earlier) is even (implicitly) contested:

> "He handled his illness serene and with dignity, without showing emotions. That's the way he died too" (6 March 2008, DS)

The construction of dealing with the own imminent death with dignity as demonstrating self-control also emerges in the coverage of the case Verbeeck. In a letter to the editor, it is argued that Verbeeck *"said goodbye to his family in a very serene way, despite all pain and sadness"* (3 February 2009, HLN). A similar articulation emerges in a review of a television documentary about Verbeeck, where the journalist writes:
"I am surprised about his incredible calmness and serenity" (3 February 2009, HLN). Here, the notion of serenity is used to refer to a dignified way of dealing with the end of life; i.e. encountering the imminent death calmly and peacefully. A dignified encounter with the own end of life, so it is assumed in the examples above, does involve emotion

(as also became clear in the discussion about revivalism), but this emotion has to be well managed and controlled, allowing the farewell to be both 'hard and beautiful'.
What learns us even more about the construction of dying with dignity as demonstrating self-control in accepting death, is the invisibility of responses of deep fear and anger in the corpus. A few contestations of the ideal of accepting death were found, mainly in the routinised coverage and in the coverage of Tuur Van Wallendael, who states that he [Van Wallendael] cannot reconcile with death. But even there, no representations of (the expression of) fear and anger were found, which contributes to the dominance of the ideal of 'managing' emotions; a controlled expressivism.

3.2. Dignity, autonomy and independence of care

A second articulation of dying with dignity is strongly anchored in a discourse of self-identity, where dignity is defined in terms of autonomy and physical independence. Here, dying with dignity is constructed in opposition to losing one's autonomy and physical independence. It comes as no surprise that this articulation of dignity emerges almost exclusively in the prominent-case coverage, where - as we saw earlier – autonomy and independence appear as key ingredients of a good death.

First, the loss of the capability of autonomy - where the lack of autonomy is linked to the institutionalisation of death and dying - regularly appears as a threat to the dying individual's dignity – precisely because it threatens his sense of self-identity. This dimension was already touched upon in the discussion above about the construction of the autonomous death, remember Mario Verstraete's mother who argues in one of the articles that staying on a palliative care unit was no option for her son, because "*he would not be able to play his music, friends could only visit during certain hours, he would not be able to eat what he wants, smoking a cigarette in his room wasn't allowed*" (28 December 2002, DM - relative). A similar construction of the institutionalisation of the dying process as a potential threat to the dying individual's dignity appears in the coverage of Van Esbeen. As for instance argued by two ethicists:

> "What dignity does an elderly have when some options are excluded in advance and when others decide for her/him about how to solve 'the problem'? (26 March 2009, DS).

In the coverage of Van Esbeen, as became clear earlier as well, the decision-making power of the medical and legal field threatens the dignity of the patient, because this power prevents Van Esbeen from manifesting herself as a fully autonomous person. Kearl's (1989) illustration of the terminally ill woman asking "who owns my body, Medicare, the hospital, the state, or me?" (see chapter VII) seems particularly applicable here. Sometimes, dying with dignity and dying autonomously are articulated together in very explicit ways, suggesting a certain equation of the right to self-determination with dying with dignity; dying with dignity is thus defined as having the right to make the own decisions about how to die: *"'It is of paramount importance that Amelie is able to die with dignity, according to her own wish', Doctor Cosyns argues"* (26 March 2009, DS).

Also the loss of the capability of self-reliance and physical independence is constructed as a threat to the individual's sense of identity and of the possibility for him to die with dignity. Not being able to take care of your own is - albeit implicitly without reference to the actual concept of 'dignity' - seen as affecting the individual's dignity. Take the following examples, both extracts from articles about an individual's request for euthanasia:

> "He couldn't do what he wanted, he could no longer visit his friends, he could no longer wash himself" (28 June 2008, DM - non-prominent case - relative),

> "Losing her ability to see and hear, being bedridden and a limited self-reliance. And all of that for a woman who had always been extremely independent" (6 April 2009, DS – Van Esbeen - president Flemish Right to Die Association)

> and

> "At the end of his life, he found the deterioration the worst thing. He lost his power, could not do anything anymore, had become weak" (Flair – non-prominent case, relative).

In the coverage of Mario Verstraete, the construction of the loss of self-reliance and physical independence takes shape through a focus on the loss of self-control. Here, 'the body' – as a nodal point of a discourse of self-identity (see chapter VII) becomes particularly relevant. The illness of Mario Verstraete, Multiple Scleroses, that is reported on in a human-interest type of journalism facilitates the importation and operationalisation of the ideal of independence – which is indeed at the core of a self-identity dimension of the extrinsic human dignity discourse. Here, the loss of physical independence and the ability of self-control and self-reliance become constructed as a threat to a dignified dying process. The focus in the coverage of Verstreaete is on the deterioration of the body, which is described as a threat to Verstraete's dignity. The ideal of the 'civilised' body, i.e. a body that is strictly policed and controlled, strongly underlies the construction of dying with dignity in the coverage of Verstraete. Although the very concept of 'dignity' is not always deployed explicitly, the deterioration of the body is constructed as an undignified and 'messy' death. As for example the following quotes from respectively Verstraete and his mother illustrate:

> "The people who criticised Mario were not there when he experienced the one disgrace after the other…when he went through the most awful things at the most unexpected moments, when he lost control over his primary functions and he had to discharge himself in the car of a friend. How already years ago, he

> walked around with a note of the doctor saying he was allowed to urinate everywhere if necessary. He was ashamed to death for that" (28 December 2002, DM - relative)
>
> and
>
> "Mario kept repeating it: 'Living is more than waking up and being there, you have to find a value. If you need care like a child, and you can no longer command your own body, life is pointless. You are better withdrawn from circulation, then'" (10 February 2002, HLN).

Also in the coverage of Van Wallendael, the loss of control is implicitly linked to the question of a dignified death. As expressed by a former Major of Antwerp (Van Wallendael's city), who is also a friend of Van Wallendael: *"He wanted to keep control. That's why he died with his head held high"* (19 November 2009, HLN). Dying with the head held high is used here to allude on Van Wallendael's choice for euthanasia, which in so doing is constructed as a good and dignified way to die.

The above-discussed construction of the loss of autonomy and physical independence as affecting the dying individual's dignity, as already suggested, comes into being through the operationalisation of a discourse of self-identity – with dignity, autonomy and the body as nodal points. We indeed saw how the lack of autonomy and the limitation of the right to autonomous decision-making are seen as affecting dignity. Also physical dependence on care of others is constructed as part of a bad dying process - a construction that is facilitated through the use of a human-interest type of journalism. In the coverage of Van Wallendael, relying on care is opposed to dying with dignity for instance as follows:

> "The nurses were busy taking care for people who called for help […] That's when I decided: never. I want to die with dignity (5 March 2009, HLN – dying individual)

> and

> "He wanted to show people how it brings him to rest, knowing that he is allowed to die before he becomes dependent of whoever" (16 December 2009, HLN).

A similar construction of depending on the care of others as part of a bad death can also be traced in the coverage of Van Esbeen, as for instance expressed by a niece of hers: *"Look, some people can be very happy with a lot of limitations. She couldn't. One day aunt said: 'Can you image that someone has to help me to go to the toilet?'"* (28 March 2009, DS - relative).

The construction of dependence as affecting the individual's dignity is further enforced by the representation of the choice for euthanasia as a 'brave' choice to not be selfish in becoming a burden to the relatives, the choice to *"spare others"* (16 March 2008, HLN – Marcel Engelborghs - dying individual). Choosing for euthanasia, then, once again becomes constructed as a 'heroic' death – a construction that also is accomplished in letters to the editor. Take the following extracts from letters to the editor written in response to the euthanasia of Claus, and more specifically as a critique towards the Catholic judgement of his euthanasia:

> "Demented people are very often a burden to others, even to the own family […] Very brave what Claus did" (22 March 2008, HLN)

> and

> "What demonstrates more courage: glorifying unbearable suffering or having the courage to stop, before being a burden to others?" (25 March 2008, HLN).

3.3. Dignity and the authentic self

A third articulation of dignity is strongly related to the notion of the 'self'. This third articulation emerges also though the operationalisation of a discourse of self-identity, and bears witness of the ongoing importance of the mind in the meaning of dignity (see chapter VII). Indeed, the underlying idea of this third articulation of dignity is that it is first of all the mind that gives humans identity and dignity. A nice illustration of the articulation of dignity and the mind is found in an article about the euthanasia of Marcel Engelborhgs, where the association between 'losing one's mind' and the notion of dignity is explicitly made. As Engelborghs himself expresses:

> "The certainty that I will get euthanasia and that I will die with dignity, in right mind, has given me the peace of mind"(8 March 2008, HLN – dying individual).

Throughout the corpus, the association between the (intact) human mind and human dignity appears several times, not in the least in articles about dementia and disorders of consciousness, where these illnesses and conditions – that affect the individual's authentic self - become constructed as threats to a dignified existence. In an article published in the popular magazine Dag Allemaal (28 February 2006), the partner of a man suffering from Alzheimer is quoted; *"I already said goodbye. This is no longer my husband"*. Losing one's mind, so it is suggested here, in a way equals losing one's humanity, and hence, one's dignity. A similar representation appears in a repo published in De Huisarts, where a man testifies about his wife with dementia and her request for euthanasia. The representation of dementia that is found in this article fits a broader set of representations that has as its essential characteristic that of seeing dementia as a disease that transforms the individual into a debased other. As this extract from the reportage for instance illustrates: *"He has no regrets [about the euthanasia of his wife]. "When I looked at her, when I talked to her, that was no longer her".* Within this same logic of articulation, dementia - affecting the individual's mental faculties - is often represented as a most dreadful disease, the ultimate threat to a dignified life. In a letter to the editor published on the occasion of the debates about the possible extension of the euthanasia law to people with dementia, it is for instance stated that living with an advanced form of dementia becomes undignified, as people are *"slipping into the oblivion of dementia"* (27 December 2005, DS). Similarly, an article published on the occasion of these same debates quotes the president of the Flemish Union of Liberal Associations. Again, dementia becomes associated with the loss of dignity, which is in turn linked to meaninglessness and hopelessness:

> "Many people fear dementia. They don't want to be subjected to the deterioration, <u>undignifiedness, meaninglessness and hopelessness</u>" (18 October 2004, DS).

Representations of dementia that fit within this logic of articulation, where the disease is constructed as an ultimate threat to human dignity, appear probably most prominently in the coverage of Hugo Claus' euthanasia. Here, the construction of Alzheimer's disease as a dreadful disease goes a step further, as euthanasia becomes represented as the only option to die with dignity. The latter can at least partly be explained by the 'high cultural' status of Claus. Indeed, Claus has always appeared in the media as a great, somewhat rebellist writer and poet, and his public identity has first of all always been one of a 'blacksmith of words'. The tendency of mainstream media to construct heroes and extra-ordinariness further enforces and facilitates the construction of Alzheimer's disease as a main threat to Claus' dignity. The conception that the mind defines human identity and dignity, combined with the special status of Claus and media-specific logics of representation (including the tendance to focus on the extra-ordinary), enables the construction of euthanasia as Claus' only option. After

Claus died, the Prime Minister argues in his eulogy that choosing for euthanasia was the only right option for Claus when facing the *"unbearable torment"* of losing the ability to *"create the right expressions and metaphors"*. He goes on to argue that Claus died *"just in time before he would have imploded into a dark whole"* (20 March 2008, DM). Here, Alzheimer's disease is metaphorically described in terms of 'darkness', which is implicitly opposed to the lightness of reason[70].

An underlying idea of the above-discussed construction about the construction of Alzheimer is that the illness reduces the individual to a 'body without a mind'; to an 'empty shell'. Other disorders of consciousness are represented in similar ways, stressing the 'undignifiedness' of no longer being aware. In an article in Dag Allemaal (25 January 2000), a partner says about her wife who has been in a coma for years: *"She is no longer the woman I used to know. This is a lifeless body that is kept alive artificially"*. The man goes on to argue that *"If I was allowed to give her an injection that stops her heart, I would immediately do so. Because this to me is no longer a dignified life"*. In an article in the same edition of Dag Allemaal, published in order to contextualise the story, a politician of the Flemish Liberal party echoes a similar approach to dignity by saying the following about prolonging lives of people in coma: *"We save lives that are no longer dignified".* The unconscious state, in this way, becomes seen as a corruption of the 'authentic self', as expressed by the dying individual's partner: *"Lorraine was always a lively woman, but I will never get her back in that state. She would not have wanted to live like this".*

The illness as a corruption of the authentic self also appears elsewhere in the corpus, more specifically in the coverage of Van Esbeen – where the self becomes articulated in terms of both the mind and the body. Concretely, it is the assumed split between the authentic body/self relationship and the current (and corrupted) body/self relationship that is represented as a threat to a dignified dying process, and that

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[70] Contestations of the construction of dementia as turning the individual into an 'inauthentic' self appear as a counter-hegemonic articulation, and deconstruct the 'superiority' of the conscious self by upgrading the value of the emotional life word of the patient as a key aspect of being « differently » conscious.

legitimises Van Esbeen's request to die. Van Esbeen's old and deteriorating body, more concretely, poses a threat to her dignity as her body no longer represents her authentic self; a proud and independent body who *"lived alone until the age of 88 and did everything herself"* (2 April 2009, DM).

In the prominent-case coverage, no longer being able to actualise and accomplish the 'authentic self' is sometimes accompanied by the construction of an 'unworthy' life. Look for instance at the appearance of an 'economic' rethoric in the coverage of Verstraete, where the dying individual states that *"If I cannot go to concerts and opera's anymore […]I want to be withdrawn out of circulation "* (10 January 2002, HLN – dying individual). In the coverage of Claus, the emphasis on his identity of 'master' of literature and the arts enables and encourages an implicit construction the value of Claus' life and even of Claus himself. Indeed, the illness condemns Claus to an *"inner banishment"* (opinion journalist 20 March 2008, DM) and threatens to transforms his from a *"beacon of light"* into a *"dark whole"* (opinion 20 March 2008, DM – prime minister).

While being reduced to merely a body is seen as affecting the individual's dignity, a certain appreciation of the body also appears in the analysed coverage. This appreciation corresponds to what has been discussed in chapter VII as a 'consumerist' construction of the body, where the appearance of the body becomes increasingly important, functioning as an expression of one's self-identity. This consumerist approach to the body becomes operationalised in the coverage of Marcel Engelborghs, where it is deeply embedded in an ideal of hedonism (see also further). Engelborghs' deteriorating body threatens to outshine his embodied identity of the bon vivant who enjoys life. This type of construction is facilitated and encouraged with the use of (narrative) techniques of human-interest journalism. Take the following extract from a repo about Engelborgh's death:

> "Before the disease undermined his physique, he was an epicure pur sang. 'I lived hard and well. I was a party type, loved to go out to dinner and travelled a lot', he said in November during his last interview with this newspaper […] 'I've

> had many girlfriends, but never have I wanted to give a woman the impression that I wanted to stay with her'"(5 March 2008, DS).

The importance of the body is illustrated also through the emphasis on 'looking good' in some articles. Examples can be found in the coverage of Amelie Van Esbeen as well as in the coverage of non-prominent cases:

> "I was such a pretty lady back then, for my age. And look at me now" (23 March, HLN – Van Esbeen – dying individual)
>
> and
>
> "If I had known that the treatment would not succeed, I would not have allowed her to go through with it. She could no longer wear a wig, while she had always looked so pretty" (F8 January 2000, Flair - relative).

3.4. Dying with dignity and the valuable life

A fourth articulation of dying with dignity that appears in the analysed coverage is closely related to the question as to what a 'valuable' and 'qualified' life looks like and builds on an underlying assumptions of what gives a human life dignity. Two main constructions of the valuable and qualified life are revealed; a first one coming into being through the importation of a hospice articulation of care, and a second one that can be described in terms of hedonism.

3.4.1. The valuable life and (palliative) care

Through the importation of a hospice discourse and its emphasis on care, *the valuable life* is constructed in terms of a 'humane' existence at the end of life, which is indeed central to a hospice or palliative care approach to death and dying. A hospice articulation of care, and its construction of the valuable and dignified life, emerges above all in the medical media and in the religious Kerk and Leven as well as in the mainstream media in articles where critiques against euthanasia are expressed; places where a hospice or palliative care discourse is dominant.

A hospice articulation of care first of all emphasises being comfortable, being free of fear as well as being well surrounded and well taken care for as crucial aspects of a qualified life that contribute to a dignified death. Take the following extracts, where respectively a palliative care worker and a Catholic physician express a hospice articulation of what it means to die with dignity:

> "A bit of help with the little things, like helping with dinner, reading from the newspaper, or just listening means a lot to the patients and can significantly adds to their life comfort" (5 May 2008, HLN)
>
> and
>
> "Our attitude is one of fully choosing for palliative care […] the only alternative is sedation […] because in that way, people can be calm and have a very dignified dying process in contact with their relatives" (29 May 2002, DA).

A humane and dignified approach to death and dying is above all a 'loving' approach that involves good and tender care. This hospice articulation of care thus fits a communitarian discourse of autonomy (see chapter VI) – stressing the importance of human relationships. Take the following extracts from articles that were published respectively in response to the euthanasia of Van Esbeen and the euthanasia of Claus, where (palliative) care is represented as an alternative to euthanasia:

> "But we should be aware of the fact that many in our society feel that they are ageing undignified because their lives are not surrounded by sufficient tenderness, love and respect" (Letter to the editor 26 march 2009, DM),
>
> "Human dignity shows itself in the extent to which people take care for each other, also in hard times" (19 January 2000, K&L)
>
> and
>
> "I wish to be able to become senile with dignity. What I mean be that is being able to become senile while being lovingly surrounded" (1 April 2008 , DH– medical professional about the euthanasia of Claus).

Articulations of dignity in terms of loving care sometimes serve a de-legitimisation of euthanasia. For instance: *"If we don't manage to offer the elderly a dignified place in society, but let them go through a lonely long night in the elderly home, they will be the first to request euthanasia"* (19 January 2000, K&L). In another article published in K&L, dignity is defined in terms of *"right to respectful care", "regardless of one's condition"* (5 February 2008). Similar articulations can be traced in the mainstream media as well, for instance in the coverage of the debates about euthanasia and dementia. One article is particularly interesting, as its plea for care builds on a resistance against a definition of dignity in terms of an authentic self. The argument here goes that people with dementia should not be seen as being in a state of non-consciousness, which would make them socially death, but in a state of being 'differently'-consciousness:

> "But if we believe that people with dementia are 'differently' conscious, care originates […] categorise people with dementia as 'non-conscious' and equating

> them – with the aid of euthanasia – to death, is degrading" (Opinion 9 December 2005, DS – medical caretakers)

Again, a communitarian discourse's focus on care underlies the argument – assuming that it is above all care and human proximity that make a human life valuable, humane and dignified.

3.4.2. The valuable/qualitative life and hedonism

Another answer to the question as to what it is that makes a human life valuable and qualitative underlies representations of prominent euthanasia cases, where an ideal of hedonism is imported into the coverage. The importation of a discourse of hedonism should, again, be seen in the light of the specific discursive dynamics of the media coverage of prominent euthanasia cases. Personalised and dramatised story-telling, combined with the tendency to construct extra-ordinariness and to 'stage' the euthanasia event, encourages the emphasis on 'enjoyment'. In the coverage of prominent euthanasia cases, an ideal of hedonism is operationalised in a way that contributes to the construction of euthanasia as a good death, and in a way that contributes to the construction of the individual opting for euthanasia as being 'extra-ordinary'. By articulating enjoyment with dignity, first, it is assumed that the dignity of the dying individual is affected when he/she can no longer enjoy life. Take the following extracts:

> "They could have postponed the moment of death, but they did not want to. To not lose anything of awareness, <u>life enjoyment and dignity</u> "(21 March 2008, HLN - Hugo Claus & Marcel Engelborghs – president Flemish Right to Die Association)

> and

> "He was an epicurean, who wanted to catch as much as possible; a concert, an exposition […]. Exactly for that reason I understood his request for euthanasia: Mario wanted to live with dignity" (6 March 2008, DS).

No longer being able to 'enjoy', as the quote above also suggests, often appears as a main reason to choose for euthanasia. Or for instance: *"Years ago, Claus decided to only stay living as long as he had fun in live"* (20 March 2008, HLN). In the prominent-case coverage, dramatised story-telling techniques, along with the tendency to create extra-ordinariness and to stage to euthanasia event, invigorate the construction of the hedonic dying patient, who enjoys 'the good things in life'. Take for instance the following extract from an article about the euthanasia of Tuur Van Wallendael, entitled *"Death of an epicurean"* (19 November 2009, DM): *"Tuur Van Wallendael: known for his many lives […] but mainly know as a lovable bon-vivant. Yesterday he passed away softly".* The specific discursive and representational dynamics of the prominent-case coverage (again) encourage and facilitate the construction of the 'heroic' dying individual, suggesting the extra-ordinariness of dying hedonicially. Especially the coverage of Engelborghs constructs the hedonic attitude of the dying individual as 'beyond the ordinary' – a construction that is facilitated by the use of a dramatised storytelling through which the euthanasia event is made into a public and staged media event. As the following extract from a repo published in Het laatste Nieuws nicely illustrates:

> "No matter how nearby death is, it seems far away. Marcel is at ease, totally 'à l'aise'. How does he do it? 'Just like this', he says. 'Just enjoy the here and now" (6 March 2008).

The media coverage of the cases Engelborghs and Verstraete, where media captured the dying process until the actual euthanasia 'event', is also marked by a construction of the hedonic *death*, rather than the hedonic *life.* Euthanasia, here, becomes constructed as a hedonic death; a choice - as we already saw – that allows the dying individual to enjoy life until the very last moments. Note, moreover, how - unlike in the coverage of non-prominent end of life cases - enjoyment refers here to material matters, such as drinking wine, which again contributes to a sense of 'extra-ordinariness' surrounding the identity of the dying individual:

> "'Without any pain, I'll suddenly be…gone'. That's how Engelborghs describes his own end, without many emotions. 'And now open that Sauterne [wine], the bon-vivant speaks'" (6 March 2008, HLN – dying individual)
>
> and
>
> "Mario calls his dad. 'Dad', he says, 'get that fine bottle'. A Chateau Lafife Rotschild of 1989. 'Nice, isn't it, Mario says, 'I'm going in style'" (28 December 2002, DM – dying individual).

Constructions of euthanasia as a hedonic death are sometimes contested in letters to the editor, where readers testify about the euthanasia of a loved one – thereby dis-identifying with the construction of the hedonic death that appears in the coverage of the euthanasia of Claus and Engelborghs. In one letter, a reader states that *"even in the case of euthanasia, the goodbye remains very hard"* and goes on to say that *"the awareness that you are about to die is very painful"* (25 March 2008, HLN). A more implicit contestation of euthanasia as the hedonic death appears in another letter to the editor, where a reader writes that his mother postponed the euthanasia until the *"very last moment*" (28 Mach 2008, HLN), which constructs euthanasia as the last (necessary) option rather than as a hedonic death.

Whereas the coverage of prominent euthanasia cases imports an ideal of hedonism, an emphasis on 'enjoyment' also appears elsewhere in the corpus – albeit in a more 'emotionalist' variant rather than in terms of a rational and material pursuit of pleasure. The coverage of non-prominent end of life cases, more specifically, frequently comes with an appreciation of enjoying life – where it appears as an important aspect of quality of life.

In the coverage of non-prominent end of life cases, the pleasure of spending time with loved ones and the pleasure of enjoying the 'little' things in life, is stressed – which indeed bears witness of a more 'emotionalist' articulation of enjoyment. For instance:

> "I enjoy every day, I see the trees growing now, something I never noticed before" (20 March 2007, Dag Allemaal – dying individual)
>
> and
>
> "We went to Bali in October. Sun, see, rest, and a glass of champagne"[…] that was our way to say goodbye with dignity" (17 January 2006, Dag Allemaal – relative).

A similar articulation of hedonism appears in the coverage of Bart Verbeeck, where the dying individual's choice to *"enjoy every day he's got left"* (13 May 2011, HLN) is emphasised.

Also personal testimonies about dementia and Alzheimer more than once articulate quality of life in terms of life enjoyment. Sometimes, dementia is described as a threat to quality of life and life enjoyment. For instance: *"We wanted to start enjoying life. Dementia decided otherwise"* (21 September 2004, DA - relative) and *"I often wonder about the 'why' of their inhumane quality of life"* (Letter to the editor 30 December 2005, DS). The lack of quality of life and the assumed inability to enjoy life are, like in the above-given examples, often used as arguments in favour of the extension of the euthanasia law to people with dementia. Simultaneously, representations of dementia are found that reconcile dementia, quality of life and enjoyment. These representations implicitly draw on a construction of dementia in terms of being 'differently'-

conscious. Like the example given below, these representations often contest the extension of the euthanasia law:

> "Even though my father did no longer recognise me […] He knew we would go outside to smoke a cigarette when I visited. How could I ever have been able to co-decide that, in case he would have made out a declaration of will, the time was there to no longer smoke that cigarette" (Letter to the editor 28 December 2005, DS).

3.5. Innate human dignity

While the four articulations of dignity discussed above are to be situated in an extrinsic human dignity discourse, a last articulation of dignity found in the corpus operationalises an intrinsic human dignity discourse. Here, dignity is seen as inherent to every (living) human being. In the analysed coverage, an articulation of innate human dignity above all appears as counter-hegemonic in articles published in response to the euthanasia of Verstraete, Claus, Engelborghs and Van Esbeen. Representations that build on an innate human dignity approach reflect often religiously inspired arguments that every human life is dignified because it is indeed *human* life. As expressed in a letter to the editor: *"But someone with Alzheimer's is alive, someone in pain is alive, someone in diapers is alive"*"(1 April 2008, HLN). Sometimes, religious critiques against euthanasia that draw on an intrinsic human dignity approach also contain traces of a Kantian discourse of human dignity (see chapter VII). In an interview, the Belgian Cardinal for instance differentiates between human dignity and animal value (see chapter VII) to argue against euthanasia: *"If it were animal suffering, I would say kill the animal if it suffers too hard. But this is not the case for men"* (22 March 2008, DS). The idea of humans having 'value' is fiercely contested, for instance through the question whether the life of *"people who are no longer able to formulate their thoughts or were never able to do so"*, is not *"worth living" (*22 March 2008, DS). Also the definition of quality of life in terms of both physical and intellectual human capacities is contested when a Catholic philosopher is quoted in another article: *"Is there still room for valuing life as such, even when these ingredients [physical and intellectual capacities] are partly or entirely absent?"*(29 March 2008, DS).

In an articulatory logic where dignity is seen as inherent to every human life, illness nor ageing are to be seen as threats to a dignified dying process. In response to the euthanasia of Mario Verstraete, an interview with people suffering from Multiple Scleroses is published in Het Laatste Nieuws, and one of the interviewees draws on an intrinsic human dignity approach:

> "'Many MS-patients are upset', Johnny from Antwerp says, who has been suffering from MS for 20 years. 'As if he gives them the signal that they're life isn't worth living, and that they better choose for euthanasia'" (18 October 2003).

A similar contestation of the assumption that illness devalues life is found elsewhere in the corpus as well; in articles where representatives of the religious field and the medical field respectively argue in response to the euthanasia of Van Esbeen and the euthanasia of Claus:

> "As if ageing is some kind of contagious disease" (26 March 2009, DM)
>
> and
>
> "It is not because you are suffering from Alzheimer, that you cannot have a dignified existence anymore" (22 May 2008, DH).

4. Death in the media: constructing 'good journalism'

The previous sections of chapter XIII generated insight into the construction of the good death, which occurs through the operationalisation of a number of discourses following media-specific logics of representation. This section looks into constructions of 'good journalism' inscribed in the analysed representations of the end of life. Central to this section is the question as to how media reflect about their own representation-practices in covering the end of life as well as how they allow reflections (and critiques) about these practices to become visible in their own products. In looking into the construction of good journalism in the selected media articles, I draw on the normative stances identified in chapter IX of the dissertation, which - as will become clear in the discussion below – become realised and articulated in concrete reflections about the representation of euthanasia. Notable is that these reflections are rather scarce; especially reflections of media-professionals themselves are rarely found. The latter suggests a certain shying away of media to explicitly reflect about their own representational practices.

It is also notable that these (few) reflections emerge above all (though not exclusively) on the occasion of prominent euthanasia-cases, which demonstrates the way these cases function as moments of elevated discursive struggle – not only entailing reflections about and resistance against euthanasia as such, but also about/against the representation of euthanasia (i.e. the representation of euthanasia not only in the print media products under analysis, but also in other media products, including television news and documentaries). The pages below illustrate how reflections about the mediatisation of euthanasia cases are discursively built up; i.e. how they draw on discourses on the role and place of media and journalism in society, and sometimes combine them with elements of discourses on (the good) death and dying. Concretely, this section zooms in on constructions of 'good journalism' that underlie respectively negative evaluations of media coverage of euthanasia and reflections that stress or assume the emancipatory potential of this coverage.

4.1. Negative evaluations: harmful media coverage of euthanasia

Negative evaluations of the role of media and journalism in representing euthanasia are by far the most dominant. Notable (though not entirely surprising) is that these negative evaluations are imported into the coverage not by journalists but by 'external' voices – mainly those of ethicists and medical professionals. Their critiques draw on two main normative frameworks; one framework that deplores the sensationalism of media and one that deplores the (ideologically) biased nature of media.

4.1.1. The sensationalisation of euthanasia

A first set of critiques denounces the sensationalisation of euthanasia through its representation and draws on a spectacle of death discourse. Reflections that draw on this discourse are mainly found in articles published in response to the coverage of the euthanasia of Mario Verstraete.

In chapter IX, it was explained that a spectacle of death discourse has 'emotion' as a nodal point, through which it is argued that representations of death and dying are surrounded by spectacle – thereby trivialising and de-contextualising the end of life. In the analysed coverage, a spectacle of death discourse is imported into the coverage sometimes very explicitly, as it is deployed in the delegitimiation of the way media cover euthanasia. The quote below - which is an extract from an article written in response to the coverage of Mario Verstraete - nicely illustrates the way a sensation of death discourse becomes actualised and realised; indeed stressing the harmful, i.e. trivialising and de-contextualising, potential of a focus on "emotion and sensation":

> "The media's attention for this first euthanasia dead does not go beyond a <u>voyeuristic gaze</u> on pain, deterioration and suffering […] These are samples of tasteless <u>media-manipulation</u> with <u>little respect for the imminent end of life</u>. The <u>self-proclaimed quality press</u> made the suffering of a man into <u>a show</u>, merely

> appealing to emotion and sensation, without wanting to stimulate a genuine ethical reflection" (4 October 2002, DS - ethicist)

The words 'voyeuristic', 'show' and 'emotion and sensation' point to the operationalisation of a spectacle of death discourse, and a closer look at the quote above reveals the way this discourse comes with a certain normative approach towards 'quality' media. Indeed, the formulation "the self-proclaimed quality press" suggests that the "voyeuristic" focus on emotion and sensation is in contrast with what 'real' quality media ought to do, i.e. stimulate "genuine ethical reflection". Arguably, a 'traditional' focus on media quality comes to the fore here; one that describes quality in terms of the rational transfer of socially and politically useful information rather than in terms of emotionality.

Critiques on media representations of the end of life that draw on a 'sensation of death' discourse sometimes denounce the very logics of representation that were discussed earlier in this part of the thesis. In the extract given below, a relative of Mario Verstraete blames the media for constructing a hedonic and in his eyes 'wrong' image of Verstraete, which he implicitly links to the media's hunger for sensation:

> "Mario was a fighter, he went beyond the extreme. Sadly, some people don't recognise this. And that's because of the media. How did they depict him? As someone who was smoking, a glass champagne in the hand and classical music in the background. What people do not know? That he damned suffered" (29 September 2004, Knack)

Critiques on media coverage of prominent euthanasia cases that draw on a sensation of death discourse sometimes come with a contestation of one of the basics of revivalism, i.e. openness, by emphasising the intimate nature of the end of life and opposing it to the way it becomes a staged public event and even spectacle in the media. As a Catholic ethicist for instance opposes the end of life as an *"intimate event"* to the euthanasia of Verstraete as a *"media event"* (2 Oktober 2002, HLN). Another

Catholic ethicist argues along similar lines, stating that *"this is Big Brother in the room of death"* (4 October 2002, DS) and thereby drawing on a critique of media voyeurism. The Belgian Cardinal echoes a similar argument, and implicitly challenges a revivalist discourse on death when he criticises the media coverage of Verstraete for being a *"high mass for the euthanasia law"*: *"Why does that needs to come on television? Animals hide to die, they don't die in public"* (16 December 2002, HLN*)*. An opposition of an 'artificial' mediatised death versus a 'natural' way of dying in private is also expressed by proponents of the euthanasia law - as for instance the chief editor of the progressive journal De Morgen argues about the representation of Verstraete: *"One has to overcome one's inhibitions in order to enter into one of the most private moments of a lifetime"* (28 September). Arguments like these, and the fact that they are also voiced by proponents of the euthanasia law, suggest how a certain remnant of a (medico-)rational discourse lingers on in case of a very 'intensified' openness of the end of life; i.e. an end of life made public in mass media.

4.1.2. Biased media coverage of euthanasia

A second set of critiques draws on the normative framework that has been labelled in chapter IX as a 'biased media coverage' discourse, where both the unrealistic and ideological are criticised.

First, a number of critiques can be traced that echo the argument that media bring into circulation both unrealistic and misleading information. In the medical media, these critiques are directed towards the mainstream media coverage of scientific research and serve a de-legitimisation of euthanasia. De Artsenkrant for instance criticises the media for creating the "*totally incorrect*" image that *"four out of five Belgians favours the depenalisation of euthanasia"* (30 March 2001), while De Huisarts describes the mainstream media coverage of a study about doctors' practices of end-of-life decision-making as *"an example of orchestrated media-disinformation"* (5 February 2006).

The fiercest critiques building on a biased media discourse are found in articles published in response to the coverage of prominent euthanasia-cases. It is above all the coverage of Verstraete, Claus and Engelborghs where reactions drawing on a biased media discourse arise, which again demonstrates the highly contested nature of the coverage of these cases. A Catholic philosopher for instance describes the coverage of Verstraete as *"pure disinformation"* (4 October 2002, DS), and in the following extract from an article published in De Huisarts, the president of the Flemish Alzheimer Liga states the following about the media coverage of the euthanasia of Claus:

> "But for many people suffering from Alzheimer's disease, <u>this image is not correct</u>. Many people do not want to request for euthanasia anymore, or are no longer capable of doing so. But also for their relatives and their informal carers, euthanasia is often not the right solution. We find it regrettable that media do not speak about this" (May 22, 2008).

Second, criticism against an ideological bias also emerges; mainly in the media coverage of the euthanasia of Claus, where it above all expressed by Catholic ethicists and medical professionals. As a Catholic philosopher for instance gets a say about the euthanasia of Claus in an article published in De Standaard:

> "Brother Stockmans [Catholic philosopher] says he mainly questions 'the way Flemish media almost unanimously applaud his [Claus's] decision'. He calls it the 'pretence and arrogance of a certain group in society that wants to impose its worldview on everyone else'" (22 March 2008, DM).

Not in the least the medical newspapers and the religious Kerk&Leven articulate criticism of ideological bias, where they are incorporated into a broader 'anti' right to die movement. Take the following extract from an article published in De Huisarts: *"All media wanted to show they were on the 'good side'. Speaking of a 'pensée unique'. Unbelievable, hardly one critical voice infringing the hysteria"* (16 October 2008). In similar vein, an article in Kerk&Leven (2 April 2008) describes the coverage of Claus as *"propaganda for euthanasia"*. Critiques like these build on a specific definition of good journalism, one that stresses the importance of neutrality and objectivity. While such a construction of good journalism is often implicitly anchored in critiques towards a one-side pro-euthanasia coverage, it sometimes appears more explicitly – for instance when the author from the above-mentioned article in Kerk&Leven concludes that the "propaganda for euthanasia" is *"not acceptable"* for *"critical journalists"*.

Arguments that draw on a biased media coverage are sometimes combined with an argument embedded within a stigmatised media discourse, where the main line of argumentation goes that a one-sided focus on euthanasia (as a good death) comes with a stigmatisation of people who do not wish to die with euthanasia. The following extract from an article published on the occasion of the euthanasia of Verstraete, where a patient suffering from Multiple Scleroses (the illness Verstraete was suffering from as well) is heard, illustrates the articulation of both discourses or normative frameworks: *"What offended him in the 'Mario Verstraete tale', is the <u>one-sided approach</u> of a number of popular media. '<u>As if the only option for a MS-patient is to choose for euthanasia</u>'"* (18 October 2003, HLN). A similar concern is echoed in a letter to the editor, where a reader raises the question as to how the coverage affects the person who *"lives an entire life with a severe handicap and has the courage and the power to keep living"* (3 October 2002, HLN).

4.2. Positive evaluations: engaging and mobilising media representation of the end of life

Negative evaluations of media coverage of euthanasia that draw on a definition of good journalism in terms of objectivity and neutrality and in terms of the transfer of politically and ethically relevant information are by far most dominant. However, a series of reflections about the coverage of euthanasia are found that draw on alternative discourses of good journalism; emphasising the emancipatory potential of this coverage. Whereas negative evaluations of the media coverage of euthanasia cases are mainly expressed by ethicists and medical professionals in meta-reflections, positive evaluations of that same coverage appear integrated in 'first-line' coverage; i.e. coverage dealing with the euthanasia case itself, not with a meta-reflection about this coverage.

The personalised and intimitised coverage of euthanasia cases is, as the analysis revealed, very much embedded in a more encompassing right to die movement. A DT analysis of media contents does not allow us to look into the intentions of journalists in writing about and covering euthanasia cases. At the same time, hints of these intentions shine through in the actual coverage – as journalists sometimes write about the way they applaud and encourage a personalised coverage of euthanasia cases. In response to the coverage of Verstraete, the editor in chief of Het Laatste Nieuws for instance states that *"For the very first time, euthanasia has a face"* (5 October 2002). Here, the media professional seemingly draws on a positive evaluation of emotionalised and intimitised journalism, suggesting its potential of mobilising and engaging the audience.

In the coverage of Engelborghs en Van Esbeen, journalists implicitly position themselves as allies of the dying individual; helping him/her in making the story public – thereby *"making the situation for peers easier"* (2 April 2009, DM) and *"making it possible to talk about euthanasia"* (5 March 2008, HLN). A similar emancipatory discourse about the potential of personalised media coverage of euthanasia underlies these reflections; one that stresses its mobilising and awareness-raising capacity. Or as for instance a journalist finishes her article about the euthanasia of Marcel Engelborghs: *"The debate about dying and dying with dignity should be kept alive"* (21 March 2008, DM).

Finally, constructions of the role of journalism in writing about the end of life are inscribed in the coverage of Bart Verbeeck. An awareness-raising potential of the media is for instance suggested by arguing that *"Bart wanted to show what palliative sedation is"* (1 February 2011, DM). Also a 'learning media' approach can be traced as a normative framework underlying reflections about the coverage of Bart Verbeeck. In the same article, it is stated that *"Bart wanted to show what it means to be terminally ill"*, which suggests the media's potential of inspiring other patients who 'learn' from Bart's way of dealing with his illness and imminent death. A similar conception of 'learning' media is imported into the coverage by quoting the dying individual himself as follows:

> "Via the social-network site Facebook, Bart wants to inform and mainly inspire other people. 'I want to tell my history, record my journey, and in that way inspire other people" (7 November 2009, DM).

A similar belief in the emancipatory potential of a personalised and intimitised media coverage of the end of life is enshrined in a letter to the editor, as a reader draws on a positive notion of the media's engagement with emotion and thereby operationalises a 'learning media' approach:

> "Bitter tears, but also tears of some kind of happiness because this boy left such a positive message. Everyone should think about Bart's words at the end of the reportage: 'Be happy with what you have. Enjoy your coca cola and enjoy your burger" (3 February 2011, HLN).

5. Discussion and Conclusion

With the above-reported analysis, I have worked towards a formulation of answers to the two research questions formulated earlier: "How, and following what logics of representation, does the Belgian print coverage of the medicalised death construct the good death (by operationalising particular discourses)?" And "What discourses on 'good journalism' are operationalised in the Belgian print media coverage of the medicalised death?"

The analysis conducted in the light of the research question as to how the selected media articles articulate the role of the media in covering the medicalised end of life has been based on a limited amount of material. Unlike the qualitative interviews (see further), media contents - at least those analysed here - do not appear as forums for extensive reflection about the role of media and journalism in covering the end of life. At the same time, some interesting conclusions can be drawn – for indeed the mere fact that the analysis revealed only a limited amount of reflections about the 'good journalism', especially by media-professionals, is itself an important observation. It indeed points to a certain absence of self-reflexion by media-professionals.

The analysis shows a dominance of a rather negative thinking about the journalistic practice of representing the end of life. Inscribed in articles giving a voice to mainly medical professionals and ethicists, potential harmful effects of media coverage of euthanasia are assumed and linked to its 'sensationalist', 'voyeuristic' and 'biased' nature. These negative evaluations above all target a personalised and intimitised way of covering euthanasia and thereby draw on a 'traditional' construction of 'good journalism'. In addition to these negative evaluations, positive evaluations of media coverage of the end of life emerge. Like negative evaluations, they are discursively built around emotion as a nodal point, but construct emotionalised and intimitised coverage of the end of life in terms of being de-tabooing, engaging, and mobilising. Unlike constructions of good journalism in terms of a neutral transfer of politically and socially relevant information, constructions of good journalism that stress the emancipatory potential of human-interest tend to be anchored in 'first-line' coverage; i.e. coverage dealing with the euthanasia case itself, not with a meta-reflection about it.

Concluding the analysis that was conducted in light of the research question as to how the good death in constructed in the selected media articles requires a more developed and comprehensive elaboration. Here, I want to highlight and cluster a number of insights that are particularly relevant, and I will do so in a twofold way. First, I dwell upon those discursive dimensions of the good death - mainly related to the ‘basics of revivalism’ - that emerge as hegemonic throughout the entire corpus. This provides insight into the uncontested (or hardly contested) nature of a number of discursive concepts; the main ‘building blocks’ of the good death one could say. A second section focuses on the discursive struggle over the meaning of the good death; a struggle that above all revolves around the construction of ‘dying autonomously’ and ‘dying with dignity’ and that cannot be seen in isolation form the specificities of the media-genres under analysis.

5.1. The basics of revivalism as the main building blocks of the good death

Throughout the corpus, the basics of revivalism appear as ‘foundations’ of the good death. First, the ideal of a death that is not hidden away or denied, but a death that is *experienced openly* and the dying individual (eventually) *accepts* – allowing him to exercise a certain *control* - seems to be shared by the different media genres and transcends the different logics of representation inherent to them. Second, patient-centeredness appears as a key discursive dimension throughout the corpus. There are some very important discursive varieties in the way patient-centeredness is constructed; in some cases patient-centeredness is articulated with patient autonomy while in other cases patient-centeredness serves to delegitimise the patient’s right to die. At the same time, the basic concern with the patient’s wellbeing appears as taken-for-granted in both mainstream and specialised media. The focus on the patient’s wellbeing shows in different ways; both in support of the right to die through emphasising the right to self-determination as in contestations of the right to die through emphasising the right to care. There is an uncontested focus in the analysed coverage on what a good death means for *the dying individual*.

In the medical media, and in articles that discuss the end of life against a medical background, the dying individual is approached and constructed as a *patient* (which inevitably involves some kind of objectification and abstracting). Here, a *patient-centred medical ethics* is operationalised, where 'care' functions as a nodal point.

Closely connected to the concern with good care for the dying patient is the construction of the 'humane' doctor who acts in the patient's best interest – whether it is by respecting the patient's wishes or by 'protecting him against euthanasia'. In articles that approach the end of life from a more personal angle (appearing primarily in the mainstream media), the dying person is above all *an individual* (with personal wishes and experiences), whose representation is very much embedded in a discursive sphere of individuality. The focus on individuality is closely related to a set of additional dimensions that run relatively uncontested throughout the corpus. First, there is the notion of the dying individual's 'quality' of life and his ability to 'enjoy' life. Again, there are some very important discursive varieties in the way these notions are articulated and connected to a good death; a more 'rationalist' hedonism dominates the prominent-case coverage and a more 'emotionalist' hedonism prevails in the non-prominent case coverage. At the same time, the recognition of the importance of being able to enjoy life - often captured in the concept of 'quality of life' - appears as a taken-for-granted part of a good death throughout the corpus. Second, and this dimension hides a potentially disciplining construction of the good death, there is the ideal of a 'well-managed expressivism'. This dimension, as became clear throughout the reportage, takes shape in balancing on a continuum between rationalism and emotionalism. Depending on the type of coverage where the end of life becomes represented, this balance tips either one way or the other, but the very ideal of a well-managed expressivism remains very dominant. The dominant ideal of a well-managed expressivism is particularly linked to a (hospice) ideal of accepting the imminent death where feelings of anger and deep fear are overcome, or are at least expressed in a well-managed way.

5.2. Dynamics of discursive struggle in the construction of the good death

In addition to this relatively stable foundation of a good death, there are aspects, mainly relating to the concepts of autonomy and dignity (functioning as nodal points of the late modern discourse on the good death), which are much more embedded in discursive struggle over what it means to die well. The discursive struggle over the meaning of a good death is indeed inscribed in the analysed media representations of the end of life and end-of-life decision-making in a number of ways. It became clear how dominant discourses on autonomy and dignity are challenged by counter-hegemonic approaches to these concepts. However, the discursive struggle appears as a key dimension throughout the entire analysis, illustrating that it is not only a matter of 'dominant discourses versus alternative discourses'. A struggle over the meaning of the good death also takes place within the confines of dominant discourses, where it above all shows itself as a struggle over the range of a good death and where 'care' is one of the most important signifiers around which there is struggle.

The way the struggle over the meaning of the good death takes place cannot be isolated from the specificities of the different media genres and the way they operationalise discourses. The following discussion is therefore structured on the basis of the different media genres, starting with an elaboration of the construction of and struggle over the good death in the mainstream media coverage.

5.2.1. Discursive struggle in the mainstream media

Throughout the analysed mainstream media coverage, a ratio-personal or liberal autonomy concepts is dominant over articulations of autonomy grounded in religious and communitarian discourses, and dignity is dominantly defined in terms of autonomy and independence, self-control and the authentic self. At the same time, some important differences in terms of the construction of the good death can be observed between the three categories of mainstream media coverage that structured the analysis: coverage of the prominent euthanasia-cases, coverage of the non-prominent end of life cases, and coverage of political debate/struggle. The latter category above all appears as a location for the materialisation of right to die arguments, endorsing a ratio-personal autonomy concept and external approaches to dignity, or – alternatively – for the materialisation of arguments contesting the right to die, which often draw on a communitarian discourse and/or a hospice discourse. What often marks articles published during moments of political discussion is their elaborated nature. Approaching the end of life from a political-ethical angle, these articles often contain highly developed arguments either for or against the right to die, which are formulated using a political/ethical/academic vocabulary. The case coverage follows a different dynamic, as (political/ethical) arguments supporting (or contesting) the right to die are brought into the realm of an individualised case. This makes the case coverage discursively more complex, and media-specifics logics of representation such as dramatisation and personification only add to this complexity. Let us therefore look at the discursive dynamics of the case coverage in more detail.

5.2.2. The struggle over the good death in the case coverage

The analysis revealed how the coverage of *prominent euthanasia-cases* often constructs the good death by glorifying the choice for euthanasia. This is achieved above all by hegemonising a ratio-personal articulation of autonomy and external approaches to dignity, while at the same time problematising 'other' ways of dying. In this fashion, the pluralism – a concept inherent to a political liberalism (see chapter VI) – of approaches on what it means to die well is severely reduced. Moreover, by reducing the visibility of the choice of individuals not to be self-determining in deciding over the own death, a minimalist approach to independence emerges (see chapter VI); one that connects independence almost exclusively to the choice for euthanasia.

The focus in prominent-case coverage on autonomy and independence, more concretely, comes with a problematisation and 'othering' of care and dependency, excluding them from the definition of what it means to die well. Care and dependency become associated with palliative care - against which euthanasia is opposed - and articulated into a chain of equivalence with a bad and passive death. Palliative care, in this fashion, becomes the ultimate 'other': the bad death. Euthanasia, on the other hand, is 'the' good death; a dignified, hedonic, brave death, the ultimate expression of self-determination, and moreover, a death that allows the individual to maintain his/her independence, self-reliance, and ability to maintain the 'authentic' self and self-identity. Notions like independence on care of others and self-reliance function as constitutive signifiers in the construction of both 'dying autonomously' and 'dying with dignity' and are at the core of the construction of the good death (and the bad death) in the prominent case coverage. The following table summarises the construction of the good and bad death in the prominent case coverage.

Nodal point of the late modern good death	**Discourse**	**Construction of the good death**	**Construction of the bad death**
Autonomy	Ratio-personalism	Self-control & self-reliance Civilised body Intact mind Hedonism	Lack of self-control and self-reliance Deterioration of the body and mind
Dignity	External approaches to dignity		

Table 9: The construction of the good and the bad death in the prominent case coverage.

When drawing conclusions about the construction of the good death in the coverage of prominent euthanasia-cases, we can observe that two signifiers, with which both autonomy and dignity (as nodal points of the late modern good death) are articulated, define the meaning of the good death. A first signifier is independence (of care from others), and defines the good death in terms of what it *includes*, whereas a second signifier, care, defines the good death in terms of what it *excludes*. The meaning of the good death is constructed through the operationalisation of a ratio-personal or liberal discourse of autonomy and through the actualisation of an extrinsic approach to human dignity, where the latter is dominantly defined in terms of self-identity.

The dominant construction of the good death (as opposed to the bad death) triggers radical contestation – mainly expressed by medical professionals and representatives of the religious field. In response to the problematisation of dependence and care, these contestations draw on a hospice approach to the end of life to present (palliative) care as an alternative to euthanasia, or as an answer to euthanasia requests. Articles (including letters to the editor) that provide an ethical and/or political reflection about a prominent euthanasia-case allow for reactions against this dominant construction to become expressed; counter-hegemonic articulations become visible in this way. However, the visibility of these counter-hegemonic representations does hardly get the chance to destabilise let alone dislocate the dominant construction of the good death – as it is frequently backgrounded and marginalised.

In sum, the construction of the good death in the coverage of prominent euthanasia-cases can be described as rather narrow as well as often highly disciplining. By excluding, marginalising and problematising deterioration, care, dependency and loosing one's intellectual capacities as ingredients of a 'bad death', the wide range of possibilities of experiencing a good death is fiercely reduced. By equating deterioration, care, and dependency with palliative care, a 'euthanasia versus palliative care' antagonism arises, and the choice for palliative care becomes constructed as a passive death; not preserved for those who want to die autonomously and with dignity.

In interpreting the ‘why’ of this disciplining nature of the discursive construction of the good death in the coverage of prominent euthanasia-cases, at least three explanatory factors can be identified. A first factor has been mentioned several times throughout the reporting of the analysis; the embeddedness of the coverage of the prominent-euthanasia cases in a broader socio-political right to die movement. Sometimes, this embeddedness is obvious, for instance when the president of the Flemish Right to Die Movement is heard, quoted, or interviewed. In ‘human interest’ reports, this embeddedness is less obvious, though not less ‘real’. Such reports have been shown to be very effective carriers of a right to die articulation of the good death. This articulation becomes actualised according to media-specific logics of representation, which can be determined as a second explanatory factor. It can indeed be observed that media logics interact with a socio-political reality - that of euthanasia and end-of-life decision-making – in a particular way; there seems to be a ‘good match’ between euthanasia and media logics of representation – especially those inherent to human interest journalism. It therefore comes as no surprise that the great majority of the prominent cases (cases that acquired significant media attention) deal with euthanasia. Why is euthanasia so appealing to media, then? First of all, euthanasia is an event with a clear beginning and a clear end. It follows a progressive sequence; starting with a request for euthanasia or, in more short-term narratives, with the saying goodbye at the deathbed before the euthanasia is being performed.

In both cases, there is often an obstacle - which can be legal, medical, or personal in nature - to be overcome, which is particularly appealing to media. For instance, the euthanasia request can be rejected by the court, the euthanasia may be postponed because the doctor refuses to perform the euthanasia (as is the case in the coverage of Van Esbeen), there might by a conflict rising between the patient and a relative and so on. In addition, a euthanasia-case is often centred around a small numbers of persons involved, which makes it particularly suitable to fit into an appealing narrative; it allows for a simplified, dramatised and personalised construction of ‘the hero’, ‘the victim’, ‘the helper’, ‘the villain’. Euthanasia cases are ‘events’ with a concrete 'momentum' of death (Van Brussel & Carpentier, 2012). With their similarity to the dramatic dying scenes in operas where the dying bed of the patient is surrounded by a small number of mourning people[71], they allow media to narrate in a very personalised and dramatised fashion, making the euthanasia into a staged and public media event. This has become particularly clear in the coverage of Verstraete and Engelborghs. One reason why the case of Verbeeck (the only one not dealing with euthanasia) is so media-genic is the way palliative sedation - like euthanasia - is initiated with a concrete action (the result of which the individual looses consciousness), which allows media to zoom in on the 'dying scene'.

The way euthanasia is well compatible with media logics of dramatisation and personification, which are particularly dominant in a human interest type of storytelling, facilitates and encourages the antagonistic construction of euthanasia versus palliative care. In this antagonistic construction, euthanasia represents 'the good death' and palliative care represents 'the bad death'. In the coverage of Verstraete, Claus, Engelborghs and, to a lesser degree, Van Wallendael, a third discursive factor contributes to this very specific construction of the good death; i.e. the discourses surrounding the identity of these prominents, which are brought into the coverage. The importation of discourses of intellectualism, artisthood and hedonism within which the subject positions of Verstraete, Claus, Engelborghs and - to a lesser extent - Van Wallendael are embedded, further encourages and facilitates the construction of euthanasia as a brave and hedonic death as well as the emphasis on enjoyment and on the importance of 'the mind' in defining dignity. It this precisely this third factor that explains the differences between the coverage of Verstraete, Claus, Engelborghs, Van Wallendael and the coverage of Amelie Van Esbeen. Because her identity not being embedded in the discourses mentioned above, for instance, the representation of Van Esbeen's death is to a lesser degree marked by the disciplining of the 'other' death. The fact that Van Esbeen is an elderly and bedridden woman instead of an artist or politician also encourages the visibility and emphasis on doctor-

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[71] Verdi's 'La Traviata' provides a good example of a dramatised dying scene.

patient conflict, a type of conflict that is indeed hardly visibly in the coverage of the prominents. The following visualisation captures the three explanatory factors mentioned above and situates the different cases:

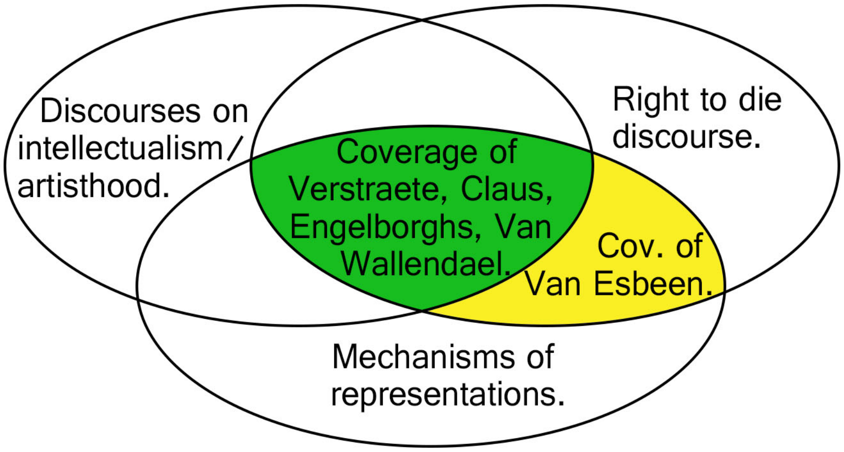

Figure 7: explanatory factors in the discursive construction of euthanasia as the good and brave death in the prominent case coverage.

The construction of the good death, with its specific dynamics of discursive struggle, looks rather different in the coverage of *non-prominent end of life cases.* Unlike the coverage of prominent euthanasia-cases, this type of coverage is very often less 'political'; exhibiting less (direct) links with the right to die movement and deploying a less politicalised vocabulary. This holds true especially for those articles published in the popular magazines Flair and Dag Allemaal, media products marked by a strong focus on the intimate, the personal and the emotional.

This less politicalised nature does not imply that the non-prominent case coverage does not operationalise discursive concepts inherent to the right to die movement, including for instance a ratio-personal concept of autonomy, but their less 'political' embeddedness seemingly allows for a more comprehensive and less restrictive definition of what it means to die well, and accordingly, for a greater visibility of possible ways of encountering the end of life – including the choice not to intervene in the own dying process. Choice, indeed, functions as a key signifier throughout the non-prominent case coverage, which results in an encompassing definition of the good death of which a variety of end-of-life decisions can be part.

In the coverage of non-prominent end of life cases, more concretely, a palliative care approach to the end of life - enshrined in a hospice articulation - is an integral part of the dominant construction of the good death. The dominant construction of the good death remains within the confines of a ratio-personal approach to autonomy and of an extrinsic approach to dignity. At the same time, care and dependency are not problematised and excluded from the dominant definition of the good death. As a result, euthanasia appears in the non-prominent case coverage as *one possibility* of dying well, existing next to dying with palliative care. The range of a 'good death' as it becomes constructed in the non-prominent case coverage is therefore much broader. By implicitly assuming the right of the individual to make his/her own end-of-life decisions, a ratio-personal concept of autonomy remains intact, but is not accompanied by a celebration of euthanasia and a problematisation of palliative care – indeed, euthanasia and palliative care sometimes appear as being both part of the same end of life trajectory. Moreover, care does not become problematised but rather appears as self-evident. In this way, 'care' becomes re-introduced into a mainstream and dominant conceptualisation of the good death. Representations of non-prominent end of life cases, in addition, sometimes add elements of communitarianism to a ratio-personal autonomy concept – focussing on the interpersonal relations of the dying individual. A 'side-effect' of the less politicalised and disciplining nature of the non-prominent case coverage is that it does not entail counter-hegemonic articulations opposing a ratio-personal concept of autonomy and/or the dominance of extrinsic approaches to dignity - precisely because of the less sharp construction of the good death inherent to the non-prominent case coverage.

A 'special case' is the coverage of Bart Verbeeck. What makes the case Verbeeck particularly interesting from a discourse-theoretical point of view is the way it combines some of the logics inherent to the prominent case coverage with some of the logics inherent to the non-prominent case coverage. The case Verbeeck is the only case that received considerable media-attention and does not deal with euthanasia[72]. While palliative sedation, like euthanasia, allows for a type of representation that zooms in on the 'dying scene', the coverage of Verbeeck significantly differs from the coverage of the other prominent cases in some important respects. What is remarkable about the coverage of Verbeeck, more concretely, is its very peculiar way of articulating elements of a right to die approach to a good death with elements of a hospice approach into a coherent media narrative. More concretely, a right to die focus on self-determination and (ratio-personal) autonomy is combined with a hospice emphasis on a 'soft' and 'natural' death. In this way, a specific construction of the good death emerges; one that balances between a right to die approach and a hospice approach. This construction retains from a right to die approach the importance of the right to self-determination in making the own end-of-life decisions, while it distillates from a hospice approach a focus on the natural death. Strengthened by media-specific logics of dramatisation and personification, euthanasia even becomes an 'other'; leaning more towards a bad death than a good death as it becomes constructed as an abrupt and un-natural way of dying. The coverage of the case Verbeeck can visually be situated as follows:

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[72] A number of other factors made this case particularly appealing to the media; a young boy suffering from a rare and aggressive and terminal cancer indeed responds to the media's attraction to the unusual and the negative.

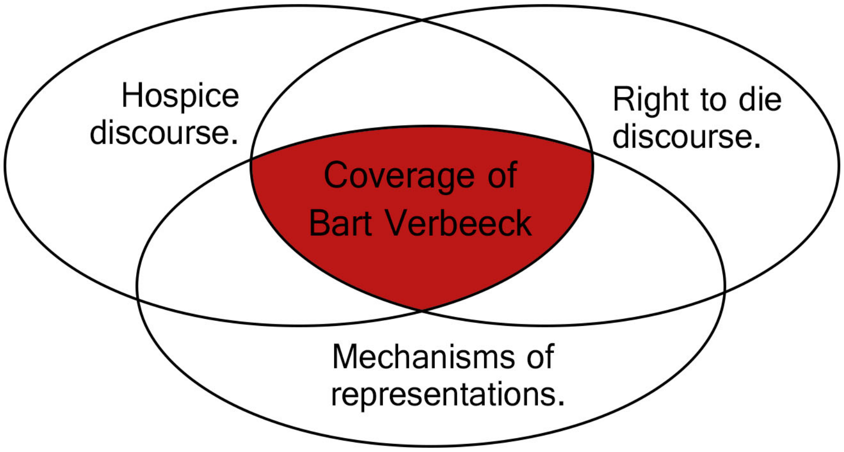

Figure 8: explanatory factors in the construction of palliative sedation as the good death in the coverage of Bart Verbeeck.

5.2.3. Reversing the logics of discursive struggle in the specialised media coverage

A number of basic articulations of autonomy and dignity very much dominate the analysed mainstream coverage, despite the differences between the prominent case coverage and the non-prominent case coverage. More concretely, the very idea of the individual who has the right to make his own end-of-life decisions remains largely intact and uncontested in the mainstream coverage. Also extrinsic discourses to dignity, and articulations building on these approaches, are very dominant throughout the analysed mainstream coverage. Some articles that bring ethical and/or political reflections about the end of life entail a certain visibility of alternative articulations of autonomy and dignity. Yet, these counter-hegemonic forces remain essentially *counter*-hegemonic. In the specialised media coverage, however, the relations between hegemonic and counter-hegemonic as they appear in the mainstream coverage are reversed. While there are of course some exceptions, the specialised media generally normalise discourses of autonomy and dignity that appear as alternative and counter-hegemonic in the mainstream media. Arguably, the hegemony of the mainstream media (which corresponds a mainstream hegemony in general) is not shared by and reflected in the specialised media and assumingly, of the medical and religious communities they target. More concretely, a communitarian (religiously inspired) autonomy concept and an intrinsic human dignity approach appear as the dominant systems of meaning in the specialised media coverage[73]. Especially in articles published during moments of elevated discursive-political struggle and on the occasion of prominent euthanasia-cases, these systems of meaning are radically opposed to ratio-personalism and external approaches to dignity. We could argue that 'care' functions as the nodal point in dominant articulations of both autonomy and dignity in the specialised media; a good death is above all a death that involves good (medical) care. Quite often, the central position of care in the construction of the good death discursively excludes euthanasia from the range of what a good death includes. The problematisation of euthanasia is further established when the signifier of care intersects with, and is brought into, a number of specific discourses - including a discourse of medical ethics and a hospice articulation of the good death focussing on the ideal of the natural death.

The opposition against euthanasia and the right to die in the specialised media, it should finally be noted, often appears in a very reflexive and elaborated way, which is the direct result of the majority of the articles published in De Artsenkrant, De Huisarts and Kerk&Leven bringing ethical reflection about the end of life. Ethical reflection about the end of life and the right to die indeed often comes with a high degree of elaboration; discourses are in more explicit and reflexive ways operationalised through the use of elaborated arguments (against euthanasia). This, as we saw earlier, does not particularly apply to personalised coverage of individual cases - where discourses are brought into a personalised media-narrative through media-specific logics of dramatisation, personification and intimisation.

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[73] Once again, this illustrates the compatibility of religious discourses and medical discourses when it comes to the de-legitimisation of euthanasia and the right to die.

5.2.4. Summary: three (competing) constructions of the good death

Ultimately, we may conclude that the DT representation analysis has revealed three (competing) constructions of the good death in the analysed print media representations of the end of life and end of life decision-making. All three constructions are embedded in a medical-revivalist discourse and share an acceptation of the basics of revivalism. At the same time, they significantly differ from each other on a number of important levels.

A first model of the good death is found in the prominent-case coverage. Here, the good death is structured around autonomy and independence of care as a central signifiers, which are centralised in the prominent-case coverage through the operationalisation of a ratio-personal discourse of autonomy and an extrinsic discourse of dignity (and mainly a discourse of self-identity). This operationalisation occurs through media-specific logics of representation, including dramatisation and intimisation and a focus on the extra-ordinary *and* in interaction with a more encompassing right to die movement. Independence (of care) is articulated both with autonomy and dignity. In articulating independence (of care) with autonomy, a focus on the right to die emerges, which comes with an 'othering' of palliative care. In articulating independence (of care) with dignity, the latter is defined in terms of self-reliance and self-control over the mind and body (the authentic self), which in turn comes with a problematisation of dependence. Through these logics of articulation, 'care' becomes discursively excluded from the definition of what it means to die well while euthanasia is often constructed as the only way to die well. The following visualisation captures the first model of the good death:

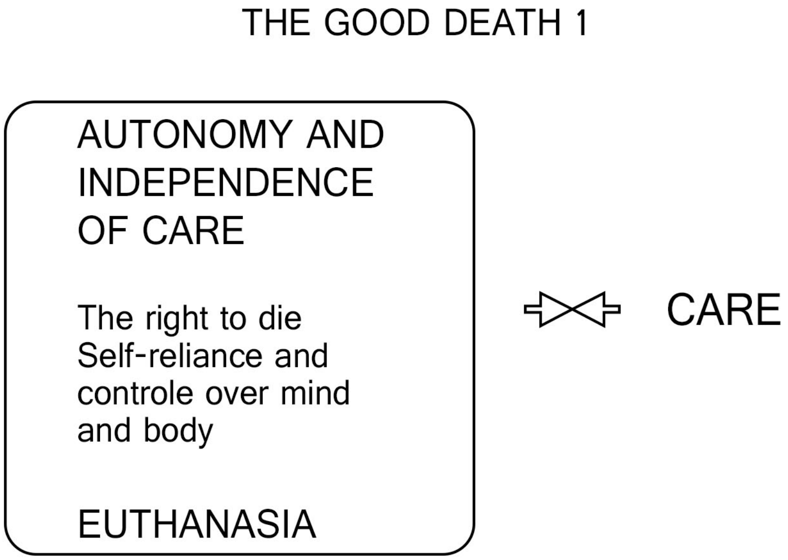

Figure 9: The good death I: prominent cases.

A second construction of the good death above all emerges in the non-prominent case coverage. This second model of the good death is probably the most pluralist and democratic one. Structured around 'choice' as a key signifier, it is – unlike the other two models - a model with 'open boundaries'. The right to autonomous decision-making and a focus on dying with dignity, where the latter is much defined in terms of self-identity, remain untouched. The operationalisation of a ratio-personal discourse of autonomy and an extrinsic approach to dignity occurs in a less disciplining way, however, and in this way 'care' is discursively brought into the range of a good death. This results in a more encompassing definition of what it means to die well, where a variety of end of life trajectories can be part of a good death. The second model of the good death can be visualised as follows:

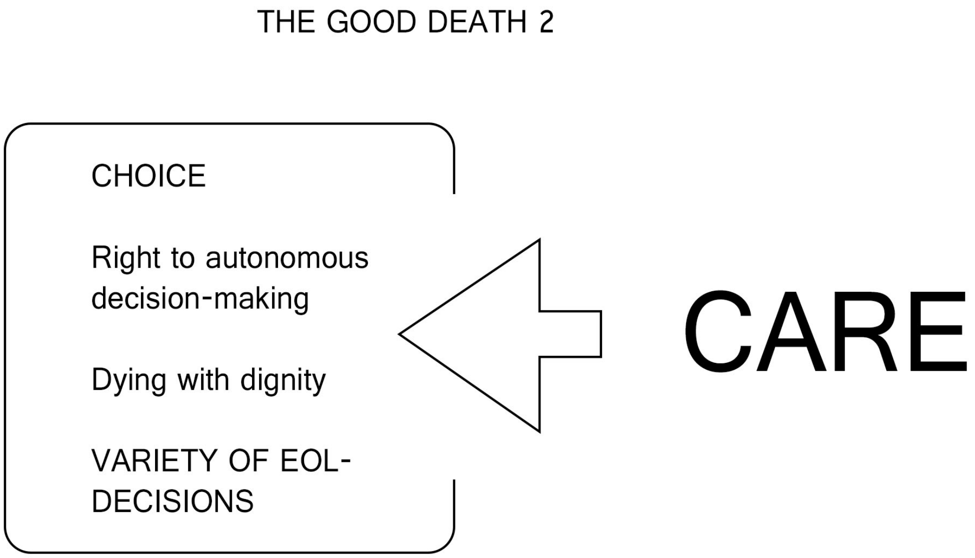

Figure 10: the good death II: non-prominent cases.

A third construction of the good death operationalises a communitarian discourse of autonomy and an innate human dignity concept, through which a (radically) different model of the good death emerges. This model appears as counter-hegemonic in the mainstream media, while it is dominant in the specialised media. In this construction of the good death, care functions as a central signifier. It is through the notion of care that patient autonomy is delegitimised and that a concept of innate human dignity is foregrounded. A good death means dying with palliative care and according to a hospice philosophy. Euthanasia is discursively excluded from the defintition of a good death. This final model of the good death can be visualised as follows:

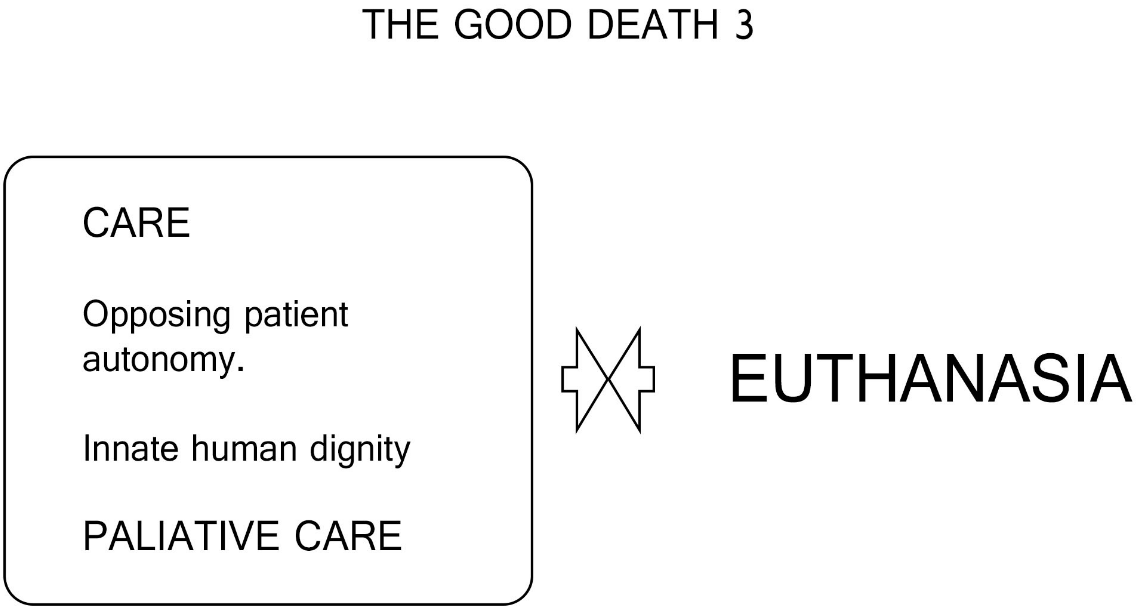

Figure 11: The good death III: specialised media.

PART E: A DTA OF AUDIENCES' RECEPTIONS OF MEDIA REPRESENTATIONS OF THE MEDICALISED DEATH

> "It's not a party. It's a goodbye" (relative of woman who died after euthanasia)

Discourses do not lead an abstract existence; they are operationalised in a variety of texts and are drawn on and identified with by individuals in giving meaning to their experiences and to the social reality surrounding them. The representation analysis (part D) has shown how discourses become operationalised in a variety of Belgian media representations about the end of life. This last part of the dissertation zooms in on what has been labelled in chapter III as the interpretation flow and the identification flow. More specifically, the discourse-theoretical reception analysis presented here focuses on audiences' interpretation and identification practices and works towards the formulation of an answer to the research question as to how audiences interpret media representations of the end of life and in so doing identify with discourses that are seen as more encompassing.

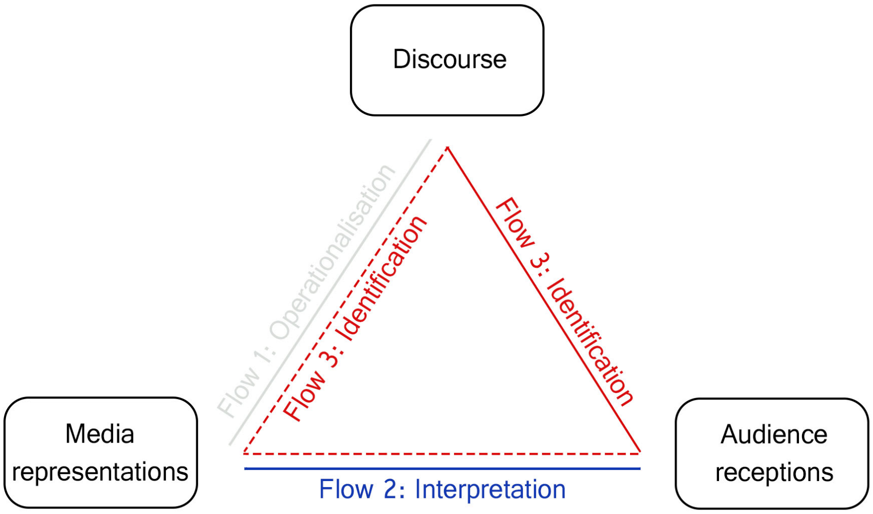

Figure 12: the analytical focus of Part E.

The data for analysing these practices of interpretation and identification are collected by means of both face-to-face and focus groups interviews. Whereas the representation analysis is based on already-existing data, qualitative interviewing involves the *production* of data. Producing data is as such a meaningful practice, one that needs to be reflected on very carefully. Assuring that the reception analysis is part of a coherent whole and fits the discourse-theoretical approach that runs through the entire research indeed also includes the process of collecting and producing the data, where the different decisions in terms of corpus-construction need to be legitimised and carefully reflected upon. Before turning our attention to the reportage of the findings in chapter XV, then, the first chapter of part E (chapter XIV) extensively elaborates on the process of constructing the corpus.

Chapter XIV: Constructing the corpus from a discourse-theoretical perspective on the qualitative interview

A great deal has been written about the process of data-collection in qualitative interviewing (Bloor, 2011; Brinkmann, 2013; Kitzinger, 1994; Morgan 1998), and a plurality of guidelines have been developed in terms of selecting respondents, drafting questions, managing interaction and so on. This body of 'how-to' literature is in itself very helpful, and drawing on it is both inevitable and necessary in order to support and legitimise the choices made in collecting the data. At the same time, as mentioned above, the decisions made are to be informed by, and compatible with, the discourse-theoretical assumptions underlying this research. It is therefore deemed necessary, first, to develop a particular view on the qualitative interview that is compatible with the basic premises underlying this research. Building on this approach to the qualitative interview, two concrete actions in constructing the corpus are dealt with: the identification and selection of respondents and the preparation of questions and focus group activities. The sections dealing with these issues of corpus-construction start with a discourse-theoretical reflection, where the existing 'how-to' is both complemented with and interpreted using discourse-theoretical arguments. The sections then go on to deal with the practical matters of constructing the corpus.

1. The qualitative interview

According to Silverman (2009: 123), we are currently part of *"'an interview society' in which interviews seem central to making sense of our lives"*. Interviews, according to Rapley (2004: 15) shape the experiences and knowledges of our authentic and private selves. It comes as no surprise, then, that interviewing is a prominent method of data gathering in a wide variety of social sciences, and that some sort of interviewing is employed in nearly all qualitative research (Lindlof & Taylor, 2002: 170). According to

Atkinson and Silverman (1997), interviewing is currently the most prominent methods through which contemporary social scientists engage with their object of analysis.

There are many different types of interviews used in both quantitative and qualitative research, such as the expert interview, the ethnographic interview, the respondent interview, and the focus group interview. What all interviews in *qualitative* research have in common, is that they encourage interviewees to produce 'thick descriptions', i.e. to produce elaborated and detailed accounts (Rapley, 2004: 15). Rather than deploying the notion of in-depth interviewing, which is usually preserved for face-to-face interviewing, the notion of the qualitative interview is deployed here to refer to a particular style of interviewing - whether involving face-to-face or group interaction - that is active, collaborative, conversational, dialogical, focused, and (relatively) open-ended.

1.1. A constructionist perspective on 'the real' and 'neutrality'

For the choice for qualitative interviewing to be compatible with the assumptions of discourse theory, it is necessary to develop a view on the nature of data generated through the qualitative interview that is compatible with the DT premises underlying this research. Two points are to be made here: one about the 'realness' of the data generated and one about the 'neutrality' of the interview practice.

First, a particular position towards the construction of knowledge in the interview is hold, one containing the idea that knowledge is not *"waiting in the subject's interior to be uncovered"* (Kvale, 1996: 3) by the interviewer, but rather is negotiated and constructed in the specific setting of the interview (Silerman, 2001: 95; Ritchie & Lewis, 2003: 140). Seale (1998) captures the different approaches towards 'the real' in qualitative interviewing by distinguishing between the 'interview-data-as resource' view and the 'interview-data-as-topic' view. The former sees the interview data as reflecting the interviewees' 'true' beliefs, which are believed to exist independently from the interview – waiting to be brought to the surface during the interview. This stance has been criticised with the argument that interviews are interactional events through and through where knowledge is locally and collaboratively produced. In the interview-data-as-topic approach, then, the interview data are regarded as forms of knowledge jointly constructed by the interviewee and the interviewer. In this approach, the interview generates data not only about the way the interviewees think and feel about a particular topic, but equally about the way the interviewee construct himself as an *"adequate interviewee"* and as *"a specific type of person in relation to this specific topic"* (Rapley, 2004: 16).

While it is crucial to acknowledge that the interview constitutes a particular interactional setting, it is – from a discourse-theoretical point of view – equally important not to isolate the interview from structures of meaning that circulate outside the specific interview-setting. It is the notion of identification, developed earlier in this thesis, which enables connecting the specific setting of the interview, where meaning is interactionally and locally constructed – to more encompassing systems of meaning. The interviewee actively and reflexively positions himself in vis à vis the interviewer, the topic under discussion and - in the case of the focus group - other interviewees, and interactional dynamics will certainly impact on the practices of meaning-making taking place during the interview. At the same time, interviewees still draw on discourses they know, they can identify with and that offer them the signifiers to understand and interpret the topics under discussion. From a discourse-theoretical point of view, then, the qualitative interview can be regarded as a specific site of meaning-making, where properties of the interactional setting create a specific context for the reproduction, negotiation and contestation of discourses through the occupation of a variety of interpretative and identificatory positions.

Closely related to the question of 'realness' of the data generated through the interview is the issue of neutrality. Rapley (2004: 19-20) identifies three articulations of neutrality: neutrality as an essential practice, neutrality as a bad practice, and neutrality as an impossible practice. While the first ideal builds on the assumption that if an interviewer is not neutral, s/he will bias the interview and thus 'corrupt' the data, the second one argues that neutrality is undesirable because it inevitably entails a hierarchical, asymmetrical relationship in which the interviewee is reduced to a research 'object'. Particularly postmodern and feminist approaches adopt the 'neutrality as a bad practice' approach (Gubrium & Holstein, 2003; Ritchie & Lewis, 2003: 140), arguing for a non-hierarchal relationship between interviewer and interviewee(s), for such a 'partnership' would stimulate an environment that is by the respondents perceived as one in which they can speak freely (Ritchi & Lewis, 2003). It is the 'neutrality as impossible' articulation that is best commensurable with the premises of DT, however. This approach does not refrain from following particular guidelines that aim at decreasing the risk of socially desirability or at creating a comfortable speaking situation, such as asking non-leading questions and maintaining a non-hierarchal relationship with the interviewees. At the same time, the approach argues that any neutrality in its conventional sense is simply impossible, for the interviewer indeed always plays an active discursive role; he sets the agenda, asks questions, guides the talk, decides which particular part of an answer to follow up and so on (Rapley, 2004: 20; Watson & Weinberg, 1982). The search for complete neutrality, in this way, turns neutrality into an 'empty signifier' (Laclau, 1996: 37) that signifies an absence and a structural impossibility.

Having developed a particular view on the qualitative interview that is commensurable with discourse-theory, we can in more practical terms discuss the specificities of two types of interviews deployed in this study: the face-to-face interview and the focus group interview.

1.2. Key features of the face-to-face interview and the focus group interview

When deployed for purposes of qualitative research, both the face-to-face and the focus group interview are directed towards the experiences of the respondents and aim at generating elaborated and detailed answers. While both aim at achieving depth, it is usually the qualitative face-to-face interview that is labelled as ‘in-depth’; described as a semi-structured and relatively open interview where a set of topics and questions are a priori drafted, but where the interviewer at the same time aims at obtaining open-ended answers and accounts in order to derive a detailed insight into the meaning-making practices of the respondents (Bury & Gabe, 2004: 354; Ritchie & Lewis, 2003: 143).

In the in-depth face-to-face interview, respondents are encouraged to express themselves freely - in their own languages and vocabularies - on a particular issue or situation, and to tap into personal biographies (Kitzinger & Barbour, 1999: 5). In order to allow people to express themselves freely, the in-depth face-to-face interview is generally marked by an atmosphere of trust and intimacy. Obviously, the interviewer plays a crucial role in creating such a climate and must demonstrate capacities of being non-judgemental, empathetic and understanding (Ritchie & Lewis, 2003: 143), thereby responding to the risk of obtaining socially desirable answers and constructing an atmosphere where the interview is perceived by the respondent as *“a satisfying encounter, as a chance to express his (or her) dislikes, disappointments, and ideas”* (Brenner, 1978, 130). For these reasons, the in-depth face-to-face interview is a suitable method of gathering information about people’s experiences with events and situations that are generally perceived as highly private, very emotionally-loaded, potentially taboo, and as fundamentally shaping peoples’ sense of personal biography (Kitzinger & Barbour, 1999; Kitzinger, 1994).

What makes focus groups fundamentally different from the face-to-face interview is the centrality of group interaction, which has been described as the defining feature of focus groups (Morgan, 1997: 2). The description of focus groups as *“group discussions* *exploring a specific sort of issues"* (Kitzinger & Barbour, 1999: 4), points to the 'focused' nature of focus groups as being centred around *"some kind of collective activity which might vary from simply discussing a set of questions, to watching a movie, reading an article etc."* (Kitzinger, 1994: 103). In defining focus groups as a particular method of data gathering, Kitzinger and Barbour (1999: 5) argue that focus groups are particularly suitable to study the way points of view are jointly constructed and expressed in small-scale settings of interaction. Kitzinger (1994: 116) summarises the key advantages of focus groups; they highlight respondents' attitudes and priorities, as well as their languages/vocabularies and frameworks of understanding; they come close to 'natural' speaking situations because of the centrality of group-*interaction*; they encourage a diversity of communication from the participants (as Kitzinger argues, everyday forms of communication such as jokes and anecdotes may tell us perhaps more about what people 'know' or think); they help in identifying group norms and values; and they provide insight into the operation of group- and social processes in the construction of knowledge (Kitzinger & Barbour, 1999).

1.3. Interviewing the general public, medical professionals and relatives

The choice for in-depth interviews and focus groups in the study of audiences' receptions of media representations of the end of life is informed by the specificities of both methods that have been outlined above. The aim is to create the most suitable speaking-situation for the respondents to speak about their experiences and impressions[74]. Three groups of respondents are included in this study: members of the

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[74] Of course, this speech-situation is not 'ideal' in the Habermassian sense; it is not free of unequal power-relations and normative expectations from both the side of the facilitator/interviewer and the interviewee/participants. Rather, the interview is a discursive setting through and through and therefore imbued with power and normativity. All of this, however, must not per se result in relativism and in abandoning the ambition to create not an ideal, but a suitable speaking-situation.

general public[75], medical professionals and relatives of deceased persons (see section 3 of this chapter for a motivation for the choice to include precisely these groups). Informed by the key features of the focus group interview and the face-to-face interview discussed above, face- to-face interviews are believed to be most suitable for interviewing relatives, while focus groups are privileged to interview both the general public and medical professionals. The choice to deploy in-depth interviews in talking to relatives is especially informed by the possibility that the topic of the end of life evokes strong emotions and perhaps painful memories. Moreover, as became clear in part B of the thesis, death in late modern societies is not per se taboo, but is often regarded as something that should be talked about during particular, usually strictly defined moments. For these reasons, the in-depth face-to-face interview seems suitable to discuss the sensitive and emotionally loaded topics of the end of life and end-of-life decision-making. That is, on the condition that the researcher succeeds in creating a space that is by the respondents conceived as 'appropriate' to talk about death and dying and, in addition, to potentially display emotion. There are a number of ways in which the creation of an intimate and comfortable speaking setting is to be achieved, of which asking 'proper questions' is probably the most important one. We will come back to this later. At this point, the more practical choice for a particular venue in creating an intimate speaking environment should be mentioned: for the respondents to feel at ease, all the interviews took place at their residence, except for one interview where the respondent preferred to have the interview in brasserie she frequently visits.

Focus groups are well suited to interview people with a similar professional background, for they have the potential of creating a speech-environment that is perceived as being close to a naturally occurring speaking-context. For this reason, medical professionals are interviewed by means of focus groups. To exploit the

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[75] The concept of the general public is essence vague and broad. In this specific context, respondents are marked as 'members of the general public' when they have not been directly involved in the dying process of a relative.

potential of creating a 'natural-like' speaking context, the focus groups take place at the workplace of the respondents. Focus groups are also well suited to interview people with limited experience with and/or knowledge about the topic under discussion. Indeed, as became clear earlier, focus groups facilitate the construction of knowledge in interaction; participants are encouraged to respond to other participants' accounts as opinions are shared, challenged and adjusted. It is for this reason that the general public (those with no direct experiences with the end of life) is interviewed by means of focus groups (taking place either at the residence of a respondent, the workplace of the respondents, or the residence of the researcher).

2. Identifying and recruiting respondents

This reception study analyses the way three audience groups interpret media representations of the medical end of life: members of the general public, medical professionals, and relatives of deceased patients. Before turning our attention to the way the respondents of these three groups were identified and selected, it is necessary to briefly draw attention to the question as to what exactly the aim is of selecting these groups from a DT point of view.

2.1. Selecting respondents with different backgrounds: a DT argumentation

Reception analysts often select groups with different cultural, professional, educational, economical and social backgrounds. The assumption behind this choice is that these different groups are likely to allocate meaning to media messages differently (Deacon et al. 1999: 54). In many instances, reception studies selecting different groups aim at drawing conclusions about the way these groups read or decode media messages in different ways. Indeed, in the cultural studies traditions of reception studies, it is emphasised that the interaction between the respondents of an interview and the media contents under discussion is always contextually embedded. Personal experiences as well as social and cultural capitals indeed impact upon the encounter between the text and the subject, as well as on the way the latter accepts, adapts or rejects the media text (Devereux, 2007: 129). In this encounter, Morley (1980: 163), for instance argues, *"other discourses are always at play besides those of the particular text in focus – discourses which depend on other discursive formations, brought into play through the subject's placing in other practices – cultural, educational, institutional"*. In similar vein, Brunsdson (1981) asserts that audiences bring to the encounter with the media texts a variety of other discourses than those represented in the text. While these arguments are very convincing from a DT point of view, the operationalisation of these assumptions in a practical design entails some traps, for indeed tracking down whether, how and to what extent different interpretation and identification practices can be traced to particular experiential, social, cultural, professional and/or socio-demographic contexts is extremely difficult. More specifically, then, there is a risk of becoming self-fulfilling: the researcher has particular ideas about how different groups may interpret media messages differently, and these assumptions steer the actual analysis. Differences in interpretation practices may thereby become reduced to a series of essential categories such as sex, age, religion and profession. Wren-Lewis (1983) has pointed out this risk by arguing that the process of selecting different groups according to different variables involves prejudging what the determining variables behind decoding are, which would put the cart before the horse. From a DT perspective, then, it seems better not to aim at tracking down the 'origins' of different interpretation practices. Not only because denoting these origins on the basis of an interview would be extremely difficult, if not impossible, but also because the interaction dynamics that shape the interview impact on the interpretation practices of the respondents. Rather, the rationale behind selecting different groups should – from a discourse-theoretical point of view - be understood as an attempt to bring a wide variety of (potentially competing) identification practices into the interview setting. It is, as explained above, indeed likely that people with different contextual backgrounds draw on different discourses in interpreting media contents. Including people with different backgrounds in a reception study brings a variety of discourses (through respondents identifying with them) into the study. Including audience groups with different contextual backgrounds, in this case, gives the researcher access to a variety of ideas about what it means to die well.

2.2. The sampling procedure

It has been mentioned above that three audience categories are included in this study: members of the general public, medical professionals, and relatives of deceased patients. Why exactly these three groups were interviewed[76] needs further clarification, and both the theoretical framework and the media analysis offer part of this explanation.

First, it is of interest to look into the way member of general public, i.e. individuals who have not in a first-line and direct way been involved in the dying process of a relative, receive the representations analysed in part D of the dissertation – which often give a voice to people directly involved (both patients themselves and relatives).

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[76] There are a series of other groups that - for the sake of the study's feasibility - are not included here, but that could bring added value to any additional research in the future. One group that comes to mind are social workers – including volunteers working in palliative centres and support groups, pastoral workers and the like. Conducting interviews with this group would definitely be interesting, considering the recent move towards psychosocial care and the psychosocial discourses on grief and mourning that have been emerging alongside of this move (Seale, 1998, Walter, 1991). Another target group that could to be included in further research is that of journalists, a group that is not interviewed in this study because of the focus on the interpretation and identification practices of people with different experiential contexts relating to the end of life.

The theoretical framework teaches us that the main subject positions constructed in and through contemporary discourses on the good death are those of the dying patient and the medical professional, while the media analysis points in the direction of a specific operationalisation of these subject positions. It is therefore of interest to look at the way patients and medical professionals interpret the construction of their own identities in the media and on what discourses they draw in so doing. Due to ethical consideration, it was decided not to include terminally ill patients in the study, however. First of all, the question of how appropriate it is to ask terminally ill and dying patients about their readings of media messages about the end of life, naturally arises. The answer to that question is not automatically that it is not at all appropriate, for some patients can experience an interview as therapeutic. However, finding out which patients are willing to participate in an interview is difficult, and the risk of contacting patients who might be seized with emotion by the invitation can hardly be avoided. Moreover, when patients willing to participate in an interview were to be find, thorough training of the interviewer in domains of end of life communication and perhaps even psychotherapy would be required. Taking into account these ethical and pragmatic arguments, the choice was made to interview relatives instead of patients. The choice for interviewing relatives is above all informed by the media analysis. First, the relative is - next to the patient and the medical professional, shown to be a key subject constructed in discourses on autonomy and dignity, which again makes it interesting to look at the way relatives perceive the mediated construction of their identity. Second, the quantitative mapping indicated that (especially popular) media frequently include reactions and opinions of relatives into their coverage, suggesting that relatives represent a key voice in contemporary end of life debates. Evidentially, interviewing relatives of deceased persons remains an ethically sensitive subject, for it potentially provokes strong emotions and painful memories. For this reason, the researcher was (informally) trained by a psychologist[77] with an expertise in communication. In addition, ethical approval for the entire reception study – with a

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[77] Many thanks to Katrien Vanderstappen.

special focus on the interviews with relatives – was applied for and obtained from the Ethical Commission of the University Hospital of Brussels.

Each of the three groups included in the study - the general public, medical professionals and relatives - is further diversified on the basis of a series of subcategories. Medical professionals, first, are diversified on the basis of medical specialism: three groups of medical professionals that frequently encounter dying patients are included in the study: nurses, general practitioners, and specialists in oncology and geriatrics. In addition to this main subdivision, the respondents are diversified on the basis of religion and philosophy and types of institutionalised care (hospital care, hospice care, home care). Second, the general public is diversified on the basis of a series of general socio-demographical variables: age, sex and education. The main objective of the study is not to draw conclusions about the way respondents from different sex, age, and education categories interpret media outlets differently, but to ensure that no obvious group is left out and to increase the chances of divergent practices of interpretation and identification, allowing us to gain insight into the richness of ways in which discourses are deployed, negotiated, contested and reflected. Third, relatives of deceased patients are diversified on the basis of relation of the respondent to the deceased, the type of end-of-life decision that applied to the deceased, and place of death of the deceased[78][79]. This diversification is informed by medical sociological literature pointing out a relation between these aspects and the way the end of life is experienced (Cohen, 2007; Higginson & Sen-Gupta, 2000; Mezey et al. 2002; Payne et al. 1996; Teno et al. 2004) and is further legitimised by a

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[78] The place of death, according to Cohen (2007: 97), plausibly influences practices of end-of-life decision-making. Moreover, it also potentially affects the way people experience quality of life at the end of life, and the quality of care. This, in turn, cannot be isolated from recent critiques against the medicalisation of dying.

[79] We also intended to diversify on the basis of illness that caused death (cancer, Alzheimer's' disease as well as other degenerative illnesses), but only relatives of patients who died from cancer responded to the call.

representativity argument (capturing the diversity of end-of-life decisions taken at the end of life and the diversification of place of death in contemporary medicalised societies). More importantly, again, the diversification outlined above makes a wide diversity of interpretation and identification practices more likely.

For all the audience categories defined earlier to be represented, non-random or non-probability sampling is used to recruit the respondents. First, the medical professionals are selected by personal invitations: with the aim of gathering pre-existing focus groups, mails were sent to entire teams and groups of colleagues of the main hospitals and hospices and care institutions (with different religious orientations) in Flanders. Recruiting by personal invitation is more difficult in the case of general practitioners, who often work in individual offices. The selection of general practitioners goes via the LOK[80] groups organised by the RIZIV[81], which are local consultation groups doctors must be affiliated with and of which they must attend no less then two meetings a year. The members of the general public, second, were mainly selected by means of the snowball method, where acquaintances from the researcher indicate potential respondents, who in turn identify new potential respondents. Also a variety of associations were contacted, but this yielded no reactions.

The relatives, finally, were contacted via a variety of channels. First, a call was published on a series of online forums: that of Flemish League against Cancer[82], and that of the Alzheimer-league[83]. These calls yielded no responses. Second, palliative centres and hospice were contacted and asked to identify potential respondents, and

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[80] Local Consultation Groups (Lokaal Overleg Kwaliteitszorg)

[81] National Institute for Sickness and Invalidity Insurance (Rijkinstituut voor ziekte- en invaliditeitsverzekering)

[82] Vlaamse Liga tegen Kanker

83 Vlaamse Alzheimer liga

third, a series of grief associations and associations for (young) widows and widowers were contacted as well[84].

In the process of contacting and approaching respondents sufficient information about the nature of the project has been given. All the recruitment letters, mails, and posters contain a short but accurate description of the research and of the topic of the focus groups and interviews more specifically. Respondents indeed have the right to be informed about the nature and the purposes of the research they participate in. It is the (ethical) task of the researcher to provide the respondents with this information at different moments in time (Hennink, 2007; Kitzinger & Barbour, 1999).

2.3. Composition and size of the focus groups

All focus groups with medical professionals consist of pre-constituted groups of colleagues and are thus marked by an internal homogeneity. The rationale behind this choice is that different institutions have different politics on end-of-life decision-making, making the end of life a rather controversial issue that potentially provokes

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[84] Recruiting relatives is ethically sensitive and therefore requires a well-thought-out approach, which is why permission for conducting the interviews was applied for with the Ethical Commission of the University Hospital of Brussels. For this same reason, relatives of deceased patients were never contacted directly, but via a series of institutions and organisations directly involved in the counselling of dying patients’ relatives and families, including social and pastoral services of hospitals, centres for palliative care, and mourning associations and support groups. These services, centres and associations were contacted with information about the research project and with the question of identifying potential respondents. This information has always been very transparent and explicated the scientific aims of the research and the interview. Also the centrality of the media aspect of the research has been emphasised. When we received the contact coordinates of potentially interested people, we first e-mailed them (when an email-address was known) and then called them to give them more information about the research and to set a data and place. Three to two days in advance, the respondents were once again contacted, not only to remind them of the interview, but also to reassure them and answer any additional questions.

uncomfortable speaking-situations amongst medical professionals affiliated to different institutions. The choice to work with pre-existing groups is supported by a number of scholars. Selecting already existing groups, they argue, would enable the researcher to create an interactional setting that approximates to 'naturally occurring data'[85] (Deacon et al. 1999: 56; Kitzinger, 1994). As Kitzinger (1994: 105) argues: *"Above all it is useful to work with pre-existing groups because they provide one of the social contexts within which ideas are formed and decisions made"*.

Ten focus groups are conducted with medical professionals. Five focus groups are conducted with nurses, two with general practitioners and three with specialists. In terms of medical specialism, most focus groups are homogeneously composed. Nine out of ten consist solely out of nurses, or general practitioners, or physicians with a particular specialisation (e.g.in oncology or in geriatrics). One focus group consists of three specialists and two nurses. Catholic institutions are represented by four focus groups (three with nurses and one with specialists), neutral institutions are represented by two focus groups (one with nurses and one with specialists), and free institutions are represented by one focus group (with nurses). Home care is represented by two focus groups (with nurses), hospice care is represented by one focus group (with nurses), and hospital care is represented by five focus groups (thee with specialists and two with nurses). The size of the groups varies between three and six participants. A total of 40 respondents (within the category of medical professionals) participated in the research.

As for the focus groups with **the general public** – given the very limited response and willingness to participate in a focus group - **three focus groups** are organised. One group consists of respondents aged 20-25, one of respondents aged 30-45, and one of respondents aged 50-67. Both men and women are present in each group. The 20-25 aged focus group consists of higher educated people, so as the 30-45 group does. The

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[85] As discussed earlier, data are never 'naturally occurring'. They are always embedded in an specific discurive setting, which is the qualitative interview, in which knowledge is jointly constructed.

50-67 group consist of people with both lower and higher educations. All focus groups consist of four or five participants. A total of 14 respondents (within the category of members of the general public) was engaged in the research.

Finally, **eight in-depth interviews** have been conducted with relatives: seven of the respondents were widow(er)s, and one was a daughter; three of the respondents' relatives died after euthanasia, and five after a process of palliative care; three of the respondents' relatives died at home, three died in a hospital, and two died in a hospice. Furthermore, three of the respondents were men, and five were women and none of the respondents is older than 67 years old.

I ceased organising face-to-face interviews and focus groups at the point when the focus groups and interviews stopped adding new insights, or in other words when saturation was reached[86].

3. Asking questions in the qualitative interview

Asking questions that achieve 'thick', deep and detailed information is often described as the primary task of the researcher engaging in qualitative interviewing (Ritchie & Lewis, 2003: 148; Yin, 2011: 27), and numerous 'how to' guidelines on asking questions in qualitative interviewing have been formulated by several authors (Braun & Clarke, 2013: 79; Lindlof & Taylor, 2002; Ritchie & Lewis, 2003: 148; Yin, 2011). This comes as no surprise, as the type of questions asked and the way in which they are formulated is indeed crucial for the quality of the interview. Indeed, the researcher is faced with

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[86] The last two interviews added no new insights and revealed no new logics of interpretation/identification. Given that the three audience categories were identified and included with the aim of generating access to a wide array of identificatory practices, reaching saturation within each of these categories has not been a goal. Nonetheless, saturation was reached within the category of medical professionals and the category of relatives.

the challenge of operationalising abstract research questions and theoretical concepts, and of asking those questions that achieve in-depth information.

A number of writers have described different types of questions the interviewer can call upon (Deacon et al. 1999; Ritchie & Lewis, 2003; Rubin & Rubin, 1995). Ritchie and Lewis (2003) identify two main categories of questions: content mapping and content mining questions. Content mapping questions, first, aim at opening up the conversation and at identifying the dimensions that are of significance for the participant(s) and the researcher. Ritchie & Lewis (2003) list a number of types of content mapping questions: ground mapping questions that introduce a subject, dimension mapping questions that focus the participant(s) a bit more narrowly on particular topics in order to structure and guide the interview, and perspective-widening questions that encourage the participant(s) to look at issues from different perspectives in order to uncover additional or deeper levels of meaning. Second, content mining questions explore these levels in more detail and generate an in-depth understanding of the participants' point of view (Ritichie & Lewis, 2003: 148). Content mining questions, Ritchie and Lewis go on to argue, involve probes, which are *"responsive, follow-up questions designed to elicit more information, description, explanation and so on"* (Ritchie & Lewis, 2003: 148). In Deacon et al. (1999: 71-74), we find another classification of types of questions. Three sorts of questions are distinguished here: questions about attributes, questions about behaviour, and questions about beliefs and attitudes. Questions about attributes allow the researcher to explore variations in responses according to features like age, gender, occupation and so forth. Questions about behaviour concern the empirical reality of what it is that people do - rather than what they think - and should therefore be more immune to social desirability. Questions about beliefs and attitudes are, for Deacon et al (2003: 72), the most delicate ones as they are most sensible to influence be the research process for two reasons. First, the way such questions are asked might encourage respondents to adopt certain stances and express certain views. Second, not everybody has an opinion on everything, which entails the risk that respondents feel obliged to improvise viewpoints.

A related issue that is often dealt with in literature about asking questions in qualitative interviewing is that of the formulating questions. A number of formulations are generally seen as to be avoided. Leading questions, first, are to be avoided because they reveal assumptions of the researcher (Merriam, 2009; Brennen, 2012: 35; Deacon et al. 1999; Ritchi & Lewis, 2003: 154). As will become clear later on, however, all questions are in a way leading as they set the agenda of the interview and as they inevitably contain interpretations of the researcher. Second, jargon and technical terms are to be avoided, which basically comes down to a proper 'translation' of theoretical concepts. Good formulations, on the other hand, are those that are clear and unambiguous, and open and broad - calling for description rather than affirmation and encouraging detailed responses, while at the providing respondents with enough direction and thus not provoking vague answers (Deacon et al. 1999; Ritchie & Lewis, 2003: 155).

Literature about asking questions in interviews also frequently deals with the order in which questions are best asked, and it is generally suggested that the more sensitive questions should come towards the end of the interview, while questions that are more general and easy to answer should open the interview. The rationale behind this logic of ordering questions is that an atmosphere of trust should first be created before sensitive questions can be raised, which basically corresponds to the general conventions that guide everyday conversations (Deacon et al. 1999).

Finally, there is the issue of preparing interview-questions, i.e. the question of *"the topic guide versus the questioning route"* (Krueger, 1998: 9). The topic guide includes a list of topics or issues that are to be dealt with during the interview. The questioning route, by contrast, contains a sequence of questions in complete, conversational sentences. While the development of a questioning route allows the researcher to carefully consider the formulation of questions, the topic guide allows for more flexibility and for a more 'natural-like' conversation (Krueger, 1998). The topic guide is often used in focus group research, where the role of the facilitator is often described as a 'background figure' or a 'theatre manager' (Bloor et al. 2001: 49) whose task is restricted to asking questions and encouraging discussion and interaction between the participants (Krzyzanowski, 2001: 164). At the same time, it is often argued that the main task of the facilitator lies in guarantying a high degree of interaction between the participants of the focus group, and encouraging that more silent voices are heard during the discussion as well (without pushing them too much at the same time). As Kitzinger and Barbour argue; the facilitator has to encourage participants to talk to one another, to exchange anecdotes and to comment on each (1999: 4). As such, the facilitator often engages in probing and asking follow-up questions, which implies a more interventionist style of facilitating.

While the 'how to' literature on asking questions helps us to develop questions in a practical research design, it is also crucial to dwell upon the activity of asking questions in a more (discourse-)theoretical fashion. Indeed, it needs to be acknowledged that asking questions is not a neutral, but a discursive activity through and through. Three points should be made about this: the way questions can be seen as carriers of discourses as well that import a particular type of knowledge the researcher holds into the interview; the way asking questions creates an 'artificial' degree of reflexivity the researcher should deal with; and the way asking questions entails a potential of conflict and disagreement between focus group participants.

3.1. The question as a carrier of discourse

Asking questions is not a neutral activity. First, the normative idea of a 'good' question is contextually situated at the intersection between academic discourses that construct a particular knowledge about interviewing and normative expectations of everyday conversations. Second, when looking at the very activity of asking questions in the interview from a discourse-theoretical point of view, it can be argued that questions contain and transmit discourses; discourses are operationalised in the questions asked by the interviewer/facilitator. In the activity of de-abstracting discourses, the interviewer/facilitator turns abstract systems of meaning into concrete positions the interviewee or focus group participants can relate to. Concretising discourses thus implies offering the participants the material that allows for identification. The operationalisation of discourses is a meaning-making activity and cannot be regarded as an activity that takes place outside of the discursive realm. The interviewer/facilitator is indeed a discursive subject. While generally keeping away from explicitly evaluating articulations that circulate in the text, the interviewer holds a particular knowledge about the topics under discussion. The interviewer/facilitator interprets the topics and media texts under discussion and does so from the capacity of being a social subject, with particular attitudes towards the subject under discussion, as well as from the capacity of being a researcher - where the practice of interpretation becomes a practice of analysing. The interpretation of the interviewer/facilitator is to be considered a specific form of knowledge that is imported into the interview through the questions asked. In the practice of posing questions, the interviewer/facilitator uses a particular lexis and syntax that relates to the particular knowledge he/she holds. What takes place, then, is an encounter/a confrontation between the discursive framework of the interviewee and the discursive framework of the researcher.

This discursive embeddedness of the interview(er) does not imply, however, that the formulation of questions should not receive any consideration because they are normative anyway. In order to create a comfortable speaking situation, it remains desirable to formulate questions in a non-normative fashion, for refraining from leading formulations increases the odds of respondents feeling that they can speak freely.

3.2. Reflexivity

In the context of an interview, people are always to certain degrees encouraged to reflect upon the views and opinions they uphold. By asking questions, the interviewer/facilitator in a way 'forces' participants to reflect on particular topics. In the case of the focus group, interactions between participants further encourage them to reflect not only upon the discourses which are brought into the focus group by the facilitator, but equally on the talk produced by themselves and by the other participants. It is hence the staged and interactional nature of the interview that entails a certain degree of awareness. This level of awareness implies that respondents reflexively position themselves towards certain discourses that circulate in the setting of the interview, as well as – in more concrete terms – towards the questions raised by the interviewer/facilitator, towards their own responses, and towards the responses of the other participants.

The phenomenon of reflexivity raises questions of reliability and more specifically, of how to deal with what could be labelled as *artificially constructed meaning*. Being reflexive about what they say and how they say it, there is always a certain risk that the respondents' answers are guided by a certain social desirability; referring to the way respondents formulate answers they think are socially accepted. In a way, then, 'society' functions as another key actor in the interview setting, which further adds to the complexity of the interview as a discursive setting.

Two ways of dealing with the issue of reflexivity can be suggested; one more practical and one more theoretical in nature. In practical terms, the researcher should find a balance between probing and accepting 'no opinion' answers, which have to be considered as legitimate when respondents cannot or are not willing to formulate opinions. In theoretical terms, it can be argued that even though respondents may reflect on a level they would not reflect on in everyday situations, we can assume that, in doing so, they draw from discourses they know and can identify with, and that offer them the signifiers to understand and interpret topics and phenomena they are familiar with. It is likely that these same discourses offer them the material to also interpret those topics under investigation they have not (much) reflected upon before. A final note to be made at this point is that not all meaning-making practices occurring during the interview are (equally) reflexive in nature. Large parts of practices of interpretation and identification indeed take place at a low level of reflexivity and are to be seen as practices of reproducing and negotiating societal discourses that fundamentally shape the respondents' experiences. Related to this, it can be assumed that not all questions entail an equal degree of reflexivity; whereas more open and general questions are likely to evoke less reflexive elaborations, directed and non-open questions can encourage respondents to reflect on an issue in a way they have not done before.

3.3. Focus group conflict

In the context of the focus group, questions evoke (or should evoke) interaction, which in turn entails the possibility of disagreement and conflict between the participants. Especially when focus group participants are more heterogeneously composed and when more sensitive topics are brought to the table, the odds of disagreement and conflict are factual. Disagreement and conflict are key sources of information about meaning-making practices and therefore merit further elaboration. To capture this potential conflict, a 'plain' discourse-theoretical definition of conflict in terms of a hegemonic struggle for meaning in which discourses attempt to stabilise nodal points that are the basis of social order such that a social imaginary is created (Laclau, 1990: 64), is not the most suitable one. The specificity of the focus group requires us to operationalise the concept of hegemony in such a way that it becomes usable to understand focus group interaction, i.e. a conceptualisation that is not situated at the macro-level of social hegemony, but one that captures disagreement in interaction in discourse-theoretical terms. We might conceptualise conflict in the focus group (about media texts) as the result of diverging or even conflicting practices of (dis-) identification with particular discourses, which not only comes about in the interpretation of media texts, but also in the negotiation of identities, in relation to the text, the interviewer, the other participants and ‘others’ not included into the focus group. Conflict in interaction, indeed, is directly related to a diversification of identification practices. The way focus group participants interpret media texts and identify with discourses and subject positions in different ways comes about in the interaction between them. It is crucial to note here that interaction is hence not merely a neutral ‘medium’ through which different and conflicting articulations are expressed. Rather, interactions are themselves significant and substantive parts of the formation of these articulations (Waterton & Wynne, 1999: 136). The struggle for meaning in the group interaction is akin to Laclau and Mouffe’s approach to discursive struggle. Rather than being a struggle between discourses, what is happening during focus group interaction is a struggle between different identifications with particular discourses, through different interpretations of the same media text. Another point that needs to be made here is that conflict is not per se antagonistic and does not necessarily involve hostility. The focus groups conducted in the light of this research, were indeed not marked by hostility. Rather, we witnessed diverging and conflicting modes of identification, which is of course something else then conflict *between participants* as such. Only once, a situation was encountered where two nurses found themselves in a somewhat ‘unfriendly’ conversation, which could however quite easily be counter into a more ‘friendly’ difference of opinion.

Moreover, focus group interactions are not always marked by conflicting practices of identification. Especially when the focus group is homogenously composed of participants with a joint identity, interaction is often directed towards the construction of a joint narrative. Consensus in the focus group does not say anything about ‘real’ agreement, which would imply that respondents draw on the *same* discourses in the *same* ways. Indeed, particular communities (for instance the professional community of doctors) have a strong sense of identity, potentially making that participants will not openly disagree with one another, particularly not on controversial subjects such as the end of life. The construction of a joint narrative, moreover, brings in another type of conflict; one where an 'us' identity is opposed to a 'they' identity, the latter functioning as a constitutive outside.

3.4. Preparing questions for the interviews: practical design

The guidelines on asking questions outlined earlier assist in formulating and designing the questions and exercises brought to the table during the interviews, while the points made about the discursive and non-neutral nature of asking questions, about the issue of reflexivity and about the nature of conflict during the focus group constitute a theoretical background that supports the development and preparation of the questions and exercises. Before discussing the actual questions and exercises deployed in the interview, it is necessary to explain the selection of the media-texts serving as discussion material.

3.4.1. The selection of media articles

It is the objective of the reception analysis to gain access to a wide variety of practices of interpretation/identification. To assure this access, it is necessary that the different articulatory logics identified in the representation analysis - rather than all the different types of media coverage as such - be taken along in the reception analysis. It is precisely the personal case coverage that contains discursively rich material and that includes the variety of - sometimes conflicting - articulations. In order to increase the chances of gaining access to a wide diversity of interpretation practices, it is also helpful to include in the reception analysis a number of 'extreme' cases; articles that for instance explicitly articulate dignity in terms of independence/self-control or that construct palliative care as a form of a 'bad death'. It has become clear in the representation analysis that these kinds of representations appear above all in the prominent case coverage.

During the opening discussion, all categories of media coverage are represented: case coverage (including both prominent-case coverage and non-prominent case coverage), political discussions and ethical discussions. Moreover, both mainstream media coverage (including articles published in both popular and quality media products) and specialised media coverage are represented. With an open question/focus group exercise (see further for a more detailed description), the respondents are encouraged to freely talk about these articles, without too much intervention of the researcher.

The following table gives an overview of the articles that were selected in light of the opening discussion.

Article	**Media Genre**	**Category**
"To go in friendship and laughing" ("In vriendschap en al lachend kunnen gaan")	Mainstream popular (newspaper)	Prominent case
"Happy she could die" ("Blij dat ze mocht doodgaan")	Mainstream popular (newspaper)	Prominent case
"I cannot reconsile with death" ("Ik kan me niet met de dood verzoeken")	Mainstream quality (newspaper)	Prominent case
"I want to inspire people" ("Ik wil mensen inspireren")	Mainstream popular (newspaper)	Prominent case
"A man cannot leave his faith in the hands of chemistry" ("Een mens kan zijn dood niet overlaten aan de chemie")	Mainstream popular (newspaper)	Ethical discussion (on the occasion of prominent case)
"Dying with dignity with a glass of champagne" ("Waardig sterven met een glas champagne")	Mainstream quality (newspaper)	Medical-political discussion (on the occasion of prominent case)
"Only death can bring me peace" ("Alleen de dood kan mij rust brengen")	Mainstream popular (magazine)	Non-prominent case
"Terminally ill Georges" ("Terminaal zieke Georges")	Mainstream popular (magazine)	Non-prominent case
"Open VLD opens euthanasia debat" ("Open VLD opent euthanasiedebat")	Specialised	Political discussion
"Palliative care underprivileged"	Specialised	Political discussion

("Palliatieve zorgen achtergesteld")		
"Nurses strongly involved in euthanasia process" ("Verpleegkundigen sterk betrokken bij euthanasieproces")	Specialised	Political discussion

Table 10: articles included in the interviews: opening discussion.

Already during the opening discussion it becomes clear that the respondents are seemingly more triggered by articles dealing with the end of life of an individual. Furthermore, at the beginning of the interviews, the respondents are asked whether and how they remember a particular media item (a news item, a television program, a movie, a documentary) about the end of life. Very often, respondents mentioned individual end of life stories such as the coverage of the euthanasia of Claus and the movie about the euthanasia of Verstraete ("Tot Altijd"). Again, this illustrates the special status of individual end of life cases.

In a second phase, the interviews proceed with a discussion on the basis of more structured and directed questions about specific articles. As this is a *reception* study, interested in the way people interpret media texts, it is crucial to have the respondents talk *about* the media articles included in the study. After two test-interviews, it became clear that case coverage invites people to do exactly this, much more than other types of coverage[87]. This is why it was decided to base the more structured part of the interviews on articles dealing with a personal end of life case. It became clear that case coverage invites people to bring their own experiences with the end of life into the encounter with the media text, and to reflect upon the way the text, and the way it represents the end of life, does or does not capture these own experiences, hence providing the material for identification. This observation comes as no surprise, as the representation analysis already illustrated how case coverage, and especially the coverage of prominent-cases, prompts sometimes fierce reactions from a variety of actors. Political/ethical coverage, on the other hand, makes it much more difficult to

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[87] This was also expected, given that the discourse-theoretical representation analysis already indicated the discursive richness of personal case coverage.

enter a reception logic, as this type of coverage above all invites people to formulate arguments for or against particular end-of-life decisions. At the same time, it is important to note that that while the analysis focuses on the reception of case coverage, respondents do talk about political/ethical coverage – which especially yields useful and interesting insights into the way constructions of 'good journalism' are inscribed in the respondents' talk.

A number of articles dealing with prominent euthanasia-cases and a number of articles dealing with non-prominent end of life cases were selected to serve as discussion material. This selection covers the diversity of articulations that was revealed in the representation analysis. The following table provides an overview.

Article	**Category**	**Main articulations**
"Euthanasia should not be horrible" ("Euthanasie hoeft niet gruwelijk te zijn")	Prominent case	Ratio-personal articulation of autonomy Euthanasia as good/brave death Euthanasia as dignified death Dignity as independence/self-control
"To go in Friendship and laughing"("In vriendschap en al lachend gaan")	Prominent case	Euthanasia as hedonic death Palliative care as bad death
"We thank God mama could de here" ("We danken God dat mama hier is mogen sterven")	Non-prominent case	Palliative care as good death Care as main ingredient of good death
"Amelie Van Esbeen dies after euthanasia" ("Amelie Van Esbeen sterft na euthanasie")	Prominent case	Patient autonomy The good doctor vs the bad doctor (serving the patient vs medical paternalism)
"Mother wanted to live" ("Moeder wilde leven")	Non-prominent case	Patient autonomy The good doctor vs the bad doctor (serving the patient vs medical paternalism)

Table 11: selection of articles for the interview discussion

3.4.2. Questions and exercises

It is crucial for the questions and activities that structure the interviews to fit into the frame of discourse theory and to be connected to the theoretical framework and the representation analysis. It is a task of the researcher to encourage talk about specific media contents, hence operationalising research questions, theoretical concepts, and conclusions drawn from the theoretical framework and the media-analysis. This is important in order to be able to analyse the way the respondents give meaning to the media texts and thereby draw from particular discourses. At the same time, it is necessary to watch over the possibility that respondents bring in new discourses into their encounter with the media text, hence respecting the openness of qualitative research. A variety of questions and exercises have been developed to this end, some aiming at generating open answers, and some at encouraging reflection about more specific aspects of the text under discussion; some entailing a lower expected degree of reflexivity, and some entailing a higher expected degree of reflexivity; and some bringing about a lower potential of disagreement and conflict, and others a higher potential of disagreement and conflict.

It is important to note at this point that the questions have been developed in light of the primarily research interest in the way audiences interpret media representations of the end of life and in so doing identify with discourses on death and dying. It has been explained earlier that the data not only generated insight into the identification with discourses on death and dying (with their respective nodal points and subject positions), but also into the way normative constructions of ‘good journalism’ are inscribed into the respondents’ talk.

The specificities of face-to-face interviewing and focus group impose different requirements in terms of both content and form of the questions asked. Let us therefore take a look at the questions developed for both formats in some more detail.

The focus groups begin[88] with a content-mapping and non-sensitive question, aiming at putting the participants at ease and giving them all a chance to speak and express any initial thoughts. Concretely, the respondents are asked whether there is something that recently appeared in the media – TV, newspapers, documentary, film or any other medium – about the end of life, euthanasia or palliative care they remember, and if so, what that would be. To avoid any feeling of 'having to remember something', it is stressed that it is perfectly possible that noting comes to mind, and that this is of course no problem at all.

After this first question follows a content-mapping exercise, where as series of articles are spread on the table about which the participants are encouraged to talk. Concretely, the respondents are asked to jointly take a look at the articles and to elaborate a bit on which of the articles they would be interested in, which ones they would read, but also which ones they would not read or perhaps bother them and why. As a follow-up (and content-mining rather than content-mining) activity, a series of cards with notions like 'informative', 'consulting', 'de-tabooing', 'misleading', 'voyeuristic' and 'sensationalist' are brought to the table and the respondents are asked to associate these notions with the respective articles, with the accompanying remark that there are no right or wrong associations and that multiple associations can be made. The main discussion exercise aims at generating horizontally rich information about the participants' first impressions and interpretations of the articles and, if the debate goes on for a while and is rather detailed, about discursive

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[88] Before the actual interview begins, the researcher introduces the interview by giving in-depth information about the research. Respondents were informed not only about the purposes of the research, but also about how data will be processed, whether their anonymity will be ensured, whether they have access to the data, and so on. All of these issues are described in an informed consent form, which is signed both by the researcher and by the respondents. The most important ethical issue covered in the informed consent is that of confidentiality and anonymity. It is explicitly stated that the identities of the respondents are protected, which implies that their names and addresses will not be revealed at any time, neither in this dissertation nor in other publications.

constructs associated with the article and discourses drawn from, deployed, and negotiated. This follow-up exercise aims at narrowing the debate down to the topic of media and at generating discussion about the visibility of the end of life in the media.

The majority of subsequent questions are content-mining in nature and deal with the contents of the selected articles. First, there is a content-mining activity, where the respondents are shown a picture of Claus and Engelborghs with a glass of champagne in their hand. The picture accompanies the article 'Euthanasia should not be horrible', but when showing the picture to the respondents the title is blinded. The respondents are asked to come up with a title they feel fits the picture. This exercise pursues the goal of identifying whether or not respondents share a particular recognition of the media article (i.e. whether they agree on what the main message is). Other goals pursued by the content-mining questions are to identify the way respondents evaluate the media message (the main articulations identified in the representation analysis); i.e. whether they accept, negotiate or reject the media message, and to identify discourses drawn from, deployed, reproduced, negotiated and contested in interpreting the media messages. In order to both gauging interpretation of the representational logics identified in the representation analysis and securing the possibility of new interpretatory categories to emerge, both very open and non directive questions (for instance: 'What is your first impression of this article?' and 'How do you feel about this article?') and more directed questions (for instance: 'What do you feel is the image of euthanasia this article generates?) are asked.

In between the questions about the media contents, another exercise is brought to the table, one where the respondents are asked to associate different concepts (identified on the basis of both the theoretical framework and the DT representation analysis) written on cards (such as 'a dignified death', 'autonomy', 'hedonists', 'care') with the articles they just read. Here, the respondents are asked to discuss the associations they make on the one hand (for instance the association of palliative care with a dignified death), and the association they feel the respective media article makes on the other (for instance the association of euthanasia with a dignified death). During this exercise, respondents on a more reflexive level engage in practices of interpretation and identification.

A final question raised during the focus groups asks the respondents about any aspects that struck them when reading the articles; any aspects they felt were overemphasised or underexposed. In addition, this last question encourages a wrapping-up debate where respondents are given the opportunity to utter any thoughts they might not have been able (or felt to not have been able) to express during the earlier focus group discussion.

The direct involvement of the interviewed relatives with the dying process of a beloved one makes the subject of the end of life potentially a highly sensitive subject. Although the questions and the order in which the questions are asked are very similar from the focus group questions and their ordering, the face-to-face interviews require a modified approach, not only in terms of questioning, but also in terms of a more general way of approaching the respondents. Before the interview starts, it is explicitly said to the respondents that they may indicate at any moment that they do not wish to talk about a particular issue, would like to take a break, or even stop the interview all together.

As the death of a loved one is an event that often fundamentally shapes (senses of) personal biographies, the relatives are at the offset of the interview given the opportunity to 'tell their story'. This above all has an ice-breaking function, constructing a sense of trust between the interviewee and the interviewer. As these stories often do not relate to the core of the analysis, bridges are then created towards more media related questions, where the respondents are asked whether they read/watch news-items/films/documentaries on the end of life, palliative care, euthanasia and so on when covered in the media (and why) and/or whether there is a specific item/film/documentary they remember (and what). The focus group exercise of discussing a selection of media texts is adapted to a more intimate interview-setting; the respondents are handed over the selected articles one by one and are asked to express their initial thoughts about the article; whether they would read it and why (not), how the article makes them feel at first sight, whether there is something about the article that catches their attention, whether there is something bothering them etc.

The questions about the articles the respondents are asked to read remain the same than those of the focus groups, but follow-up questions and probes are often more directed towards the way they relate the article under discussion to their own experiences. The exercise of associating words and concepts with articles also is maintained in the face-to-face interviews, but again adapted to a more intimate approach; not spreading the cards on the table, but raising them to be reflected on one by one. Like with the focus groups, the closing question asks the respondents for any last remarks on the articles read and discussed; on anything that bothers them, that catches their attention, things they feel are overemphasised or underexposed and so on. At the very end of the interview, the respondents are asked whether there is something that did not come up during the interview they would like to elaborate on. Any lasts comments made or stories told here rarely generate data related to the research questions, but again provides the respondents with the opportunity to express any feelings that might have come to the surface during the interview.

Chapter XV: Audiences' receptions of media coverage of the medical end of life: A DTA

The previous chapter discussed the different aspect and facets of collecting and producing data by means of qualitative interviewing, and simultaneously sketched the complexity of the qualitative interview as a site of meaning-making. It is within the context of the qualitative setting as a site of meaning-making, mediated by all sorts of discursive dimensions, that respondents interpret the media representations discussed in part D and in so doing identify with particular discourses (identified in parts B and D). This chapter presents the discourse-theoretical analysis of these practices of interpretation and identification.

Respondents often draw on a variety of discourses when reading and discussing media items, which makes that interpretation and identification are highly complex practices. To structure the highly complex nature of practices of interpretation and identification, the reporting of the analysis of audiences' receptions of media constructions of the good death, captured in sections one to four, is in first instance structured on the basis of the main categories of interpretation and identification the discourse-theoretical reception analysis revealed. Four main categories of interpretation and identification have been identified: patient autonomy and the right to die (section 1), autonomy and the social network (section 2), independence (section 3), and hedonism (section 4). These categories are closely connected to the key dimensions that structured the representation analysis, but do not completely overlap with them. The key dimensions that structure the representation analysis are indeed not necessarily those dimensions that trigger the respondents the most.

In discussing the main practices of interpretation and identification, I first centralise the question as to whether respondents recognise the connection between the media text and the discourse(s). The underlying question here is whether the respondents recognise a similar message in the media items under discussion; in other words, do they agree on the fact that a certain discourse becomes operationalised in the media text[89]. The analysis reveals that there is a high degree of recognition; the respondents share an understanding of the dominant discourses operationalised in the media items under discussion. They recognise the dominance of a ratio-personal discourse of autonomy, of an articulation of dignity in terms of independence of care, of an ideal of heroism and so forth.

I then go on to focus on the way the respondents evaluate that what they take to be the main message. Two questions are central here: do the respondents accept, negotiate or contest the message, and on which discourses do they rely (and how) in doing so? Here, the analysis reveals a rich variety of logics of identification, going from a high degree of acceptation of discourses operationalised in the media items to a radical contestation of these discourses. In general, we observe a high degree of resistance – especially from relatives and medical professionals - against the construction of the good death in the prominent-case coverage, where the good death is defined in terms of autonomy, independence of care, and hedonism.

A secondary intern structure of sections one to four takes the different audience categories into consideration, as claims are produced on the level of differences in practices of interpretation/identification between members of the general public, medical professionals and relatives.

A final section that reports the analysis (section 5) focuses on the different evaluatory frameworks on death in the media anchored in the respondents' talk and elaborates on four main logics of interpretation through which 'good journalism' is constructed: a logic drawing on arguments of sensationalism and voyeurism; a logic drawing on a biased-media discourse; a logic building on arguments of the media's de-tabooing and

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[89] It is a task of the researcher to identify this recognition in the talk of the respondents. It goes almost without saying that the respondents themselves do not use theoretical concepts of discourse and operationalisation.

mobilising potential and their potential of contributing to a 'revival of death' through personalised story-telling; and a logic that emphasises the 'unspeakability' of death and the 'impossibility' of covering a complex and emotionally-loaded issue like the end of life in mass media.

The reporting of the discourse-theoretical reception analysis, like that of the discourse-theoretical representation analysis, includes many citations - some of them more concise and some of them more extensive. Citations again serve to support the analysis and provide the reader with a more concrete idea about how media articles are interpreted and how respondents draw on, deploy and identify with discourses. The use of citations should also be seen in the light of furthering the validity of the research by pursuing transparency. Here, the concept of transparency can be linked to the notion of authenticity, referring to the extent to which the research reflects the *"experiences of the respondents as they lived them and perceived them"* (Fade, 2003: 144).

Each quote will be accompanied with information about the interview during which it was produced[90]. Considering the anonymity that was guaranteed to the respondents, no names are given with the quotes that support the analysis.

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[90] The focus groups with nurses are indicated with the following codes: FG1Nurses, FG2Nurses, FG3Nurses, FG4Nurses, FG5Nurses. The focus groups with general practitioners are indicated with the following codes : FG1GenPrac, FG2GenPrac. The focus groups with medical specialists are indicated with the following codes : FG1specialists+nurse, FG2specialists, FG3specialists. The focus groups with the general public are indicated with the following codes : FG1GP, FG2GP, FG3GP. The focus groups with the relatives are indicated with the following codes : I1R, I2R, I3R, I4R, I5R, I6R, I7R, I8R.

1. Patient autonomy and the right to die

This section discusses a first category of interpretation and identification; a category encompassing responses where the interviewees interpret the discursive construction of patient autonomy and the patient's right to die in the selected media items. The section looks into the way the respondents communicate their understanding of the media articles under discussion, and the way they endorse, negotiate and/or contest the media message through identifying with a variety of existing discourses.

The picture exercise, where the interviewees are asked to come up with a title they feel fits the pictures of Claus and Engelborghs with a glass of champagne in the hand, bears witness of the way the respondents share an understanding of what they suppose the main message of the article to be. Respondents from all audience categories recognise a similar focus on autonomy and self-determination in the article. When asked to reconstruct the main message, the respondents often draw on a liberal discourse of autonomy and self-determination and use its vocabulary to reconstruct the media message. As quite a number of the responses illustrate: *"Take death in your own hands, you own your death"* (FG2specialists), *"It is also possible to take the decision yourself"* (FG1nurses), *"They took the decision themselves, they are relieved"* (FG2nurses), *"The decision has been made"* (FG2GP). Also after having read articles about the death of Engelborghs in more detail, signifiers of a liberal autonomy discourse are deployed to reconstruct the main message. One of the respondents for instance argues that the article depicts euthanasia as 'beautiful' by drawing attention to the way *"he [Engelborghs] made his own decision, he was able to say goodbye from his relatives the way he wanted to"* (FG2GP). Also the article "Last wish of 93-year old" - about the euthanasia request of Amelie Van Esbeen - evokes reactions where the respondents draw on a liberal autonomy discourse, reconstructing the main message of the text by using typical signifiers that are part of this discourse. As a short conversation between two nurses (FG4N) illustrates:

N1: "That elderly are still…"
N2: "<u>allowed to decide</u>"
N1: "yes, allowed to decide"
N2: "<u>are capable of deciding</u>"

Responses like those discussed above illustrate how the respondents share the interpretation that the media text emphasises the individual's right to self-determination and his right to die. When reconstructing this message, the respondents draw on a liberal autonomy discourse by deploying signifiers that refer to self-determination. This means that the respondents both recognise and deploy the ratio-personal discourse of autonomy in reconstructing the media text, which confirms the dominance of a liberal ratio-personal concept. At the same time, this does not imply that the respondents also always subscribe to a liberal or ratio-personal autonomy ideal.

In evaluating the media message of autonomy, indeed, respondents (dis-)identify with a ratio-personal or liberal autonomy discourse in different ways. Three logics of identification can be distinguished; each of them relating to particular discursive grounds on the basis of which the dominant messages of patient autonomy are accepted, negotiated or rejected.

1.1. Accepting the message of patient autonomy at the intersection of ratio-personal autonomy and patient-centeredness

A first logic of identification is one where the ideal of autonomy as represented in the media articles under discussion is accepted and endorsed. This identificatory logic is found in responses of all audience categories, as respondents indeed often accept the basic message of autonomy that in anchored in the articles under discussion.

Members of the general public, first, often identify with and reproduce a ratio-personal discourse of autonomy. As for instance the following reactions, extracted from discussions about the articles describing the euthanasia of Claus, Engelborghs and Van Esbeen, illustrate: *"I think that people should have the right to decide that it's enough"* (FG1GP), *"I think that as a human being you should have the freedom to choose for euthanasia"* (FG2GP), *and "There are limits and everyone should be able to set these limits him-or herself"* (FG3GP). The signifiers adopted by the respondents to formulate their opinions consists of a rather politicalised vocabulary; one that shows resemblances with the 'typical' right to die vocabulary that is present in the coverage of prominent euthanasia-cases. In discussions triggered by the articles "Last wish of 93-year old" and "Mother wanted to live, even in pain", respondents also draw on a ratio-personal discourse of autonomy. The articles' focus on patient-doctor conflict seemingly invites respondents to identify with a patient-centred discourse. Concretely, respondents often explicitly identify with the ideal of *patient autonomy*, an ideal that indeed emerges at the intersection of a ratio-personal discourse of autonomy with a patient-centred discourse. As a conversation between two respondents for example (FG1GenPrac) goes:

> D1: "It is not up to the doctor to judge, if the family or the patient himself does not want it, than that should be respected"
> D2: "Yet, the doctor should not decide that"

Through a patient-centred discourse, the subject position of the patient is articulated as 'the empowered patient'. During the focus group with the 50-67 age group, one of the respondents occupies this subject positions and thereby similarly identifies with the ideal of patient autonomy as embedded in a patient-centred discourse: *"I like to retain control, especially over myself. And when I don't like an examination anymore, I want to be able to say to the doctor at a certain point: remove that probe, and take it to someone else"* (FG3GP).

In responses of relatives, second, the own – often very emotional - experiences with the end of life play a key role in the way the ideal of patient autonomy is accepted and defended. Mainly articles that deal with a conflict between the patient and the medical professional such as "Last wish of 93-year old" evoke reflection about patient autonomy. One respondent, for instance, brings her experiences with her mother struggling to obtain euthanasia into her encounter with an article about Amelie Van Esbeen. When reading the article, her immediate response goes:

> "<u>This is very recognizable to me</u>….I suppose this lady was in an institution where euthanasia is not really supported. As I said before, it is not enough to say 'I want euthanasia' (…) My mam obtained euthanasia ten days after she fell down for the last time. The head of the palliative department actually was more supportive of making her go through a waiting period of one month (…) That, to her, was very frustrating. Not to be heard. She said: it has been enough. He said:' it has not been enough'" (I7R).

At another time during the interview, the same respondent again brings in her own experiences to evaluate the focus on autonomy in the media items about Claus and Engelborghs, arguing that *"it seems very easy as it is depicted here"* and that "*Both articles emphasise that you shouldn't wait until the bitter end, that you can choose your own moment. But I have to make a comment here: when you have the support of your doctors"* (I7R). This reaction can be regarded as an implicit critique towards the low visibility of the potential of patient-doctor conflict in the coverage of Claus and Engelborghs, which - as we saw in part D – also provokes critiques of newspaper readers formulated in letters to the editor.

Relatives' interpretation/identification practices, like those of members of the general public, often find their origins at the intersection between a ratio-personal discourse of autonomy discourse and a patient-centred discourse on medicine and end of life care. It is indeed not the doctor, but *'especially the patient'* (IR5) who should be heard in end-of-life decision-making. Or as one of the interviewed relatives remarks after reading an article about Amelie Van Esbeen: "*The woman says: 'I've had a good life, it's been enough'. I really would fully support that"'* and, "*This is not a dignified death, because it is* *the doctor who decides and not the patient"* (IR6). The latter comment also suggests an identification with a particular articulation of dignity; one that defines dignity in terms of respect for the patient's autonomy.

Also in responses of nurses, a strong identification with the ideal of patient autonomy appears - where it is often formulated using a medical-ethical vocabulary. The dominant discourse drawn on, in nurses' reading practices, is one of patient-centeredness, emphasising the importance of *listening* to the patient and *respecting* his/her wishes. Whereas relatives often draw on their personal experiences with the end of life of a loved one in reading the articles, nurses frequently draw on an - to them very familiar – medical ethical framework that stresses the value of patient autonomy. Particularly the article "Mother wanted to live, even in pain" evokes responses where the ideal of patient autonomy is strongly defended and that build on a dis-identification with medical paternalism. For instance:

> N1: "What bothers me here is that patients cannot make their own choices. In both directions, the choice for euthanasia, but also the choice for further treatment, even when this treatment won't make a difference"
> N2: "yes, indeed, it all comes down to respecting the patient's choices"

The two nurses (FG1nurses) engaged in this conversation clearly identify with a same patient-centred discourse, deploying signifiers such as 'choice' and 'respect'. In response to the same article another nurse argues:

> "It is sad; the way patients are sometimes not listened to. This patient wanted to live, with or without pain. She just wanted to enjoy the simple things, she wanted that treatment, and it was decided not to give her that treatment. And I don't think they (the doctors) can decide that" (FG5nurses)

In these kinds of responses, nurses sometimes refer to an ideal of curing - embedded in a medical-rationalist discourse (see chapter V) - they feel is often hidden behind a (perceived) medical paternalism they themselves reject. The 'obsession with cure' thus becomes a constitutive outside for the ideal of patient autonomy the nurses subscribe to. As the following conversation between two nurses more explicitly illustrates:

> N1:"Many doctors say 'we want to cure people, not kill them"
> N2: "Yes, but that is because they were thought that school: the doctor cures and does not perform life-ending acts" (FG1nurses)

Listening to the patient and being non-judgemental mark a 'good and ethical nursing practice' based on the principle of patient autonomy, and constructions of 'the good nurse' thus are sometimes inscribed in the respondents' talk. During the opening discussion, one nurse for instance argues that *"whether you are pro or contra euthanasia, I think that as a nurse you ought to take a step back and put your personal opinion aside"* (FG2nurses). Or similarly, in response to an article about the euthanasia of Claus/Engelborghs:

> "When you read this, you can understand […] but you can't judge. If you do, you say 'this is the right thing to do'. In our job, you ought to be open towards different contexts, different points of view, and you should not judge" (FG2nurses).

Identifications with the ideal of patient autonomy can also be found in responses of doctors. In accepting the message of patient autonomy, doctors sometimes identify with the subject position of the physician who is 'at the service' of the patient. Take for instance the following quotes: *"The way in which people die is not for us to determine. That is up to the patient; he has to say what has to happen, what he expects from us"* (FG1GenPrac), and *"I don't think you can be for or against euthanasia, you ought to respect the will of the patient"* (FG3specialists).

In other cases, doctors explicitly contest an ethics of paternalism, which they sometimes associate with an 'older generation' of doctors. In discussion the article "Mother wanted to live, even in pain", one of the respondents for instance argues:

> "Autonomously deciding like 'I know better'. That is wrong. […] Typical for the older doctors who rule like a God over the lives of patients, like 'I know what is best'" (FG1GenPrac*)*.

It has been shown that respondents in all audience categories often accept the basic message of autonomy that is anchored in the articles under discussion. However, accepting the basic principle of autonomy by drawing on a ratio-personal or liberal autonomy discourse and a patient-centred discourse does not imply that *the way* autonomy is articulated and represented in the media articles is accepted (or applauded) as well. Indeed, when further looking into the respondents' reading practices, two more subtle logics of identification come to the surface – logics where the respondents, with a greater or lesser degree of reflexivity, negotiate a series of articulatory logics underlying the construction of the good death in the articles under discussion. A first articulation that is negotiated is the construction of euthanasia as the ultimate act of self-determination versus the construction of palliative care as a passive way to die, and a second articulation is the construction of euthanasia as the brave death.

There are some examples where the construction of euthanasia as an active and determined choice versus palliative care as a passive dying process is accepted. A nurse arguing that *"I feel this is more of a choice than this"* (FG2nurses) and a relative saying that *"they [Claus, Engelborghs and Van Esbeen] take fate into their own hands, and she accepts her destiny, she undergoes her dying process"* (I7R) when asked to compare an article about the euthanasia of Claus and Engelborghs with the article "I thank God that mama could die here" are illustrative of the reproduction of this articulatory logic.

Often, however, the construction of euthanasia as the ultimate expression of self-determination is rejected as the respondents endorse a broad definition of determination - one that not only includes the choice for euthanasia, but also the choice for other end-of-life decisions. Respondents in all audience categories indeed very often, either implicitly or explicitly, approach end-of-life decisions other than euthanasia as equally active and autonomous decisions. Members of the general public, first, frequently emphasise that the choice for euthanasia and the decision to die with palliative care are of equal value. As one respondent for instance argues in comparing the articles "Euthanasia should not be horrible" and "Mother wanted to live, also in pain": *"It is <u>a different kind of determination</u>, those men were determined to die, and this lady was determined to live"* (FG2GP). Another example is found in the 50-67-age focus group (FG3GP). After reading "Mother wanted to live, also in pain", the conversation goes:

> R1: "That is <u>the choice of the patient</u> as well, right".
> R2: "Well yes, absolutely. That's <u>a personal choice"</u>
> R1: "Whether I want euthanasia, or I want to live two more days".

Also medical professionals identify with a broad definition of autonomy, thereby again drawing on a patient-centred medical ethics. Take for instance this reaction from a nurse in response to the articles "Mother wanted to live, even in pain" and "Last wish of 93-year old woman": *"It goes in both directions<u>, the choice for euthanasia, but also the choice for further treatment</u>, even when this treatment won't make a difference".*

Choice, for the interviewed medical professionals, does not necessary include the choice to die, but also a choice to be cared for. When asked to compare the articles "Euthanasia should not be horrible" and "We thank God that mam could die here", a nurse for instance argues that *'it's a different context, it's a different choice'* (FG3nurses), hence associating ‘choice’ not only with euthanasia, but also with other end-of-life decisions. A conversation between two general practitioners (FG1GenPrac) illustrates a similar logic of identification:

> D1: “That is equivalent to me. It’s the wish of the patient, it deserves the same respect”
> D2: “Everyone makes his choice, whether it be it for euthanasia or for palliative care”

Resisting the construction of euthanasia as the ultimate expression of self-determination sometimes conflicts with other logics of identification. A short conversation extract from a focus group with nurses illustrates how respondents perform different practices of identification. In the extract below, we see how one nurse understands autonomy as making the decision to die (i.e. euthanasia), thereby latently reproducing an active/passive dichotomy, while another nurse identifies with a broader definition of autonomy, encompassing a variety of end of life choices:

> N1: “She underwent her dying process, I mean, if it lasted another week, she would have undergone it, the others made a determined decision”.
> N2: “But she made the determined decision to go to a palliative centre, she also could have stayed at home” (FG5nurses)

Relatives, thirdly, most explicitly and fiercely reject the construction of euthanasia as the ultimate expression of self-determination. Responses of relatives often assume that autonomy goes beyond the choice for euthanasia, and also includes other decisions. In bringing her own experiences with the end of life of her husband into the encounter with the media text, one relative constructs dying with palliative care as an active and determined choice – which here shows through the use of an agency-assuming language:

> “In any case, I think that the relatives, and above all, the patient, should have a voice. Raf [her deceased husband] said: ‘I do not want that, I want to live until the very last minute’. That was actually a nice way […] it was his will” (I5R).

Identifying with a comprehensive definition of what it means to be autonomous sometimes comes with a critical-reflexive reading of the way media articulate euthanasia as (the only) act of autonomy self-determination. As one relative for instance deconstructs the equation of autonomy to euthanasia in the article under discussion: *“The media give the impression that only those who choose for euthanasia make a choice and the other don’t […] I think everyone makes a choice, but it is not depicted like that”* (I5R). A similar deconstruction can be found in the response of a woman ending the interview with the remark that she would like to read in the media coverage more *“stories of people who make a choice. And that does not have to be a choice for euthanasia, but any choice”* (I8R).

A second articulation that is negotiated relates to the representation of euthanasia as a brave death. Nurses and the general public are the only groups where (implicit) acceptations of this construction are found. During a discussion that follows the picture exercise, one nurse formulates a remark that implicitly reproduces the association between euthanasia and a brave death: “*There are lots of people who say ‘I want it’, but those who actually go through with it, those are the people with perseverance”* (FG2nurses). Members of the general public sometimes reproduce the construction of euthanasia as the brave death in similar vein, remarking that *“it is brave to take that decision yourself”* (FG2GP) or that *“It is a decision that requires courage”* (FG1GP). Another interviewed member of the general public also reproduces the ‘euthanasia-brave death’ association, but goes on to adjust his reaction from a reflexive reading-position. When comparing the articles “In Friendship and Laughing” and “We thank God mama could die here”, the respondent argues: *“I actually think it is brave and courageous […] But I don’t want to say anything about the braveness of this lady, it just does not come out in this article”*(FG2GP).

Reproductions of this ‘euthanasia-braveness’ articulation sometimes conflict with other logics of identification. The conversation extract below, for instance, demonstrates how a nurse reproduces the association between euthanasia and dying bravely while her conversation partner suggests a broader definition of what ‘dying bravely’ means or can mean:

> “N1: ‘I admire that, people who choose their own moment’
> N2: ‘Yes, that is one point of view, I respect that, but I also admire people who fight until the very last moments’” (FG1nurses).

In many cases, indeed, the discursive construction of euthanasia as dying bravely is contested. As a response of one the interviewed relatives illustrates: “*If you say: I do want the pain and will suffer until the very end because I want to be with you for as long as possible. That is one's own right and that too is a sign of strength*”(I5R).
The identity ‘the hero’ that is inscribed in these comments is that of a hero that endures pain and suffering in order to stay with his/her beloveds for as long as possible.

Doctors very often strongly oppose the discursive construction of euthanasia as a brave death, especially in responses to articles that deal with the euthanasia of Claus and Engelborghs. As one doctor says: “*A lot of people die in different ways, and they are brave too*” (FG1specialists+nurses). Another doctor, participating in the same focus group, draws from his professional experiences to suggest another definition of ‘braveness’ as the one inscribed in the articles about Claus and Engelborghs:

> “I saw a woman last Friday, a young woman your age [referring to the researcher] who asked me: ‘can you help me to spend the holidays at home, with my family. That is courageous too, right… making every effort to spend the holidays together”

Closely related to the construction of euthanasia as a brave death is the assumption made in some media-items that 'prominent' people choose for euthanasia more easily than ordinary people, which is sometimes contested by doctors. As one of the interviewed doctors resists the construction of euthanasia as a choice preserved for 'extra-ordinary' people: *"I had a patient in the hospital this morning, who had been a worker her whole life, and she said 'I want an injection'. It wasn't the whole intellectual story"* (FG1GenPrac.).

1.2. Contesting patient autonomy: the autonomy of the medical professional and the medical ideals of caring and curing

A second logic of identification, which is absent in the responses of the general public, is one where the ratio-personal ideal of patient autonomy inscribed in the articles is contested and rejected. This contestation comes about through a variety of identificatory practices – where remnants of the medical-rationalist discourse (focussing on curing) and the medical paternalistic discourse (centralising the autonomy of the physician) as well the discourse of care play a crucial role. Contestations of a ratio-personal autonomy concept are most prominently present in responses of doctors, where rejections of patient autonomy often come with arguments against euthanasia. Arguments formulated in this context show significant similarities to those found in the medical newspapers De Artenkrant and De Huisarts, which points in the direction of a set of arguments on the end of life, grounded in a number of discourses, that are specific to the medical field.

Concretely, two main discursive grounds can be identified on the basis of which the right to die is contested. First, there is the contestation of what can be understood as 'the euthanasia market', which threatens the autonomy of the doctor. Take for instance the following quotes, illustrating the way medical professionals dis-identify with a discourse where the good doctor is constructed in terms of serving the patient:

> "These articles create the idea that euthanasia is a right, like 'we have the right to choose for euthanasia and you have to make it happen'" (FG2specialists)

> and

> "They have made euthanasia into something that is enforceable" (FG2specialists)

The quotes above at the same time bear witness of how the interviewed doctors quite often blame the media for forcing the doctor into a subject position of 'service provider' – a subject position the interviewed doctors tend to dis-identify with. As one of the respondent states after reading the article about Amelie Van Ebseen: *"The one who did it [performed the euthanasia], is the good guy. That's the point"* (FG1specialists+nurses).

A second discursive ground on the basis of which the right to die is rejected, is the medical ideal of 'curing', grounded in a medical-rationalist definition of medicine (see chapter V). Explicit identifications with this ideal only appear rarely, though. For example: *'I was not educated to end people's lives'* (FG1specialists). Some of the interviewed doctors draw on an ethics of curing in more implicit terms, for instance when the argument is raised that patients are free to make the decision to die, but that the doctor cannot be saddled with the task of 'killing' people. After reading the article "Euthanasia should not be horrible", one doctors says:

> "You can commit suicide, but you cannot saddle the physician with it [….]. People should have the courage to end their own lives and not to pass that responsibility on the doctor" (FG2GenPrac).

Unlike doctors, nurses only rarely contest the ideal of patient autonomy. The following quote contains an example of such rare contestations, where the interviewed nurse endorses a medical ‘market’ model, albeit one where the doctor has the final decision right: *“If a doctor says: this is the end, than it is the end. Of that I’m sure […] It is like you can’t claim euthanasia. I think that if you really want further treatment, you should go to another hospital”* (FG2nurses). Another way in which the ideal of patient autonomy is sometimes contested in the nurses’ narratives, is through the privileging of an alternative type of ethics - one where euthanasia is not seen as an appropriate answer to increasing dependence, deterioration and suffering. The following extract from a conversation between two nurses about a media item (not included in this study) telling the story about the euthanasia of an elderly woman reveals two different (and conflicting) practices of identification. Whereas one nurse implicitly seems to contest the construction of the loss on independence as a threat to a dignified existence and rather subscribes to an ideal of care, another nurse identifies with the ideal of patient autonomy:

> R1: “The lady was alive, but she could no longer do much…Well it was time for euthanasia now. That goes a bit far…”
> R2: “But that woman asked for euthanasia herself!’ [devastated].”
> (FG2nurses)

As mentioned earlier, relatives of deceased patients defend the decision-right of the patient at the end of life. One exception was found in the judgement of a respondent after reading an article about Amelie Van Esbeen’s right to die: *‘I guess the doctor will have had good reasons not to approve the euthanasia request of Amelie, reasons that she perhaps did not want to hear or did not understand’* (I4R).

1.3. Negotiating patient autonomy: the condition of unbearable suffering

While absolute contestations of patient autonomy are rare in responses of nurses and relatives, the right to self-determination is often not regarded as absolute and unlimited. Rather, patient autonomy needs to be considered *legitimate.* In reading and discussing the articles, it indeed seems that the respondents not only draw on a ratio-personal autonomy concept, but equally on a discourse that constructs dying as something that is best postponed as long as possible, i.e. as long as suffering remains 'bearable'.

A third logic of identification that can be identified, then, is one where the respondents do not contest the principle of patient autonomy, nor totally embrace it, but rather, where they either implicitly or explicitly introduce 'unbearable suffering' as a condition for the right to die. It was explained earlier in this dissertation that unbearable suffering is inscribed in the Belgian euthanasia law (as well as in the euthanasia laws of other countries) as a condition to be eligible for euthanasia, and that this the formulation of this condition also means that the right to die is not an absolute right – showing that discourses (of autonomy) are always subjected to practical and material limitation. Whereas the notion of unbearable suffering as a condition that makes euthanasia legitimate did not prominently feature in the analysed media representations, and certainly not in the coverage of personal cases, this notion plays a more significant role in the talk of the respondents.

The interviewed relatives and nurses are often very critical towards the article "Euthanasia should not be horrible", arguing that it depicts dying as *"a party"* (I3R, I4R, I5R, FG4nurses, FG5nurses), which originates in a dis-identification with a discourse of hedonism. The article "To go in friendship and laughing", where Engelborghs' illness and deterioration are described, generally triggers more positive evaluations when it comes to the legitimacy of his choice for euthanasia. The focus on suffering and deterioration indeed makes the choice for euthanasia 'more comprehensible' for many respondents. As a conversation between two nurses for instance goes after reading the article 'To go in friendship and laughing':

> N1: "That to me is a more realistic image"
>
> N2: "Yes, you can support it more here, that decision…because he really describes the physical deterioration process here" (FG4nurses).

A general practitioner's reaction to the same article illustrates a similar logic of interpretation: *"The deterioration process….while the other article gives the impression that he was in the prime of his life, but he did have serious pains. That, makes it comprehensible, that gives a very human impression"* (FG1GenPrac). During one of the focus groups with specialists, the same article triggers a reaction from an oncologist where 'unbearable suffering' is implicitly constructed as a condition that makes the choice for euthanasia more legitimate: *"As a caretaker performing euthanasia, I find it more difficult to perform euthanasia on such patients [Engelborghs] who are still in good shape than on ill patients who are bedridden, to me that's a difference"* (FG3specialists).

Also relatives sometimes bring in implicit references to unbearable suffering when reading the article about Engelborghs dying process. For instance: *"Ah, but what he says here is something completely different (…) Terrible pain in the back… that is a totally different story, isn't it? That makes his request for euthanasia much more legitimate"* (I3R). Suffering, besides, should not necessarily be physical. Also mental suffering makes a euthanasia request legitimate: *"That woman [Van Esbeen] was probably a widow […] My mom was a widow too (…) She's in good condition at the moment, the quality of life is good. But if something were to happen that makes the quality of life minimal […] So I can life with this"* (I4R).

2. Autonomy and the social network

The set of responses discussed in the previous section mainly encompasses talk about the right to die. A second set of responses, discussed in this section, is also structured around the notion of autonomy, but here interpretations are focussed on the representation of the dying individual in relation to his/her social network. In the reporting of representation analysis, reflections about the representation of the social network were integrated in the overall discussion. The reception analysis has shown how respondents intensively pick up on the representation of the dying person vis à vis the social network, which appears as an important point of dis-identification. This is why it was decided to deal with the way the respondents adopt autonomy of the dying patient vis à vis the his/her social network as an interpretation category in a separate section.

Respondents in all audience categories share an understanding of the representations of Claus and Engelborghs in the articles under discussion, as they describe them as somehow 'socially isolated'. Take for instance the conversation between two doctors during the discussion about the pictures of Claus and Engelborghs:

> D1: "They stand there as <u>singletons</u>"
> D2: "Yes, that's what I mean; there is <u>no connectivity there, no connection</u>"
> (FG1specialists)

It is above all during discussions about the articles dealing with the euthanasia of Claus and Engelborghs that a shared interpretation of what can be labelled as 'the socially isolated dying patient' is revealed. It is the article "To go in friendship and laughing" more particularly that triggers reactions such as *"He is <u>a solo-man</u>, right"* (FG2GenPrac) *"I wonder whether that man was surrounded by a family […] he seems <u>someone who stands alone</u>"* (I7R), *'His environment will have had to <u>agree with what he</u>*

decided" (FG3GP). Reactions like these illustrate that respondents recognise the dominant media messages constructing the dying person as highly individualised and not very much embedded within a social network; someone who makes his decisions in absolute autonomy. As a conversation between two general practitioners (FG2GenPrac) also illustrates:

> D1: "That man has no family, he has nobody"
> D2: "Yes, indeed. 'Only my sofa, my bed and my three televisions'"

The respondents not only reconstruct the discursive construction of individuality and independence present in the prominent-case coverage, they also interpret the non-prominent case coverage about palliative care in similar ways – deploying signifiers like 'care', 'connectivity', and 'beautiful' to describe the process of dying with palliative care.

Many of the articles dealing with the euthanasia of Claus and Engelborghs evoke reactions about the autonomy of the dying individual vis à vis his social network. Above all relatives, but also the other audience categories[91] - to certain extents – tend to contest the (perceived) construction of the socially isolated death as present in many of the prominent-case articles. In positively evaluating the article "We thank God mam could die here", about an 'ordinary' woman's dying process in a palliative care unit, respondents often identify with emotionalist models where care features as a nodal point, including a hospice discourse and a communitarian discourse on

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[91] Responses of the general public are the least embedded within the 'autonomy and the social network' category. While Claus and Engelborghs are identified as people who make their decisions in absolute autonomy, the way in which they die is rarely criticised from within this category of identification. Rather, members of the general public draw from closely related discourses of independence – with care and dignity as central signifiers – to evaluate the coverage under discussion.

autonomy - thereby often implicitly constructing dying with palliative care as a 'good' and 'warm' death. One main logic of interpretation can be identified, then, one that boils down to the contestation of 'individuality' and the endorsement of 'connectivity'. The discussion below focuses on the two poles of this logic of identification; the contestation of the socially isolated death and the celebration of dying in loving surroundings.

2.1. Contesting the socially isolated death

The relatives' own experiences with the death of a loved one play a significant role in interpreting the articles. Often, the individuality of the dying patient as represented in many prominent-case articles seems to fail in offering the material in which the respondents recognise their own experiences, and hence, the material to identify with. As one relative for instance says in response to an article about the euthanasia of Marcel Engelborghs: *"When I went shopping, I could return from the door like three times to give him [her deceased husband] a hug before I left. Oh my [appalled], I don't think he [Engelborghs] had that"* (I3R).

From a media-critical logic, also the visibility of those dying in absolute autonomy at the expense of those who die in closer connectivity to the social network is sometimes criticised. As a relative for instance argues: *"Those two, or three, or couple of dozen who died like that, that is extensively covered. But <u>those others are not given a voice</u> […] If you say: I do want the pain and will suffer until the very end because I want to be with you for as long as possible. That is one's own right and that too is a sign of strength"* (I4R).

From a similar logic of identification, choosing for euthanasia before the illness and the deterioration process take over is sometimes constructed as a form of 'bad death', where the dying patient looses more than he/she wins with the choice for euthanasia. In this way, 'quality of life' implicitly becomes constructed in terms of connectivity with relatives, which corresponds to a the focus on avoiding social death in a hospice discourse. As one of the interviewed relatives for instance argues: "*They left things behind; they could have enjoyed life for still a long time, despite their pain. <u>Their children, friends, girlfriend or whatever, they suddenly left them behind</u>*" (I2R). Also respondents whose relative chose for euthanasia criticise the absoluteness of the autonomy of the dying patient vis à vis his/her social environment as represented in a number of articles under discussion. As two interviewed relatives argue: "*She was the least emotional during the last days, but she did realise that the relatives found it very important to let the tears flow*" (I7R) and *"I find it a pity that he says 'no cuddling, no tears', I feel that's a part of it"* (I8R).

Reactions like these that criticise the (perceived) rationalist and de-emotionalised nature of the farewell of Engelborghs also illustrate how respondents identify with an emotionalist variant of revivalism, where 'the goodbye' is experienced in terms of emotionalism and expressivism.

Criticising the construction of the socially isolated patient sometimes comes with a positive evaluation of the article "I cannot reconcile with death. I am no hero", an interview with Tuur Van Wallendael about his choice for euthanasia and his fear of leaving his loved ones behind[92]. Van Wallendael's story is one the interviewed relatives identify with and relate to. In comparing the interview with Van Wallendael with the article "In Friendship and Laughing", one of the interviewed relatives argues that *"He can admit 'I'm only human, I'm no hero', this is more superficial: difficulties, let's get rid of them, over and out"* (I3R).

The responses discussed above demonstrate that the interviewed relatives quite explicitly resist what they experience as the construction of euthanasia as a socially isolated death, which is above all present in the coverage of Claus and Engelborghs.

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[92] Although this article was initially only included in the opening discussion, respondents sometimes re-introduce later.

Instead, the respondents identify with communitarian and emotional models of autonomy by referring to the dying process of their relative - whether or not involving euthanasia – as a very emotional event. Also medical professionals dis-identify with the socially isolated death. Above all specialists - oncologists and geriatricians - contest the construction of the individualised dying process as represented in the article "In Friendship and Laughing". As the following reactions given during the focus group with (palliative) oncologists (FG1specialists+nurses) illustrate:

> "It is pure autonomy, it annoys me…these first three sentences: 'I'm not into sad emotions and now that I'm sick I certainly don't want people to hug me. I don't want people to show me their feelings'. Eum, I would not want to live with a man like that"
>
> and
>
> "He is poor in terms of affection".

Reactions like these, where absolute autonomy vis à vis the social network is described in terms of being 'superficial' or 'poor', sometimes come with explicit media-critic reflections, criticising the way media applaud and celebrate individuality. As for instance voiced during that same focus group: *"A man who does not have a bound with his family, that is being preached up in like 'Wow, that's strong', and than this minister saying 'that's a strong man, like he handles that'"*. Medical professionals also refer to their own experiences with the end of life, suggesting that the socially isolated death of Engelborghs does not correspond with 'real-life' dying experiences: *"Whether it is someone who worked for the garbage truck or someone who has been professor, or a minister, they al have the same question […] 'I want to be together with my loved ones for a while, so that the family and the people with whom I lived can still be with me for just a while'"*(FG1specialists+nurses)

While the reactions discussed above indicate a dis-identification with a discourse of liberal autonomy and individuality, some reactions explicitly demonstrate how respondents identify with a discourse of communitarianism: *"Whether we want to or not, we all have links with our colleagues, family members, children, parents, and friends"*(FG1specialists+nurses).

2.2. Dying in loving surroundings

Whereas the articles about Claus and Engelborghs fail in providing the material for identification, articles dealing with a non-prominent end of life case often contain contents the respondents relate to. More concretely, respondents tend to relate to the article "We thank God that mam could die here", identifying with the way the dying process in a palliative care centre is described in the article. Members of the general public, first, often draw on and identify with a hospice discourse in talking about the article "We thank God…" – describing the dying process described in this article as *'a painless and dignified death'* (FG1GP) or as a dying process where *'care'* (FG1GP, FG3GP) prevails. But above all medical professionals, and specialist more concretely, often positively evaluate the article, for instance with the argument that *"That is a testimony of the other side, illustrating the idea that people do not have to decide everything alone. That it is also possible to die in relation with others […] There it is the person who decides alone, and here it becomes a process where others are involved"* (FG2specialists). Also relatives tend to read this article in a positive way. After reading the article, one respondent for instance says that palliative care is all about *"making things as comfortable as possible"*, aiming at *"helping people to die with dignity"* (I1R). Another respondent, whose wife died after euthanasia, remarks: *"If only my wife could have experienced that, such a palliative unit, but that was no longer possible"* (I4R). When further discussing the article, he goes on to label the dying process as described in the article as *"very comfortable, surrounded by family and volunteers"*, while the euthanasia described in the article "In Friendship and laughing" as being '*abrupt*'. Also relatives whose loved one died on a palliative care unit positively evaluate the article 'We thank God…'. Drawing on his own experiences, one respondent remarks: *"I experienced it in the same way. You are surrounded with love there, that is true"* (I2R).

The responses discussed here demonstrate that relatives, in identifying with a communitarian discourse and its focus on (the ethics of) care, subscribe to a less distinct distinction between the medical system and the social network, but rather speak in terms of a 'community of care' – including family and friends as well as medical staff. In similar vein, nurses too see medical staff and volunteers as (potentially) part of a broad community of care. As one nurse, for instance, draws from a discourse of care in arguing: *"I think that is just beautiful, it is wonderful how these volunteers care for these people" (*FG1nurses*)*. During another focus group, a nurse working on a palliative care describes the article "We thank God mama could die here" as follows: *"That article about that mom, when I read it […] She might as well stayed here with us"* (FG2nurses). However, not all medical professionals identify with a palliative care discourse as present in the article "We thank God". A geriatrician for instance is annoyed by the *"glorification of the actions of the nurses"* (FG2specialists). An oncologist says that the *"silly"* article gives her a *"headache"* (FG3specialists) and a palliative care nurse similarly criticises the *'mellifluent'* (FG1specialists+nurses) imaging of palliative care that undermines the 'serious' nature of palliative care:

> "As if we do nothing else than sandwiches and champagne…while it really about developing a system of care for the patient: what needs to be done, for the family, for the patient?" (FG1specialists+nurses).

3. Independence of care

A third set of responses, discussed in this section, relates to the reception of the construction of the good death in terms of independence of care and self-reliance. In part D, the construction of the good death in terms of independence of care and self-reliance was discussed as one of the articulations of dignity. The respondents, the analysis shows, are particularly triggered by this construction, which is frequently contested – not in the least by medical professionals, relatives and older members of the general public.

Again, members of all audience categories recognise the dominant ideal of independence of care and self-reliance in the media texts under discussion. This ideal is most prominently recognised the articles about Claus and Engelborghs. During discussions about Claus and Engelborghs being pictured with a glass of champagne in their hand, respondents often describe these two men as being *"in good shape"* *(*FG1nurses), conveying a message that you *"shouldn't be a terminal patient to choose for euthanasia"* (FG1nurses) or that Engelborghs and Claus died *"in full awareness"* (I1R) or *"with self-esteem and not totally helpless like a plant"* (FG2GP). Or as one general practitioner argues*: "I would expect to find the following message in the article: don't wait until complete deterioration"* (FG2GenPrac).

Especially members of the general public agree on the idea that a person being independent and in good shape, capable of self-reliance, is not the image that comes to mind thinking about euthanasia. As these reactions illustrate: *"It's not the euthanasia you have in mind, right. That is a person who is in good shape and who says 'it's been enough' […] I think most people think about someone who really suffers"* (FG2GP) and *"It does not correspond with what I thought […] I mean, I know someone who got euthanasia because he suffered from cancer and he was very much deteriorated by then. He was that emaciated he couldn't do anything. Really, that's my image of euthanasia"* (FG1GP).

Also when asked to summarise the main contents of the articles about Claus and Engelborghs, respondents often reconstruct the ideal of independence of care. As these responses for instance illustrate:

> "People want to be ahead of the deterioration process" (FG1nurses)
>
> or
>
> "Step out before you become dependent" (FG1specialists+nurses)

The word-association exercise triggers reactions in which the respondents reproduce the ideal of independence of care. When asked to associate the concepts of dependence and independence with the articles under discussion, the respondents consensually associate 'independence' with the articles about Claus and Engelborghs. As a conversation between two palliative care nurses (FG2nurses) for instance illustrates:

> N1: "Yes, he wanted to be ahead of the dependency, right"
> N2: "Yes, yes, yes, it indicates that he wanted to be independent"

The article "We thank God that mama could die here", in contrast, is often associated with dependence and care. As one nurse describes the lady whose dying process is described: *"This lady, yes, was perhaps a person who had less difficulties with deteriorating and becoming dependent"* (FG2nurses). Or as a member of the general public argues in similar vein after having read the same article*: "Yes, she is cared for. While in the other articles […] they do not want to let it come that far, they want to be well aware when they die"* (FG2GP).

The way the respondents interpret messages of independence is often connected to a dimension of extra-ordinariness. In a number of responses, the desire to maintain independence is – especially by medical professionals - linked to a certain status of extra-ordinariness, and more specifically to the domain of 'intellectualism'. The following reactions for instance illustrate how choosing for euthanasia motivated by the loss of independence is assumed to be preserved more for intellectuals rather than for ordinary people: *"Those two men have always been master of their decisions and had a high degree of control, so for these people every form of dependency is horrible, while there are of course people who can deal with this better"* (FG1nurses) and *"With his image…having to die when you don't know whether it's dinner time or sleeping time"* (FG3GP) and:

> N1: "For Claus, it was the mental deterioration…."
> N2: "That's an intellectual person, right"
> N1: "Indeed"(FG4nurses).

In a number of responses, irony is used to highlight the assumed desire of intellectuals to maintain their independence, for instance by arguing that choosing for euthanasia motivated by the loss of self-reliance is something *"trendy" or "respectable"* that happens above all in *"progressive leftist circles"* or *"certain circles"* (FG1specialists+nurses, FG1Genprac, FG3GP).

When further digging into the way the respondents accept/negotiate/contest the dominant media message of independence, three logics of identification can be distinguished: one where respondents contest the message of independence through identifying with a discourse of care, while at the same time often reproducing a palliative care-euthanasia dichotomy; one where respondents also identify with a discourse of care, but reconcile the concept of care with euthanasia; and one where the respondents accept the message of independence – not only by identifying with a discourse of independence as such, but also by drawing on personal and professional experiences with the end of life.

3.1. Rejecting the ideal of independence of care: dependency as a part of life and the alternative of care

By far the most dominant logic of identification is one where the respondents dis-identify with a discourse of independence through which dependence and deterioration tend to be constructed as part of a 'bad' and 'undignified' dying process. In the audience category of the general public, it is above all (but not exclusively) the age group 50-67 that contests the ideal of independence of care as it appears in a number of articles under discussion. More concretely, respondents from this group tend to criticise the articles about Claus and Engelborghs by arguing that dependence and deterioration are inevitable parts of life as you age. One of the respondents clearly contests the idealisation of independence and the perceived construction of dependency as a type of illness. As she reacts after reading the articles 'Euthanasia should not be horrible' and 'To go in friendship and laughing':

> "We will all end up like that, and these big 'shouters' [Claus and Engelborgsh] proclaiming 'I shall not and I will not', that makes me shiver. […] Being dependent on others is something people see as the biggest disease that will affect them, and I don't think you should look at it like that…there are different phases in life, and you have to learn to let go" (FG3GP).

During the discussion that follows, another respondent subscribes to a view where dependency is seen as a 'natural' part of ageing in a similar way, arguing that *"[…] I can't run anymore, other people my age can. I had to learn to live with that. […] It will only get worse, but that doesn't mean you have to choose for euthanasia […] enjoying the small things in life is very important, even if that means watching people run while sitting on a terrace".*

Responses like those given above emerge through an identification with a discourse of care, where the latter is constructed as evident rather than as a 'necessary evil'. As articulated by one of the respondents from the 20-25 age group: *"It should not be a 'brave' decision to say 'I am sick and I need to be cared for'. That should be obvious"*. Other respondents, then again, speak about losing independence in terms of 'accepting' the process of ageing and deterioration, which comes with an articulation of accepting care as not easy or self-evident: *"You need the mental defensibility, you need the realistic enough to accept that"* (FG3GP).

Medical professionals most fiercely contest the ideal of independence of care as is frequently appears in prominent-case coverage. More concretely, specialists very often criticise the perceived message of "Step out before you become dependent". What is above all contested is the assumption underlying many of the prominent-case articles that choosing for euthanasia before the deterioration process takes over, results in a dignified dying process, which - according to some of the interviewed doctors - comes with the assumption that other dying processes are not dignified. The quote below, for instance, illustrates a dis-identification with an articulation of dignity with independence:

> "What bothers me is the sentence "It remains dignified". So the other 95% of the people who die in another way are undignified. That is inferior. That's what they say, right?" (FG2specialists).

This quote contains devices of legitimisation and authority to solidify the argument, such as the use of percentages. Also in other reactions, doctors occupy an expert-position in dis-identifying with the discourse of independence and in criticising the media for privileging a construction of the good death in terms of independence. In the following reaction, a doctor opposes a mediated 'non-reality', as presented in the article "In friendship and laughing", to a medical 'reality':

> 'That [dying] is expressed in terms of terrible and horrible like 'I will paralyze and be incontinent' (…). The message is almost: 'you should be mad if you let that happen'. People get the impression that it will be horrible and terrific. […] 'Journalistically this is presented as 'dying must be horrible, make sure you are ahead of that'. That's the message. So again, the message is the opposite of reality' (FG1specialists+nurses).

Nurses too sometimes draw on their own experiences in contesting the ideal of independence of care and the construction of dependence as part of a 'bad' death. After having read the article "Euthanasia should not be horrible", for instance, one nurse contests the construction of loss of control over the mind as 'undignified': *"And who says his quality of life would be bad? […] Professionally, I know lots of dementing people who have a dignified existence that is meaningful. That is why I have difficulties with this article"* (FG1specialists+nurses). The quote is also an example of a contestation of the articulation of dignity with the 'authentic self', where the dignity of the dying person is believed to be affected with the demise of awareness.

Contestations of the message of independence often find their origins in an identification with a hospice discourse and its focus on (palliative) care. In medical professionals' interpretations of the articles, palliative care is often presented as an alternative to the ideal of independence. Responses where interviewees identify with a hospice discourse of care indeed often privilege a palliative care model, where palliative care is associated with 'affection', the 'essentials of life' and 'dying with dignity'. As a conversation between two palliative oncologists (FG1specialists+nurses) goes:

> D1: "Then the proponents of euthanasia start yelling: 'will you stop with that mellifluent stuff already?'"
>
> D2: "But being affective is not mellifluent […] saying goodbye is one of the essentials that are part of life"

The interviewed medical professionals often suggest care as an alternative to euthanasia, which in their view is not the right way to deal ageing and deteriorating. After reading the article about Amelie Van Ebseen's request for euthanasia, one of the interviewed nurses reacts: *"But I assume that there is a lack of care here, a dignified life before death. Well, that's the feeling I'm getting, as if something was missing in her ageing process"* (FG4nurses). In similar vein, another nurse constructs the palliative care system as a place where people can die with dignity, without having to choose for euthanasia. During the discussion about the article 'We thank God that mama could die here', she argues that it is "*good that there are people and institutions, that there are places where people can die with dignity without choosing for euthanasia"* (FG4nurses). These responses bear witness of an identification with a hospice articulation of dignity, where dying with dignity is above all a matter of good and loving care.

Also relatives strongly identify with a discourse of care. More concretely, they contest the media construction of euthanasia as 'more dignified' than palliative care. In so doing, they often reproduce the dichotomy between palliation and euthanasia. In comparing the dying process of Claus and Engelborghs to the dying process of the woman described in "We thank God mama could die here", one of the relatives argues that *"Palliative care it something totally different than euthanasia, of course. It is caring, caring, caring there"*. He goes on to argue that *"palliative care is care, euthanasia is life termination"* (I2R). Another respondent, in similar vein, differentiates euthanasia from palliative care while privileging the latter over the former. He comments: *"The goodbye is too abrupt […] It's different from this [palliative care], where people are accompanied for weeks and lovingly surrounded. It goes too fast I think"* (I4R).

3.2. Negotiating the ideal of independence of care: reconciling euthanasia and care

The discussion above illustrated how respondents identify with a discourse of care – contesting the assumption that euthanasia provides a better or more dignified way of dying than palliative care, while at the same time often reproducing a dichotomy of palliative care versus euthanasia. In some responses, however, we find a re-articulation of 'care', coming with a reconciliation of euthanasia and care, or, in other words, a deconstruction of the 'care versus euthanasia' dichotomy.

Reconciliations of care and euthanasia above all appear in responses of relatives whose loved one chose for euthanasia – responses where it is stressed that euthanasia is a form of care, rather than merely life termination. Take for instance the following response of one of the interviewed relatives: *"It is another type of care, but it is also care"*. Or: *"Whether you are cared for until the very last day or you look for someone to help you do it your way, it's both caring"* (I8R). Another relative criticises the way media associate only hospitalisation with care, which conflicts with her own experiences with the euthanasia of her father: *"This caring […] They give the impression as if only people in a rest home receive the best care. But I think that also people who choose for euthanasia get good care. That also entails a lot of care"* (I8R).

Also medical professionals sometimes re-articulate the concept of care, associating it with euthanasia and not only with palliative care. During the word-association exercise, where the respondents are asked to link the concept of care to the different articles under discussion, a conversation follows where three nurses negotiate the meaning of 'care':

> N1: "Care, for me that's the last article" ['We thank God mama could die here']
>
> N2: "Yes, that's palliative care"

> N3: "But, but you can associate care with both euthanasia and palliative care. Because <u>a well performed euthanasia is about care, caring until the last moments</u>. If it is done here in our unit, it is a certain ritual performed with great caution."
>
> N2: "It is <u>shorter</u>."
>
> N3: "It's <u>shorter, but it is part of a same frame of care"</u>
>
> N2: "Yes, but if you look at the article…he steps out before he becomes dependent and needs care, while the last article is only about care" (FG5nurses).

During a focus group with general practitioners, care is reconciled with euthanasia from a media-critical reflection, as one of the respondents criticises media for associating *"testosterone characteristics"* with euthanasia, and *"female characteristics"* with palliative care, while – as he goes on to argue – *"we see <u>euthanasia as part of palliative care</u>"* (FG2GenPrac).

At other times, euthanasia is brought within a frame of medical care in a more subtle way, for instance by arguing that total independence is not possible in an end of life care situation, as euthanasia implies medical intervention and hence, dependency on the medical professional. As one nurse for instance argues: *"Independence, because it's his own choice. And dependence, because you don't do it yourself, you need a doctor"* (FG2nurses).

3.3. Accepting the ideal of independence of care: dignity and autonomy

A third logic of identification is one where the respondents accept the construction of dying with dignity as dying before losing mental and/or physical independence, as well as the discursive dichotomy between palliation and euthanasia - where the former is associated with care and the latter with independence and dignity. Here, respondents identify with a discourse of independence as it emerges in the prominent-case coverage under discussion. Reproductions of the construction of a dignified death in terms of independence can for instance be found in responses of younger members of the general public. As one of the respondents describes her interpretation of someone who dies 'with dignity': *"Someone who can still be independent, before he dies"* (FG1GP). During the same focus group, also another respondent reproduces the construction of dying with dignity as dying before deterioration takes over. As the respondent compares the dying process described in "To go in friendship and laughing" with the dying process in "We thank God mama could die here"*: "I would associate this with a dignified death, because there […] that's also possibly a good death, but I think this is more dignified because indeed you are not deteriorated too much before you die".* In addition to deterioration and dependence as such as threats to a dignified dying process, also hospitalisation and institutionalisation are constructed as part of a bad dying process in a number of the respondents' responses. During the discussion that follows the picture exercise, two respondents engage in a discussion about what it means to die 'well' and 'with dignity' and how they feel hospitalisation affects a good death. Take the following examples:

> R1: "It's like, you can no longer decide yourself, you cannot be independent no more. Like 'we are going to do this now, we are going to have dinner now', it's only 5 pm, but at 6 we need to go to our rooms to go to sleep. No, I would never want to end up in a resting home".
> R2: "I once knew an elderly man answering one of the nurses: 'Do you always talk in diminutives? I could be your father' (laughing). And that man was right. I mean, it was Mister Janssens instead of Jean Paul" (FG2GP).

From within this logic of identification, the article about Amelie Van Esbeen's wish to die is evaluated positively, as the respondents interpret the text as containing an emancipatory dimension that counters stereotypes of ageism: *"It depicts her as a brave* *woman who knew what she wanted"* (FG2GP) and *"it demonstrates that ordinary people too can be brave and courageous"* (FG2GP).

The third logic of identification, where the ideal of independence of care is accepted, is also all found in responses of relatives whose loved one choose for euthanasia. For instance: *"she didn't want the illness to take over"* (I7R). An extract of an interview with a young woman, whose mother chose for euthanasia, is also illustrative for this logic of identification. After reading articles about the death of Claus and Engelborghs and an article about palliative care, she formulates a response that is grounded in a dis-identification with a discourse of care:

> "The story about euthanasia reflects what I understand by dying with dignity. It is also how we experienced it with mama. That is something I would not want to experience myself. Needing help with everything and in fact waiting for death for months. I see that as a punishment" (I7R).

Also nurses sometimes endorse and accept the construction of independence as present in articles about Claus, Engelborghs and Van Esbeen. They often do so by bringing their own experiences with the end of life into the encounter with the media contents under discussion, emphasising that the loss of self-reliance is *"very hard for some people"* (FG3nurses). As one of the interviewed nurses argues: *"Not being able to drive a car or a bike, not being able to go shopping, there exists no medication for those problems"* (FG3nurses). Or, within a similar logic of interpretation, as two nurses for instance talk about the way they deal with increasing dependency of patients on care of others:

> N1: "I mean, what people can do themselves; we won't take that from them, right. Maybe accidentally".
> N2: "Yes, accidentally, it happens"
> N1: "But we will do pay attention to that, that you don't…"

> N2: “Yes, of course, we pay attention” (FG2nurses).

Knowing from experience that people find it difficult to loose their independence and self-control, makes that nurses often sympathise with the euthanasia requests of Claus, Engelborghs and Van Esbeen: *“I think lots of patients fear the loss of control, that you just have to sit and wait… this article presents an alternative”* (FG1nurses). In accepting the construction of independence as part of a good and dignified dying process, nurses in the first place draw on a discourse of patient autonomy; the patient’s wish not to let the deterioration process take over or not to become dependent on care of others should be respected. The idea of choosing to die before deterioration takes over is accepted, then, because it is an example of determining *“your own boundaries”* (FG1nurses). Or as illustrated in this conversation between nurses during another focus group (FG2nurses):

> N1: ‘I also read about destitution here. When you say: ‘I’ve come to a point that I can no longer take care of myself, they have to wash me or something […]. That goes too far.
> N2: ‘Yes and for one person it will be like that, for the other it will not. For these men it was clear, they didn’t want to be helped.
> N3: I understand that.

At the same time, and this has been discussed earlier, nurses often see deterioration and suffering as conditions that make a euthanasia request understandable and comprehensible. We can already link to the category of hedonism here, where the construction of euthanasia as a party conflicts with nurses’ experiences with patients at their end of life. For example: *“If the quality of life is no longer sufficient, and that’s why you choose for euthanasia […] that is a real story. But if you, like in that first article, only see the partying and the euthanasia, that makes me feel uncomfortable’* (FG4nurses).

4. Hedonism

A fourth set of responses, discussed in this section, relates to the reception of the hedonic death. Especially articles about Claus and Engelborghs, where the ideal of a hedonic death is very much present, trigger responses that fit this fourth category of interpretation/identification. In the reportage of the representation analysis, a discussion about the construction of the hedonic death was integrated in the elaboration of the construction of dying with dignity – as it appeared in the analysed media products as related to the question of what it is that constitutes a valuable and dignified life. In the analysis of audiences' receptions, hedonism emerges as a very significant and important category of interpretation/identification. The construction of the hedonic death as is appears in the prominent-case coverage evokes rather emotional responses; it seemingly represents a mismatch between media constructions of the end of life and the respondents' own perceptions and experiences.

Once again, respondents of all audience categories reconstruct the media's discursive construction of the dying patient as hedonic, i.e. as enjoying life until the very last moments, in similar ways. The picture exercise often entails reactions where respondents appeal to signifiers of enjoyment. To give a few examples of titles the respondents came up with: "*Euthanasia can also be pleasant*" (FG3GP), "*Dying with a smile*" (I3R), "*Cheers to live, cheers to death*" (FG4nurses), "*Enjoy until the last day*" (FG1GP) Or as one doctor describes the main message the pictures carry in similar vein: "*Those people are enjoying imminent death. This man has got a glass in his hand, the other one in standing there with a smile on his face*" (FG2GP) And also the following conversation between two nurses illustrates how respondents draw from a discourse of hedonism in reconstructing the media text:

N1: “Those who are dying salute you”

N2: “Or maybe better with the pictures: ‘Those who are dying enjoy now’” (FG2nurses).

It is clear, then, that the respondents share an understanding of the articles under discussion, agreeing that articles about Claus and Engelborhgs depict euthanasia in positive terms; as *“something cosy”* (FG2GP), *“something with a pleasant atmosphere”* (FG1GP), or *“some kind of exuberance”* (I6R). When the respondents are asked to summarise the key message of the articles “To go in friendship and laughing” and “Euthanasia should not be horrible”, they equally draw on a discourse of hedonism. As members of the general public for instance describe Claus and Engelborghs after reading the articles: “*R1: They are hedonists' R2: Yes, they made the decision and enjoyed life until their last days”* (FG1GP). During another focus group with the general public (FG2GP), the dominant message is reconstructed in similar vein:

R1: “Being happy until the very last moments”

R2: “And enjoying, right”

Or later during that same focus group: “*It is depicted like ‘Let's have a party’*”. Similar reconstructions are found in reactions of other audience categories; as nurses for instance answer the question of what they feel the main message of the articles about Claus and Engelborghs is: “*Well, enjoying, yes!' The choice has been made and now: enjoy the last days”* (FG2nurses) and *“that it is a dignified and beautiful way to die, that it is almost a party”* (FG1nurses). In addition, the respondents often recognise the construction of the hedonic death as both a brave and an extra-ordinary death, preserved for people with high status. As these reactions illustrate: *“Beautiful, and brave too*” (FG3nurses), *“In friendship and laughing, that 's the best, that is extra-ordinary”* (I6R), and: “*These are people, I would dare to say, who own it to their status to die like this”* (FG3specialists)

The constructions of the hedonic dying patient and the hedonic death are very often contested. The dominant logic of identification is indeed one where the respondents criticise and resist the subject position of the hedonic dying patient – fearlessly awaiting the scheduled euthanasia while fully enjoying the last days/weeks. This logic of identification is often found in responses of relatives and medical professionals, where the encounter between the own experiences with the end of life and the media texts under discussion entails fierce contestations. An alternative logic of identification is one where hedonism is - at least to a certain degree - accepted.

4.1. Contesting the hedonic death: it's not a party

Contesting the construction of the hedonic death is by far the dominant logic of identification adopted by all audience groups, but is most prominently present in responses of relatives and medical professionals - who strongly dis-identify with a discourse of hedonism. In responses of the general public, a more general sense of uneasiness towards the hedonic death of Claus and Engelborghs often appears, with the interviewees describing their death as *"a show"* (FG3GP), *"a party"* (FG2GP); a way of dying you *"don't identify with"* (FG3GP) and *"you don't feel good about"* (FG3GP). Relatives go further in resisting the construction of the hedonic death, thereby drawing on their personal experiences with the end of life of their loved one to contest the hedonic death as constructed in a number of articles under discussion. First, the normalisation of accepting the imminent death without giving in to feelings of fear and anxiety is fiercely criticised. Especially the article "Dying in friendship and laughing" evokes comments such as *"Engelborghs says 'Not a minute did I think about death', I don't believe that"* and *"there are things in life you simply cannot accept"* (I2R). One respondent begins the interview by spontaneously arguing that *"it's* *different to what they write in the magazines"* (I5R). When asked what it is she means exactly, the respondent refers to the dying process of her husband and comments: *"because he did not want to die. Because he kept on denying",* thereby distinguishing between the rational-hedonic responses to death the media foreground and the responses to death experienced in 'real life'. These responses contain a implicit challenge of awareness and acceptance, the 'basics of revivalism'. Unlike the articles dealing with the euthanasia of Claus and Engelborghs, the article about Tuur Van Wallendael, "I am no hero" provides relatives with contents they can relate, as it presents an alternative to the hedonic and fearless dying patient. As one relative remarks: *"'I am no hero'. Nobody is a hero. We are all afraid"* (I5R).

When asked to describe the dying process of Engelbroghs and Claus as depicted in the articles under discussion, the respondents frequently use the notion of *'a party'.* In so doing, they often contest the perceived construction of the dying process as a joyful event. As one relative for instance argues:

> "It <u>ain't a party, it is suffering'</u>. He doesn't want it to be sad. I don't agree with that, <u>It's not a party. It's a goodbye</u>" (I2R).

It is particularly the article's focus on the 'goodbye party' of Engeborghs that evokes negative evaluations. The respondents frequently refer to the concept of superficiality to describe the dying process of Engelborghs and Claus as constructed in the articles under discussion. For instance:

> "But actually it is all rather superficial, isn't it? I mean, cracking bottles, eating, laughing. But it [dying] is much more than that right?' […] 'The article only deals with the pleasant things before death, before the euthanasia. But if that's the only thing in his life…." (I3R).

The discursive construction of hedonism and the 'joyful' death in the analysed media articles often seems to fail in providing the respondents with the material to identify with. Indeed, in bringing their own experiences with the end of life of their relative into the encounter with the media texts, many respondents dis-identify with the 'hedonic death' of Claus and Engelborghs. Take the following account of one of the interviewed relatives, which describes a moment where family and friends gathered around the death bed of her husband: *"Then I said 'Ok, …, is anyone thirsty?' There was not one person who was physically able to drink. For me, that [dying, euthanasia] can't be a party"* (I5R). Another interviewed relatives similarly argues after reading the article "Euthanasia should not be horrible": *''Dying laughing, I don't think so"* (I2R).

Another way in which the construction the 'joyful death' is resisted, is through the contestation of its articulation with 'dignity'. After reading the article "Euthanasia should not be horrible", one of the interviewed relatives' attention is automatically drawn to one particular sentence *"Not to lose anything of awareness, enjoyment and dignity"*. In her response, she criticises the way the notion of dignity is associated with enjoyment and awareness. As the following extract from the interview (I3R) illustrates:

> R: '"Not to lose anything of awareness, enjoyment and dignity"!'
>
> Facilitator: "Is that a sentence that…"
>
> R: [interrupting]"Yes, that strikes me"
>
> "In your life, as you are little until you grow old, there are always moments that enjoyment is not always high, moments your dignity is not always high"

The responses discussed above also suggest the implicit construction of what many of the interviewed relatives perceive as a 'normal' death; i.e. a death that is unwanted, a dying process that includes suffering, sadness and pain. Sometimes, the media coverage is blamed for idealising the perceived 'aberrant' dying processes of Claus and Engelborghs. For instance: "*They indicate that these people are* *brave and extra-ordinary….'In friendship and laughing' That is the best, that is something extra-ordinary"* (I6R).

In contesting the perceived media construction of dying - and more specifically of euthanasia - as a 'party', a series of the interviewed relatives' responses construct a dichotomy between euthanasia as a joyful death on the one hand, which is often fiercely criticised, and euthanasia as the only possibility to avoid unbearable suffering, which is evaluated as legitimate and 'normal'. For example: *"That you eventually give up because you're in too much pain, that I can understand. But 'to go in friendship and laughing', I won't say it is sensationalist, but for me that is distorted"* (I6R). The construction of this dichotomy often most explicitly appears in accounts of respondents whose relative choose for euthanasia after a long illness and deterioration process. One respondent for instance narrates: *"My wife was hoping to stay alive, and I also had that hope. Until we realised that this wouldn't be the case, when there was no hope left, only then we chose for euthanasia"* (I6R), and later in the interview goes on to argue that *"I want people to say goodbye in the best circumstances, but it is not a party",* thereby latently excluding feelings of happiness and joy from the dying process. In similar vein, another respondent argues:

> 'What <u>bothers me is the goodbye party</u>, I <u>cannot image he enjoyed that</u>. I can image if I read this, considering the deteriorating referred to, that he decided that he did not want to go much further and preferred active euthanasia. But <u>the partying is too much for me</u>' (I2R).

Also medical professionals often fiercely and explicitly contest what is perceived as the representation of euthanasia as a party. The dying processes of Engelborghs and Claus are ironically described as "*almost a party*" and *"happy"*. The following statement of a nurse illustrates the use of irony in describing the euthanasia of Claus and Engelborghs: *"Party-like, wedding-like….we're having a jubilee, we're having a euthanasia"* (FG5N). An oncologists similarly describes the goodbye party of

Engelborghs as 'artificial', emphasising that *"having to say goodbye from those you love"* does not call for a party (FG3specialists).

Some responses of medical professionals also come with the assumption that the 'party-like' euthanasia of Claus and Engelborghs contrasts with a 'discrete' and 'humble' death. The dichotomous construction between a 'party-like' and 'discrete' death is clearly illustrated in the way a general practitioner remarks: *"Something that should be discrete, they make in into a party"* (FG2GenPrac). A conversation between this same doctor and one of his colleagues points in the direction of a normative construction of what euthanasia *should* be like and of a construction of what a 'normal' death is (not). The hedonic death, here, is opposed to a 'serene' way of dying:

> D1: "There are many people who are, in a serene and serious way, ill and choose for euthanasia. That is perfectly possible. But there shouldn't be all that fuss about it".
>
> D2: "Let's be honest. That's not how it goes, that is absolutely rare [referring to the euthanasia of Engelborghs]. All those times that I performed euthanasia, things were very serene. And that's how it should be"

Medical professionals, and especially doctors, often draw on their own experiences in further criticising the construction of the hedonic death. By occupying a reading- and subject position of 'expert', one geriatrician for instance argues: *"I have performed the function of second doctor several times, and sorry, but none of my patients looked like that. Not one patient had a glass in his hand"* (FG2specialists). Another example is found in a conversation between nurses discussing the article "Euthanasia should not be horrible", which again illustrates the way the dying process of Claus and Engelborghs is perceived as somewhat 'aberrant':

> N1: “I don’t think we ever witnessed it here like that”
>
> N2: “Hugo Claus was not an average man”
>
> N3: “Artists and actors…”
>
> N2: “The death he chooses for is in a way representative of his way of living, he was a man who lived in a very Burgundian way. (…) But I indeed think that an average Fleming who lived in a very humble way, and soberly, eumm, will perhaps choose a totally different way of dying” (FG3nurses).

While the responses above *suggest* a dis-identification with a hedonic discourse, this dis-identification is sometimes expressed in an explicit and more reflexive way. More concretely, one geriatrician combines a media-critical reflection with a dis-identification with a discourse of enjoyment. She argues: *“In a certain way, you get the feeling that you cannot make your own choice anymore, like suffering is no longer allowed, no longer ‘modern’”* (FG2specialists). Later in the interview, she goes on to say that *“What I think is wrong is that they are depicted a heroes, and that in this way you are forced into a society […] where you only can enjoy and where, from the moment that goes away, you have to choose for euthanasia”.*

Sometimes, then, it is not so much the hedonic death as such that is contested, but the way in which the hedonic death is represented. In some responses of medical professionals, first, it is the construction of euthanasia as the only possible way to die hedonically - as often assumed in prominent-case coverage - that is contested. As one of the interviewed nurses remarks after reading the article “To go in friendship and laughing”: *“I know that palliative care units also have champagne in the fridge for people who wish to drink a last glass”* (FG3nurses), or as a doctor similarly argues that also palliative care *“involves drinking champagne”* (FG2specialists). Other responses of medical professionals, then again, criticise the *idealisation* of the hedonic death rather than the hedonic death as such. A discussion between two geriatricians offers an example of the way media logics, rather than the hedonic death of Claus and Engelborghs, are criticised:

> D1: "What bothers me, I agree with those people, but it implicitly contains the idea: this is the only good way to go"
> D2: "That is the heroic act"
> D1: 'And if you don't do it, you're a coward. This is why I would like some examples of people who died in other ways too' (FG2specialists).

In other responses of doctors, reactions such as *"Most people experience it in a more difficult way. It gives the impression of being pleasant and nice"* (FG2GenPrac) also imply a media-critical logic of interpretation. A media-critical logic of interpretation also sometimes appears in responses of members of the general public, who point to the interplay between the personal preferences of the dying patient (i.e. the wish to die hedonically) and the way media *"want to bring the story"* (FG3GP) or bring the story of a man *"who probably did not want to make a show" "perhaps in a wrong way"* (FG3GP). With these comments, the respondents implicitly refer to the publicness of media and the way they 'stage' the euthanasia event.

4.2. Accepting and re-negotiating the hedonic death

A final logic of interpretation/identification is one where respondents (largely) accept the hedonic death as constructed in the articles about Claus and Engelborghs. In some cases, respondents identify with an ideal of hedonism and in so doing reproduce the construction of the hedonic death as a brave death as it emerges in the articles about Claus and Engelborghs. As argued by members of the general public during the discussion about the articles "To go in Friendship and laughing": *"I think that's <u>brave</u> and I respect that"* (FG2GP), *"I find that <u>a sign of braveness</u>"* (FG2GP) and *"I would not be* *that strong. I might have a big mouth now, but if a doctor would tell be tomorrow that the end is near […] I would be crushed"* (FG3GP).

Often, however, accepting the construction of the hedonic death is anchored in another logic of identification – one where respondents subscribe to the idea that death is part of life and should not necessarily be a sad event. Here, responses find their origins in identifications not so much with an ideal hedonism, but with a discourse of revivalism, where dying is not necessarily a purely negative experience. A conversation about the article "In friendship and laughing" for instance shows how a nurse upholds a different opinion about Engelborghs' hedonic death than her colleague - identifying with the idea that dying is a part of life and should not necessarily be a sad event:

> N1: 'I find this too happy'
> N2: 'But why not? <u>Why should dying be sad</u>?' (FG5nurses).

A similar logic of identification appears in a focus group with oncologists. During the opening discussion, the article "Dying with dignity with a glass of champagne" catches the eye of one of the doctors. Triggered by the title of the article, she draws on a revivalist construction of 'the farewell' in narrating her own experiences with patients choosing for euthanasia:

> "Dying with dignity with a glass of champagne, I think that's a beautiful title, because it reminds me of a couple of euthanasia's we performed here. One of my first ones was in a room where the patient….[hesitates] I would not say a party, but there were many people, there was self-chosen music, there was alcohol and flowers and actually, <u>that was even beautiful, you cannot describe that in another way</u>" (FG3specialists).

This extract illustrates how the hedonic death as it is represented in many of the prominent-case articles becomes negotiated or re-constructed; dying with euthanasia is not a party, but it does (potentially) involve a 'beautiful' death.

Relatives too sometimes reproduce the idea that dying should not necessarily be a sad process, but can also be a 'beautiful' process - where laughing and enjoyment are part of a good death. After seeing the pictures of Claus and Engelborghs with a glass of champagne in their hands, one relative immediately shows a picture of her laughing mother, one that was taken only a couple of hours before the euthanasia was scheduled. When looking at the picture, the respondent reproduces the vocabulary deployed in the article, commenting: *"This is my mama [showing the picture]…And I must say that from the moment the euthanasia was approved, she again became that strong laughing woman…To her that [the euthanasia request being approved] was an enormous relief, which I think this picture illustrates"* (I7R). A second relative too identifies with the hedonic dying process of Claus and Engelborghs. Unlike many responses to the articles about the death of Claus and Engelborghs, she does not interpret their dying process as represented in the articles under discussion as superficial. Rather, she argues: "*we too laughed a lot and enjoyed a lot. There was a lot of humour, too. That was one of the best periods of my life, no matter how sad it was. Only the essential was left, that must have been the same in the case of these men. It gives me a warm feeling"* (I8R).

The above-given quotes can be seen in terms of a re-negotiation of the hedonic death; introducing an 'emotionalist-revivalist' variant that stresses the emotional value of the farewell that is both sad and beautiful at the same time.

A reaction from a member of the general public, finally, can also be situated within a similar logic of identification; while in first instance - after reading the article "To go in friendship and laughing" - dis-identifying with the hedonic death, the respondent later goes on to negotiate and adjust his interpretation by not focussing on the hedonic *death*, but on *dying* hedonically as part of a way *living:*

> "I first raised by eyebrows when he invited his friends over to party hard"
> (…)
> "But if he was the kind of person who gave a lot of parties, then it is not weird at all that he gave another party knowing he had not long to live" (FG3GP).

A second logic of identification from within which the dominant ideal of the hedonic death is accepted, builds on a ratio-personal autonomy concept. An extract from a conversation between two general practitioners shows how the interlocutors evaluate the article "To go in friendship and laughing" differently; while one doctor rejects the hedonic death, the other doctor accepts this same construct through identifying with an ideal of patient autonomy:

> D1: "Something that should be discrete, and they make it into a party"
> D2: "Yes, but that is the individual wish of the patient" (FG2GenPrac).

At a later time during the focus group, the second doctor (D2) goes on to argue that *"If people feel ok with this, then why shouldn't it by ok? You cannot say: 'You have to be sad, you cannot drink champagne, there can't be too much joy"*. Also members of the general public sometimes accept the message of the hedonic death with a similar autonomy argument; the death of Claus and Engelborghs is not beautiful because *it is* hedonic, but because Claus and Engelborghs *"said goodbye the way they wanted to"* (FG2GP).

5. Death in the media: constructing good journalism

The previous sections reported on the reception of media constructions of the good death. Talk about the media articles, as was explained earlier, does not only contain reflections about representations of the end of life. The articles under discussion also trigger reflections about what ‘good journalism’ should do when covering the end of life. Specific constructions of good journalism in relation to the representation of the end of life are inscribed in the respondents’ talk, and this is precisely what this section focuses on.

The discussion below zooms in on the different normative frameworks on death in the media anchored in the respondents’ talk and elaborates on four main logics of interpretation through which ‘good journalism’ is constructed. A first logic of interpretation draws on the discourse of the spectacle of death, where good journalism is constructed in terms of serenity and discretion. A second logic blames the media coverage of the end of life for being biased and constructs good journalism in terms of neutrality and objectivity. A third logic of interpretation echoes arguments of the de-tabooing and mobilising potential of (emotionalised) media coverage of the end of life and its potential of contributing to a ‘revival of death’ through personalised story-telling. A final logic emphasises the ‘unspeakability’ of death and the ‘impossibility’ of covering a complex and emotionally-loaded issue like the end of life in mass media.

5.1. Sensationalism and voyeurism: death as a private event

In a first logic of interpretation, respondents perceive the selected media coverage as sensational and voyeuristic. Looking into the respondents’ reactions allows us to distinguish a series of accusations towards the media coverage under discussion and to trace the way they are rooted in particular discourses. Responses using concepts such as ‘sensational’ and ‘voyeuristic’ to evaluate the coverage under discussion first of all often find their origins in a discourse where death and dying - and the euthanasia ‘event’ more specifically - are seen as private events that should not be covered in the media. Such a discourse, one might argue, challenges the revivalist ideal of an openly experienced death. Here, respondents identify with the belief that death is a private event that should be experienced in an intimate sphere, and that should not be all too visible in mass media. Particularly responses to the articles about Claus, Engelborghs and Van Esbeen contain identifications with the idea that death and dying are private events that should not necessarily be covered in the media. As a nurse for instance replies after reading the article "In friendship and laughing": *"For me, that is something very personal […] something you want to experience in an intimate sphere […] that is sensationalist to me"* (FG4nurses). Or another nurse, in response to the article "Wish of 93-year old": *"It think it has been covered too much in the media […] is an intimate happening […] And I don't think it should be taboo, but I don't think people should make their story public either"* (FG4nurses). Similar responses emerge during a focus group with oncologists, take the following example: *"What bothers me: should it appear in the media like this? That [euthanasia] is something very, very personal"* (FG3specialists). Another oncologist, participating in the same focus group, similarly argues that euthanasia is a *"dignified"* and *"beautiful"* moment that "*should not appear in the media"* (FG3specialists). This respondent is especially annoyed by the articles' focus on the details of the dying process, which would make them *"populist"* (FG3specialists).

Relatives sometimes react to the articles in similar ways, with responses such as "*I don't think that should all appear in the media. If I want to die, if I want to do something in private…those are thinks that are nobody else's business […] That's a private happening"* (I2R) and "*That is something you decide in an intimate sphere, for yourself and your family"* (I3R). Responses like these are not only linked to the conviction that death is a private event that should not be discussed too much in the media, they also build on specific discourses that normatively construct 'good' and 'bad' journalism. Bad journalism, for the respondents, equals a sensationalist way of covering. They understand bad journalism as journalism that follows commercial logics through which euthanasia becomes represented as *"a show"* (FG3GP) and *"a fair attraction" (*FG2specialists*)*. Instead of focussing on *"extreme situations"* (FG1GenPrac), *"controversy"* (FG2GenPrac) *and "strong emotion"* (FG2GenPrac), 'good journalism' should cover the end of life in a *"serene"* and "*discrete"* way (FG4nurses, FG1GenPrac). Personal anecdotes, according to the respondents, are irrelevant and *"unnecessary"* (FG1nurses). As for instance a member of the general public evaluates the article "terminally ill Georges continues to fight": *"That is a personal case, only applicable to this certain Georges, but is <u>adds up to nothing</u> […] it's sort of <u>a zero-event, a personal drama</u> for his and his family of course"* (FG2GP). Later during the same focus group, the 'anecdotal' is again criticised. As this extract from a conversation during the opening discussion illustrates:

> R1: "'98-year old is denied medication', 'Doctor refuses to treat terminally ill woman'…that's all about just one doctor, that's a bit…
> R2: "Yes, that is seeking conflict, right'

Similarly, a nurse says that she does not tend to read personal stories of patients in the media because *"they do <u>not contribute to the debate</u>"* and *"you <u>don't learn anything from them</u>"* (FG1nurses). Another nurse adopts a similar line of thinking, stating that she does not read personal cases as she already has *"enough examples like that on the unit"* (FG2nurses). Also doctors often identify with the normative argument that journalism should stay away from *"strong emotion"* (FG2specialists), mere *"cases"* (FG1specialists+nurses, FG2specialists, FG2GenPrac) and *"extreme situations"* that *"do not matter"* (FG2GenPrac). Opposed to this irrelevant and non-informative coverage is, in the eyes of the respondents, informative coverage of the end of life; coverage that not (only) contains personal stories, but also *"medical explanations"* (FG2nurses), *"background and legal aspects"* (FG1nurses), *"scientific foundations"* (FG1nurses), *"philosophical debates"* (FG2GenPrac), "*information about the different possibilities at the end of life*" (FG3GP) and so on. In some responses, the notion of information is more explicitly distinguished from what it is not. Talk about the article "Seven ways to die with dignity" (DS) evokes comparisons with the article "Terminally ill Georges continues to fight" (DagAllemaal), and contains identifications with a normative stance that defines good journalism in terms of information:

> "This seems to be an interesting article because it goes deeper, while the other article from Dag Allemaal only focuses on the emotions. This makes you think about the possibilities" (FG2GP)
>
> and
>
> "Yes, the sensational and the emotional, I think nobody is helped by that. While on the other hand, a good article that makes you think about what to do when you end up in that situation can be useful" (FG1GP).

Normative expectations towards 'good', 'informative' and 'relevant' journalism often come with expectations towards who should be heard in the media; rather than patients, the media should give a voice to experts. As a doctor expresses his annoyance: *"[…] should it really be depicted in the media like that? Without explanations of people with expertise?"* (FG1specialists+nurses). Or as a member of the general public in similar vein states that she would like to see more *"opinions of educated people"* (FG3GP).

There are exceptions according to the respondents, however; emotionalised and individualised coverage is permitted under the condition that it 'informs'. The article "I am terminally ill, but I want to inspire people" about the palliative sedation of Bart Verbeeck does exactly this according to the respondents: *"Yes, that palliative sedation, I know that since it appeared in the media here. Because if they would have asked me before, I would have though: 'What is that'?"* (FG3GP) and *"Yes, that article about Bart…that has been in the media, but that I found rather informing, to make people aware of the fact that palliative sedation exists"*(FG5nurses).

5.2. Biased media: misinformation versus information

Quite often, the respondents' reflections about good journalism are structured around a 'bias-accusation'. Here, respondents identify with a construction of good journalism in terms of neutrality and objectivity. When zooming in on responses structured around a bias-accusation, it becomes clear what exactly the interviewees understand as 'correct information' and what they understand as 'misinformation'. More concretely, correct information is opposed to both 'publicity' and 'incorrect' representations. A response of a member of the general public clearly illustrates the dichotomous construction of 'information' versus 'publicity', as the respondent mockingly says: *"The informative aspects in the media, I support….But glorifying it, like let's all go for euthanasia..."* (FG3GP). In most cases, an 'information versus publicity' contrast emerges in a more subtle way, with respondents implicitly subscribing to a negative media effects paradigm, where it is believed that media possess of the power to mislead people. As these relatives' reactions to the article "To go in friendship and laughing" illustrate:

> "They [the media] shouldn't praise it all too much, they shouldn't emphasise it. That's what I think. I think that people are influenced by big titles like these" (I3R)
>
> and
>
> "I think that it gives people a wrong impression of euthanasia" (I6R).

Such negative evaluations are especially dominant in the focus groups with medical professionals, where responses are often structured around the argument that media 'promote' euthanasia. The following extract from a focus group with palliative care nurses, for instance, illustrates how the interlocutors engaged in the conversation negotiate ‘media-effects’, with one of the nurses clearly identifying with a negative media effects paradigm (and the other rejecting it):

> N1: “Now Hugo Claus says ‘I am dement’, but if next week somebody like Wilfried Martens[93] says the same, you would start to think…I mean, it’s not an obligation, right”.
> N2: “Media play a major role”
> N3: “Maybe, but I don’t believe that media can persuade people to choose for euthanasia” (FG2nurses)

Also doctors often draw on this negative media effects paradigm in arguing that media promote euthanasia, and more specifically, the idea that doctors are obliged to meet the patient’s request for euthanasia. As these responses illustrate:

> “There are people who <u>consider it a right because of the media</u>” (FG2specialists)
>
> and
>
> “Media plays <u>a very negative role</u> there, in stimulating the population to ask these questions” (FG2GenPrac).

According to some of the interviewed doctors, the ‘promotion’ for euthanasia often comes with a negative and stigmatising construction of the doctor, who is believed to be represented as some kind of bogeyman or villain who does not *“fulfil his obligation”* (FG2GenPrac). Not only prominent case coverage triggers these kinds of responses; also articles about ‘ordinary’ cases that do not involve euthanasia such as “Doctor refuses treatment of palliative patient” entail similar reactions: *“It is stigmatising for doctors”* (FG1GenPrac), or *“I know the situation personally, and then you know the*

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[93] Prime minister of Belgium (1979-1993) and politician for the Flemish Catholic Party.

complexity […] I sent that doctor an email with the message 'I support you for 100%, what happens to you is scandalous'" (FG1specialists+nurses).

Responses of doctors drawing on a biased media discourse also sometimes echo the argument that media distribute unrealistic images that falsely inform the audience. Here, medical professionals often contrast a media 'non-reality' with a medical 'reality'. In response to the article "To go in friendship and laughing", a doctor for instance states:

> "This is a perception of someone who is being interviewed and who wants to convey a certain message. Does this correspond to the reality we see on a daily basis? No. No." (FG1specialists+nurses)

During a focus group with geriatricians, similar arguments are brought to the table – where the media are criticised for not or falsely covering what is believed be one of the key issues in the debates on end-of-life decision-making: *"The grey zone in the euthanasia law, and how the press handles it with little or no nuanced arguments that harm certain professional groups"* (FG2specialists.). And later during that same focus group, in response to the article about Amelie Van Esbeen:

> D1: "It is a very biased coverage"
> D2: "They could have added: 'This is the grey zone, and that makes it difficult'. But they didn't" (FG2specialists).

Subscribing to a similar critique against 'false' or 'incorrect' coverage, a general practitioner negatively evaluates the way media often cover euthanasia rather than other end-of-life decisions, arguing that *"I personally feel that the media focus too much on the euthanasia debate, while it is in fact a very very small percentage that actively asks that….people have little awareness of the other possibilities"* (FG2GenPrac).

5.3. De-tabooing and mobilising coverage of the end of life: ritual functions of (emotionalised) media

Responses that fit a third logic of identification contain arguments where media are believed to have a key role to play in sensitising and mobilising people in relation to the issue of euthanasia. These responses are often grounded, first of all, in an identification with a revivalist reaction against the perceived hidden nature of death in contemporary Western societies. Arguably, these responses often contain arguments that media can make euthanasia *"discussable"* (FG1nurses, FG2GP, FG3GP), can *"open up"* (FG5nurses) the discussions on end-of-life decision-making, or can *"draw people's attention to the issue of euthanasia"* (FG1nurses). Nurses often deploy arguments like these. For instance: *"When it appears in the daily media, in the newspaper or on the news, than that's often an <u>impetus to make euthanasia discussable</u>"* (FG5nurses). Or in similar vein, after reading the articles about Claus and Engelborhgs: *"When they read something like this, people can start to think it over and discuss it with their doctors, which they might not dared before. It <u>makes things discussable</u> I think"* (FG1nurses). Similar arguments appear during a focus group with oncologists, where respondents make the link between the fact that patients more and more tend to ask information about the end of life and the *"de-tabooing role of the press"* (FG3specialists). Media, according to the oncologists participating in this focus group, inspire patient to action and have to capacity of mobilising people and changing their mind-set. Take the following extracts:

> "Many people know it's possible in Belgium […] and it's just a question whether for average Joe who has got nothing to do with medicine, reading about this [euthanasia] from time to time might work as a stimulus. Knowing that it is possible and there are other people who make this choice."

and

> "10 years have passed since the euthanasia law was established, and looking at the way people talk about euthanasia now compared to 10 years ago, then you can ask yourself the question whether these types of articles, however populist, have contributed to that evolution".

Also members of the general public and relatives sometimes emphasise the media's potential of 'un-hiding' the end of life. As these responses illustrate*: "By talking about it, you open the debate"* (FG2GP) and *"I think people don't talk about death very often, they walk around it. I think it should be discussed more in the media"* (I8R). Yet, according to some relatives, focussing on the isolated euthanasia 'event' as the articles about Claus and Engelborghs do, is not the best way of removing the end of life out of the taboo-sphere. Rather, "*euthanasia is the end of a process"* (I8R), which is why they prefer a focus on the *"trajectory they followed to get there"* (I7R).

Responses that implicitly assume the potential of media as de-tabooing platforms often come with (relatively) positive evaluations of emotionalised media coverage, which often implies an identification not with traditional journalistic values such as objectivity and neutrality, but with more ritual functions of mass media – including connectivity and accessibility. As a geriatrician argues: *"I think those cases and this emotion is good because you feel connected"* (FG2specialists). Or similarly, as a general practitioner argues when comparing an article from a popular newspaper to an article from an elite newspaper: *"It's not always bad. You cannot come with an article like this [article from elite newspaper] to the kind of patients I have. Because they simply don't understand"* (FG1GenPrac). Also members of the general public sometimes identify with 'alternative' or more ritual functions of personalised stories in the media, emphasising the way these stories can work emancipating and mobilising for the patient. As a reaction to the article "Mother wanted to live" illustrates:

> "Media awakens people. The story always applies to someone. And even though it's not always necessary to sue, people know that they don't have to accept things, and that they can say: 'damn you doctor'" (FG3GP).

And similarly, when discussing the articles about Claus and Engelborghs:

> "People might think that it won't work, that it's pointless of starting a procedure, but it is possible, if the doctors cooperate" (FG2GP).

One respondent, a general practitioner, does *not* believe emotionalised story-telling to be the most suitable way to mobilise people. He argues that sensational and spectacular coverage does not work emancipating, as it does not "*increase the support for euthanasia with the general public*" (FG2GenPrac). For coverage to do so, it should be '*serene*' and focus on *"the issue itself"* (FG2GenPrac) rather than on personal cases. Here, identification occurs at the intersection between a discourse that stresses the mobilising potential of media and a discourse that constructs good journalism in terms of serenity and discretion (see part 5.1).

Identifications with arguments of de-tabooing and emancipation sometimes conflict with identifications with a 'death as a private event' discourse, which illustrates how identificatory logics sometimes overlap and contradict one another. A response from a home care nurse nicely illustrates the intrapersonal 'struggle' between two logics of identification:

> "I do think…it should appear in the media for a while, but it shouldn't be…I mean, I should be in the media and the taboo should disappear. But on the other hand, I still think it's an intimate event" (FG4nurses).

Also responses of the general public sometimes contain a same tension:

> “Claus was one of the first to make it public, and at the time I though, ‘is that necessary?’ But as you say, it makes people think and it makes them conscious” (FG2GP)
>
> and
>
> “My wife was shocked, saying ‘should that appear on television?’ And indeed, I wouldn’t do it, but then again, someone has to” (FG3GP).

5.4. The un-representability of the end of life

A final way in which the media coverage under discussion is evaluated, is through emphasising the ‘un-representablity’ of the end of life. While this is a rather rare logic of evaluation, it is all the same an important one. Responses that fit this last category, which are only found in interviews with medical professionals and relatives, often stress the complexity of the end of life that cannot be represented in media coverage. Medical professionals mainly point to the incompleteness of the coverage and its failure to present an overall picture of an end-life-life decision-making situation. As these responses illustrate:

> “What you read in the media does not offer…I mean, you <u>never get the entire story</u>, they don’t offer the overall picture” (FG4nurses)
>
> ,
>
> “A lot <u>more is happening that can be put into words</u>, that is the difficult task of the journalist” (FG1specialists+nurses)

and

> "It is so incomplete, and contrasts the complexity of reality. They give some slogans, but in reality we see it so much more complicated" (FG1specialists+nurses).

The quote given above also illustrates how responses that draw from an 'un-representability of death' discourse often come with a critique against media logics that reduce complexity. As this reaction from a doctor, expressed during the same focus group, also illustrates:

> "I think it is an incredibly difficult task to represent this properly. Something this complex they have no affinity with, how are they supposed to…they listen to a story, and say 'hey, this is nice, that is well formulated', but it is much more complex, much more complex" (FG2specialists).

Relatives draw on personal rather than professional experiences with end-of-life decision-making in expressing the 'un-representablity of the end of life'; arguing that *"it's noting like what they say in the magazines"* (I4R) or that *"you simply cannot communicate things as they are"* (I3R).

The responses discussed above look a lot like Kearl's argument (1989: 379) that media rarely portray 'real' grief and 'real' death, and subscribe to the argument that media cannot convey the lived experience of death and suffering as also expressed in literature about the 'unspeakability' of the Holocaust (see chapter IX).

6. Discussion and Conclusion

A twofold structure is followed in this concluding section. It starts with a more basic summary of the construction of the good death in the respondents' talk about the media items under discussion and of the main practices of interpretation and identification, added with a number of reflections about the specific nature of these practices; including their media-criticality and their emotionally-loaded nature. Here, attention is particularly drawn to the differences between the three audience categories under analysis, which allows us to approach them as communities of interpretation that receive media articles in similar ways by drawing on and identifying with the same discourses. Second, the section continues with a meta-discussion about the contribution of a DT reception study to the field of media reception studies by focussing on the concepts of polysemy and the active audience.

6.1. Interpretation and Identification in the three audience categories

In the responses of all audience categories, we observe a focus on the patient's wellbeing and an acceptance of his right to be involved in the organisation of the own dying process. Again, then, we encounter a hegemony of the basics of revivalism, which also emerges in the analysed media representations (see part D). At the same time, the image of the good death that emerges in and through the respondents' talk about the selected media items is one that differs significantly from the image of the good death that is inscribed and constructed in media coverage of prominent euthanasia cases. While, as mentioned above, the meaning of the good death as it becomes constructed in the respondents' talk shares with the selected media items a focus on the patient's wellbeing and his right to be participate in the organisation of the own dying process, it does very often not share with the prominent-case coverage the disciplining celebration of independence, autonomy and hedonism that indeed comes with a problematisation of dependency and/on care and a focus on dying hedonically. The respondents draw on a series of systems of meaning to contest and resist the construction of the good death as it is inscribed in the prominent case coverage. We may visualise this as follows:

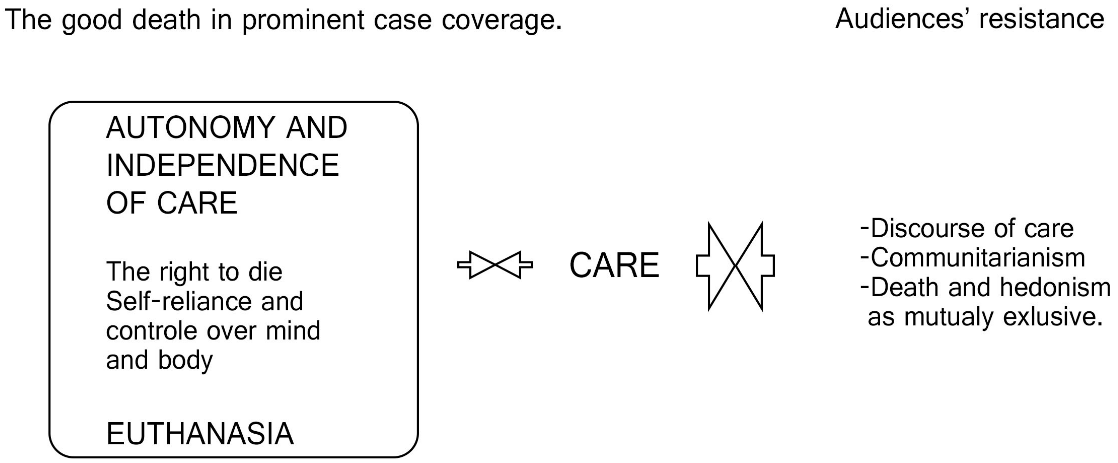

Table 12: audience resistance against the construction of the good death in the prominent case coverage.

The image of the good death that comes to the fore in the interviewee's responses is actually quite close to the way non-prominent case coverage constructs the good death. Like in the non-prominent case coverage, care is often discursively brought into the range of what it means to die well in the respondents' talk. Even more than in the non-prominent case coverage, reactions that do not fit scripts of a heroic and hedonic death (like deep fear and non-acceptance) become visible in and through this reception analysis. This, as well as the diversity of identification practices the analysis revealed, points in the direction of a variety of ways in which the respondents experience the very idea of 'dying well'.

Notwithstanding the fact that, in general terms, a broader and less disciplining construction of the good death is inscribed in the respondents' talk about the media items under discussion, there are some important differences to be noted in terms of interpretation and identification practices between the different audience categories. The way respondents draw on, deploy and identify with discourses cannot be *reduced* to one or more explanatory factors. It has not been the ambition, as should be clear by now, to expose a (linear) relationship between the contextual background of the different audience groups and their interpretation and identification practices, for indeed a variety of factors - situated 'outside' as well as 'inside' the interview setting - potentially impact on these practices. At the same time, however, it is possible to identify a series of trends and patterns pointing in the direction of the different audience categories as - albeit not strictly defined and non-coherent - 'communities' of interpretation and identification. These are groups in which people often interpret media texts in (more or less) similar ways because they draw on the same discourses they are familiar with and that provide them with the signifiers to comprehend and narrate their experiences with the end of life. The groups that can be identified as 'communities of interpretation and identification' do not completely overlap with the audience groups as they were initially composed. Concretely, the category of 'medical professionals' would be too broad, as the differences between nurses and doctors in the way the articles under discussion are interpreted are sometimes rather sharp. The discussion below provides a summary of the categories of interpretation and identification and in so doing pays special attention to the differences between the audience groups included in the study.

In allocating meaning to patient autonomy and the right to die, the ratio-personal discourse of autonomy plays a key role and is indeed the dominant discourse the respondents draw on in giving meaning to the articles under discussion. The ideals of patient autonomy and the patient's right to die as present in the articles are often accepted (whether or not under the condition of 'unbearable suffering'), while the articulations of euthanasia as the only and ultimate act of self-determination and euthanasia as 'the' brave death are often contested. Doctors, and above all specialists, are the main exception here; rather than accepting the dominant message of patient autonomy, many physicians in the first place identify with the doctor's autonomy and with an ethics of curing – which comes with sometimes fierce critiques against the media articles under discussion. In interpreting representations of patient autonomy vis à vis the social network, second, members of all audience groups contest the construction of what they perceive as the 'socially isolated dying patient' in the articles dealing with a prominent euthanasia case. The perceived image of a 'warm' death as represented in the non-prominent case coverage, in contrast, seemingly provides them with the material for identification. There are some (subtle) differences to be noted when in comes to the specific discursive grounds on which interpretation/identification is based; whereas nurses and relatives are for instance more likely to draw on their own personal experiences in contesting the socially isolated death, doctors identify with a more abstract communitarian discourse.

In interpreting the ideal of independence of care in the representations under discussion, third, the different audience groups interpret the coverage in more diverse ways – identifying with particular discourses in divergent ways. While meaning-making practices are mainly structured around signifiers such as care and dignity, a number of key differences between the audience groups in the way these signifiers are used to evaluate the coverage under discussion can be noted. Relatives of patients who died with palliative care as well as doctors (with of course a number of exceptions) interpret the coverage in similar ways as they draw on a (hospice) discourse of care that constructs palliative care as a good and dignified death. Also older members of the general public often tend to contest the ideal of independence anchored in the media representations under discussion, albeit from a slightly different logic of identification – one where the respondents adhere to the idea that deterioration and becoming dependent on care of others is not part of an undignified dying process, but is an inevitable part of life. Also younger members of the general public sometimes step into this logic of interpretation, but here the dominant logic is one where the ideal of independence is accepted by reproducing the discursive association between independence and dignity. While this latter logic of interpretation is also found in responses of relatives of patients who died with euthanasia, responses here in the first place also draw on a discourse of care, but they do so in such as way that palliative care and euthanasia are not articulated in an antagonistic relation, but as different types of care. Such an (re)articulation of care is also found in responses of nurses, where it exists next to other logics of identification. In the category of hedonism, fourth, the dominant logic of interpretation/identification is one where the image of the hedonic death is contested and resisted by members of all audience categories. While members of the general public interpret the constructs of the hedonic death and the hedonic dying patient with a general and somewhat vague sense of unease, members of the other audience groups contest them in more explicit and clear ways – often with the argument that the end of life is 'not a party'. An alternative logic, where the idea of the hedonic death is – to certain degrees- accepted, is found in responses of all audience categories, except in those of relatives whose loved one died with palliative care.

When drawing conclusions regarding the differences between the audience groups included in this study, it is rather safe to state that relatives of deceased patients and doctors are often most critical towards the articles under discussion. They tend to dis-identify rather fiercely with the discourses (of autonomy, independence, and hedonism) operationalised in the articles. Both groups are particularly critical towards the (perceived) dominant message of individuality and independence and seemingly share an identification with a discourse of care, albeit by drawing on other types of knowledge (personal experience versus more abstract belief systems). Here, we can make the link with the DT representation analysis; the resistance against the construction of the good death in terms of autonomy, independence and hedonism echoed by the respondents corresponds to the type of resistance that appears in the media and where it is indeed often expressed by medical professionals (in opinion pieces) and by relatives (in letters to the editor).

What distinguishes doctors from the other audience groups, and particularly from relatives, is the way they sometimes dis-identify with a discourse of patient autonomy. Relatives and nurses, on the other hand, often similarly embrace the (medical-ethical) ideal of patient autonomy, albeit by drawing on different types of knowledge and their respective vocabulary (personal experiences versus a medical-ethical jargon). In this sense, relatives and nurses seemingly share an ethics based on patient autonomy (at least in interpreting the media articles under discussion) that is not always embraced by doctors. The contestations of patient autonomy by some of the interviewed doctors suggest a lingering existence of a modern approach to medicine, one where 'the doctor knows best' and where an ethics of cure prevails (see chapter V). This hypothesis is strengthen when we make the link with the DT representation analysis, where we observed that medical media not rarely contest patient autonomy, not in the least when it manifests itself in the capacity of a euthanasia request – which again points in the direction of an ethics of cure that lingers on in the hearts and minds of physicians.

It is most difficult to produce claims about the general public as a community of interpretation. The younger members of the general public often tend towards an acceptation of the dominant messages inscribed in the articles under discussion, while the older members often tend to join the more critical reading of doctors and especially relatives. Age, then, which is in turn related to other factors such as personal experience with the end of life of acquaintances and religious background (many of the older members of the general public describe themselves as Catholic while the majority of the younger members describe themselves as secular) appears as a relevant factor in the analysis. Further pinning down the relation between factors such as age and religion and practices of interpretation and identification is tricky however, and no further claims in this direction will be produced.

All audience categories, but above all relatives of deceased persons, react in sometimes highly emotional ways during the interviews. The articles under discussion remind the respondents of their own experiences with the end of life and the way they do or do not provide the material to identify with touches them, angers them, or makes them sad. Articles about prominent euthanasia cases (and above all articles about Claus and Engelborghs) tend to evoke more negative emotional reactions, precisely because they fail in providing the respondents the material for identification – much less, so it seems, than non-prominent case coverage. This immediately brings us back to the special and somewhat dual status of prominent-case coverage. On the one hand, prominent-case coverage triggers the respondents the most. When asked at the beginning of the interview what they remember of media portrayals of the end of life, the respondents very often refer to prominent cases. Also when asked to discuss the different articles spread on the table, respondents often pick up on articles dealing with a prominent case. At the same time, it is this type of prominent-case coverage that angers and annoys respondents the most; precisely because they do not relate to the stories being told there.

The analysis also demonstrates the media literacy of the respondents of all audience groups as well as their critical attitude towards media. More concretely, it has been demonstrated that the respondents often recognise and criticise the mechanism of representation that have been identified in the representation analysis, like the tendency to create heroes, the tendency to simplify and to emphasise conflict[94]. This is especially the case when these mechanisms result in representations with which the respondents do not identify, including for instance the antagonistic representation of 'palliative care versus euthanasia' and the equation of euthanasia with a brave death and a dignified death. Many of the respondents remark in some way, either explicitly or implicitly, that the dying processes represented in the prominent-case coverage do not correspond to those experienced in 'real life'. This observation, in the talk if the respondents, is linked both to media-specific logics of representation and to the fact that people like Hugo Claus are not considered representative for the 'average Fleming'.

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[94] If there is one mechanism of representation that is to a lesser degree recognised by the respondents, it is the publicness of media and the way media stage the euthanasia event. Very rarely do respondents refer to the way media 'make a show' out of the euthanasia. In general, respondents blame the individual/the patient for making a show out of his own death.

Given the respondents' reflexive and critical position towards the way the media articles under discussion represent the end of life, it comes as no surprise that the respondents' talk not only targets the construction of the good death inscribed in the media articles as such, but also revolves around the question as to what 'good journalism' about the end of life should be like. The interviewed audience members agree that good journalistic coverage of the end of life should be 'serene' and 'realistic'. There is fewer consensus when it comes to the way the respondents interpret and evaluate emotion in end of life coverage. Here, a variety of logics of identification can be determined; logics where people identify with different normative models regarding the place and role of media and journalism in society. Most dominant are identifications with models where good journalism is defined in terms of the neutral and rational transmission of politically and socially relevant information, where emotionalised coverage is often thought of in terms of 'dumbing down'. Alternative constructions of good journalism emerge as well, though; these are constructions where the de-tabooing, mobilising and engaging potential of (emotionalised) coverage of the end of life is emphasised.

6.2. Polysemy and the active audience: a DT interpretation

The discourse-theoretical analysis of audiences' receptions of media representations of the end of life conducted here makes a specific contribution to the debates within the field of audience reception studies. Conducting a reception analysis inspired by discourse theory, more concretely, sheds new light on the concepts of polysemy and the active audience. Concretely, the analysis points in the direction of limited polysemy – at least when defining polysemy in the traditional sense of a text having 'many meanings' that have not yet been fixed (Jorgensen & Phillips, 2002: 27). The analysis demonstrated how the respondents draw on common discursive frameworks in interpreting the media articles under discussion. Starting from a theoretical position where media cannot be seen as the 'origins' of discourse, but rather as specific spheres of the social where discourses are materialised and brought into circulation, it can be argued that the analysis illustrates the reciprocity between media and the social; respondents recognise in the media articles existing discourses and deploy signifiers they are familiarised with, party but not exclusively through mass media - to reconstruct the media message. Hence, as different audience members recognise the connection between discourses and media-representations; they recognise the discourses that are operationalised in the media text and, often, they also recognise the mechanisms of representation through which this operationalisation occurs. Recognising the connection between discourses and media texts, is not imply that there is also identification. The analysis has indeed pointed in the direction of a rich variety in which respondents evaluate the media articles under discussion. Respondents accept, negotiate or reject the media message, depending on to what extent they identify with the discourses operationalised in the media text. As touched upon several times throughout the analysis, respondents identify with discourses and discourse elements in different ways – giving rise to a diversity of evaluations and perceptions of the same text.

The above discussion urges us to redefine the concept of interpretation in the context of audience reception as a multi-layered discursive practice. More specifically, on the basis of the discussion above, an approach is demanded that distinguishes two different levels of interpretation. A first level is that of recognition; referring to the way audiences recognise the discourses that are imported and deployed in the media text. A second level is that of identification and refers to the way audiences do or do not identify with discourses and discursive elements (operationalised in the text) and relates to the way these discourses and discursive elements – and the way they are operationalised in the media text – succeed or fail in providing audiences the material to relate to their own (personal) experiences. Recognition, as illustrated throughout the analysis, does not presume identification. Through recognition, audiences validate the operationalisation of a particular discourse in a particular media text and deploy the signifiers of that discourse in discussing the media text, while at the same time actively negotiating this discourse; articulating it with other discourses, bringing signifiers from another discourse into its range, or simply fiercely dis-identifying with it and subscribing to a radically different discourse.

At this point, we can re-introduce our meaning-making triangle and provide an adjusted version that adds recognition as an additional meaning-making level in the process of interpretation. The visualisation below makes clear that interpretation, indicated by the light orange area, in fact encompasses *two distinct processes*: the process of recognition (the orange arrow) and the process of identification (the red lines), where identification often goes via talk about the media text, but sometimes – when the talk moves further away from the specificity of the text – occurs 'unmediated' by the media text.

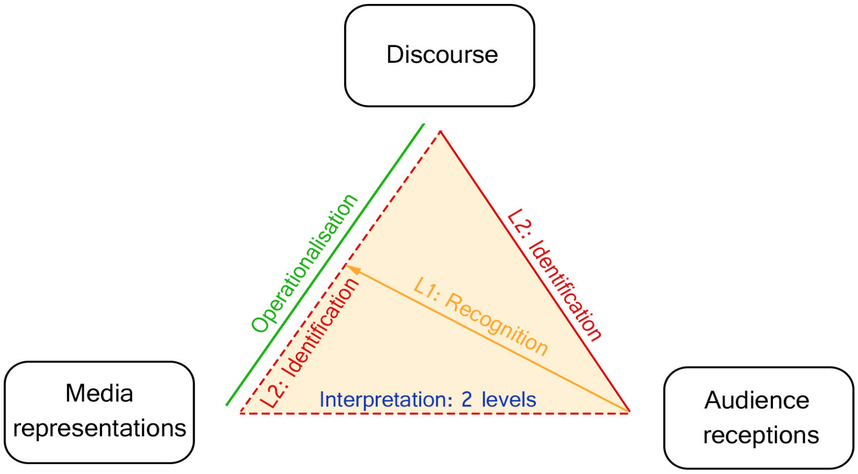

Figure 13: Recognition and Identification: two levels of interpretation.

If we link the above to existing (media- and cultural studies) theories about audience reception, we move away from the concept of polysemy and arrive at the concept of polyvalence, which Condit (1991: 369) describes as occurring *"when audience members share understandings of the denotations of a text but disagree about the valuation of those denotations to such a degree that they produce notably different interpretations"*. While subscribing to Condit's approach, a discourse-theoretical perspective gives it an extra dimension in bringing in the relationship between media-representations, audiences receptions and more encompassing discourses circulating in the social, which in turn allows us to distinguish recognition and identification as two separate levels of a more encompassing interpretation process.

To be sure, limited polysemy does not imply an un-active audience. Quite on the contrary, the analysis has demonstrated how audience members actively deploy discourses and combine elements from different discourses. Indeed, discourses that sometimes seem irreconcilable in the analysed media text are combined and reconciled in creative manners, allowing the respondents to make sense of and to narrative their own experiences with the end of life in the encounter with media contents. The most important example thereof is probably the way respondents combine and reconcile elements of both a liberal autonomy discourse and a discourse of care – discourses that exclude one another in the analysed coverage of prominent cases. It is important to note here, finally, that we should not use the terms 'inconsistency' to describe the way audience members draw on and identify with different - at first sight perhaps contradictory – discourses, but rather about creativity and flexibility in deploying more encompassing discourses in small-scale meaning-making practices.

GENERAL CONCLUSIONS

Medical decision-making at the end of life is one of today's most debates issues. It is an often heated debate that captivates not only ethicists, medical professionals and politicians, but also social organisations and many individuals concerned with their own (future) dying process and the wish to die 'with dignity'. This broad societal attention for the issue largely boils down to a concern with the good death – which is indeed the concept this dissertation centralised.

In academia, the issue has sparked wide attention as well – not in the least the attention of medical sociologists and (medical) ethicists. This dissertation has added to the existing academic body of knowledge about medical end-of-life decision-making by looking at the issue from a discourse-theoretical lens, which allowed shedding new light on it – highlighting its discursive dimension by centralising the (struggle over the) meaning of the good death.

To conclude this dissertation, a fourfold structure is followed. A first part provides reflections with regards to the different research questions that guided the dissertation. Parts two and three draw, from different perspectives, attention to the main contributions of the dissertation and the key insights arrived at throughout the research process. Part two of the conclusion zooms in on the interdisciplinary nature of this dissertation – situated at the intersection of thanatology, discourse theory and media studies. There is cross-fertilisation between these fields, through which a number of very specific contributions are made to each of them. Section three returns to the three basic components of the dissertation; the theoretical framework, the methodology, and the empirical analysis – and contributions are made on the level of each of these components. On a first level, the dissertation has contributed to existing literature on the medical death by answering the theoretical research question. The dissertation indeed provided us with a particular (theoretical) interpretation of the medical(ised) end of life and the debates on medical end-of-life decision-making, and the way these are embedded in a particular discursive configuration that is marked by dynamics of contingency and hegemony. On a second level, this dissertation demonstrated the methodological applicability of discourse-theoretical analysis and more specifically the analytical usability of the concepts of operationalisation and identification. On a third level, the dissertation has made an empirical contribution at the intersection of thanatology and media studies.

This dissertation finally hopes to inspire further research at the intersection of discourse theory, media studies, and thanatology. Section four of the general conclusions formulates these suggested directions for further research.

1. Re-introducing the research questions

A series of research questions have (iteratively) been answered throughout this dissertation, and all of them aimed at revealing particular dimensions of the discursive (and contingent) construction of the good death. Below, the research questions are re-introduced and a summarising answer is formulated to each of them.

The theoretical research question was directed towards the identification of the discourses on (the medical) death and the good death, their constitutive nodal points and the way they engaged in a discursive struggle over the meaning of the good death. A discourse-theoretical reading of existing (thanatological) literature allowed us to identify **the medical-revivalist discourse as the contemporary dominant (and relatively stable) system of meaning, structured around openness, control and awareness as nodal points**. Under medical-revivalism, the dominant discourse on medicine is **a patient-centred discourse, structured around quality of life and patient autonomy as nodal points**. It is within this specific discursive configuration that the late modern discourse of the good death comes into being. **Autonomy and dignity are**

the nodal points of this discourse of the good death. The dissertation illustrated that these nodal points, despite them being strongly anchored in Western thought, are **anything but fully saturated with meaning; they are instead floating signifiers that are articulated differently within different discursive settings**. Competing articulations of both signifiers have been identified that are particularly relevant in the context of medical end-of-life decision-making. As for autonomy, **a dominant liberal focus on self-determination (in making the own end-of-life decisions) finds itself challenged by a focus on care and the right to care**.

The different meanings dignity takes up in the debates around end-of-life decision-making are linked to two main approaches; an approach where dignity is defined as innate to all humans, and an approach were dignity is defined in extrinsic terms – not in the least in terms of autonomy and self-identity. It has been illustrated how the right to die movement and the hospice movement, which are at the forefront of discussions about medical end-of-life decision-making, actualise discourses on autonomy and dignity. **The hospice movement and the right to die movement appeal to the concepts of autonomy and dignity and actualise them in the capacity of a number of concrete demands and/or a concrete end of life philosophy - which are at the core of the hospice discourse and the right to die discourse**. The hospice discourse and the right to die discourse find their origins in the respective movements, but are at the same time dispersed throughout the entire social field (including media representations circulating in the social). **In articulating the nodal points of autonomy and dignity with a number of other signifiers – like acceptance, control, self-determination, care – the hospice discourse and the right to die discourse are engaged in a discursive struggle over the meaning of the good death.**

In order to support theoretical support for the analytical identification of constructions of good journalism, the theoretical framework also identified discourses on death in the media. Here, **multiple normative frameworks that construct the role of media and journalism in society in sometimes radically different ways have been identified**. A careful reading of the three bodies of literature identified in chapter IX pointed in the direction of **seven discourses that evaluate media portrayals and coverage of death and dying in specific ways**. Roughly speaking, four of these discourses evaluate media representations of death and dying negatively: ‘media and the pornography of death’, ‘media and the spectacle of death’, ‘biased media coverage of death’, and ‘stigmatising media coverage of death’, while three approaches a stress the potential emancipatory nature of media portrayals of death and dying: ‘Engaging media coverage of death’, ‘media coverage of death and social cohesion’ and ‘”learning” media representations of death and dying’.

The theoretical framework iteratively informed the discourse-theoretical representation- and reception analysis. The discourse-theoretical analysis of media representations of the end of life and their audience receptions looked into the meaning-making flows of operationalisation, interpretation and identification and has shed light on the specificities and particularities of these flows.

The DT representation analysis zoomed in on the operationalisation flow and centralised the following research questions:

- **How, and following what media-specific logics of representation, does the Belgian print media coverage of the medicalised end of life construct the good death, through operationalising particular discourses on death and the good death (with their respective nodal points)? (RQ1)**
- **What discourses on ‘good journalism’ are operationalised in the Belgian print media coverage of the medicalised death? (RQ2)**

As for RQ1, the analysis has shed light on the construction of the good death through the articulation of autonomy and dignity, within a hegemonic context of medical-revivalism. It has been shown, indeed, that **the basics of revivalism, including the ideals of openness and awareness and a patient-centred focus on quality of life, form the hegemonic context within which the nodal points of autonomy and dignity are articulated.**

A ratio-personal discourse has shown to be dominant in the articulation of autonomy. **Through the operationalisation of a ratio-personal discourse of autonomy, the patient's right to make the own end-of-life decisions is accepted**. Interestingly, it has also become clear how **the interplay between this ratio-personal discourse with other discourses and with media-specific logics of representations results in a very particular construction of the good death**. Here, the analysis pointed in the direction of **on the one hand a democratic and pluralistic representation** of the good death in the non-prominent case coverage, where the individual's right to choose is emphasised, and **on the other hand a disciplining representation** in the prominent-case coverage, where euthanasia – the right to die - is constructed as *the only* good death (as opposed to the bad death). In addition to the operationalisation of a ratio-personal discourse (in either a pluralistic or a disciplining way), we also encountered **an operationalisation of a communitarian discourse, through which the patient's autonomy and right to self-determination in deciding over the own death are denied and contested and through which the emphasis is put on a right to care.**

The analysis revealed a series of articulations of dignity – demonstrating the complexity and multi-layeredness of dignity as a nodal point of a late modern discourse of the good death. **Most dominant are articulations that, encouraged and triggered by specific mechanisms of representation, draw on the operationalisation of an extrinsic approach to dignity, and more specifically of a discourse of self-identity through which autonomy, independence of care and the deterioration of the mind are constructed as threats to a dignified existence and death. Counter-hegemonic is an articulation that builds on a discourse of innate human dignity.**

As to RQ3, the analysis has shown **a dominance of a rather negative thinking about the journalistic practice of representing the end of life. Inscribed in articles giving a voice to mainly medical professionals and ethicists, potential harmful effects of media coverage of euthanasia are assumed and linked to its 'sensationalist', 'voyeuristic' and 'biased' nature**. These negative evaluations above all target a personalised and intimitised way of covering euthanasia and thereby draw on a ‘traditional’ construction of ‘good journalism’. In addition to these negative evaluations, positive evaluations of media coverage of the end of life emerged. Like negative evaluations, they are discursively built around emotion as a nodal point, but construct emotionalised and intimitised coverage of the end of life in terms of being de-tabooing, engaging, and mobilising. Unlike constructions of good journalism in terms of a neutral transfer of politically and socially relevant information, constructions of good journalism that stress the emancipatory potential of human-interest tend to be anchored in ‘first-line’ coverage; i.e. coverage dealing with the euthanasia case itself, not with a meta-reflection about it.

The DT reception analysis of media representations of the end of life zoomed in on the meaning-making flows of interpretation and identification, and centralised the following research questions:

- **How do audiences interpret the Belgian print media coverage of the medicalised death and in so doing identify with more encompassing discourses on death and the good death? (RQ2)**
- **What discourses on ‘good journalism’ are inscribed in the audiences’ interpretations of the media coverage of the medicalised death, i.e. with which discourses on good journalism do they identify? (RQ4)**

As to RQ2, the analysis revealed **a rich variety of practices of interpretation and identification**. In the responses of all audience categories, we observed a focus on the patient’s wellbeing and an acceptance of his right to be involved in the organisation of the own dying process. Again, then, we encountered a hegemony of the basics of revivalism, which also emerged in the analysed media representations. **Respondents often identify with a patient-centred discourse as well as with a ratio-personal discourse of autonomy, but at the same time the image of the good death that**

emerges in and through the respondents' talk about the selected media items is one that differs significantly from the image of the good death that is inscribed and constructed in media coverage of prominent euthanasia cases. While, as mentioned above, the meaning of the good death as it becomes constructed in the respondents' talk shares with the selected media items a focus on the patient's wellbeing and his right to be participate in the organisation of the own dying process, it does very often **not share with the prominent-case coverage the disciplining celebration of independence, autonomy and hedonism that indeed comes with a problematisation of dependency and/or care and a focus on dying hedonically**. **While the analysis has shown that respondents *recognise* the connection between the discourse and the media text, i.e. the way certain discourses are operationalised in media representations, it has also been demonstrated that respondents tend to disagree with the (disciplining) construction of the good death in the prominent case-coverage**. It has been shown how the respondents draw on a series of systems of meaning to negotiate, contest and resist the construction of the good death as it is inscribed in the prominent case coverage and, importantly, how they **demonstrate agency in (creatively) combining elements of discourses that tend to exclude one another in the media representations of prominent euthanasia case** (e.g. a discourse of care and a discourse of autonomy).

Respondents' talk not only targets the construction of the good death inscribed in the media articles as such, but also revolves around the question as to what 'good journalism' about the end of life should be like. As for RQ4, then, the analysis showed that **the interviewed audience members agree that good journalistic coverage of the end of life should be 'serene' and 'realistic'. There is fewer consensus when it comes to the way the respondents interpret and evaluate emotion in end of life coverage**. Here, a variety of logics of identification have been determined; logics where people identify with different normative models regarding the place and role of media and journalism in society. Most dominant are identifications with models where good journalism is defined in terms of the neutral and rational transmission of politically and socially relevant information, where emotionalised coverage is often thought of in terms of 'dumbing down'. Alternative constructions of good journalism emerged as well, though; these are constructions where the de-tabooing, mobilising and engaging potential of (emotionalised) coverage of the end of life is emphasised.

2. Cross-fertilisation between discourse theory, thanatology and media studies

The research conducted in this dissertation is to be situated at the intersection of three academic fields: discourse theory, thanatology and media studies. Below, I discuss the cross-fertilisation between these three fields, demonstrating how each field contributes to the others.

First, the discourse-theoretical perspective adopted throughout the research contributes to both thanatology and media studies. In adopting a discourse-theoretical perspective, the dissertation has added to the existing body of thanatological knowledge about medical end-of-life decision-making in a very specific way. This dissertation foregrounded the concept of the good death, and the latter was approached from a discourse-theoretical perspective in a way that allowed us to preserve a critical distance from existing discursive structures and configurations. Throughout the dissertation, a discourse-theoretical perspective has drawn attention to the contingency of discourses on death, medicine, and the good death, the dynamics of continuity and discontinuity surrounding them as well as the sphere of discursive struggle in which they are embedded.

Discourse theory not only contributed to thanatology, but also to the field of media studies. This dissertation, together with previous work – produced not in the least by my own colleagues (see Carpentier and De Cleen, 2007) – sheds light on the meaning-making circuit of mass media from a discourse-theoretical point of view. Adding the moment of media reception to a discourse-theoretical media analysis is something that is quite new and that contributes to the development of a more established discourse-theoretical research agenda in the field of media studies. One of the key contributions of this dissertation is indeed the way a discourse-theoretical analysis of audience receptions allowed us to arrive at a discourse-theoretical model that captures two different processes in the moment of media reception: recognition and identification. Recognition, as explained in the conclusion of part E in more detail, refers to the way audiences recognise the connection between discourse and media representation – the way they validate discourses by acknowledging their operationalisation in the media text. Recognition does not necessarily mean that these validated discourses are accepted and subscribed to as well, which is why we need the concept of identification to refer to the way audiences endorse, negotiate or contest the discourses operationalised in the media text.

Second, the way this dissertation is situated in the field of media studies contributes to both discourse theory and thanatology, precisely because bringing these two fields into the realm of media studies is not entirely new, but still rather innovative, implying that there is still a large surface of uncharted territory. Media studies contributed to discourse theory, precisely by enriching discourse theory with a number of insights about the relationship between discourses, media representations and audience receptions as well as by drawing the discourse theorist's attention to the specificity of media as discursive machineries. Media studies' contribution to thanatology is situated at a similar level; the dissertation has illustrated the importance and specificity of media as places where death and dying derive their meaning.

Third, a thanatological focus on the social-scientific study of death and dying contributed to both media studies and discourse theory. More concretely, the embeddedness of this dissertation in the field of thanatology has enriched the field of both media studies and discourse theory; in the tradition of what a number of scholars have done (see Carpentier & De Cleen, 2007; Carpentier, 2010; Carpentier & Spinoy, 2008), the field of media studies has been stretched by bringing the study of death and dying into its research agenda, while the scope of discourse theory has been extended beyond its traditional focus on topics like nationality, the extreme right, social movements and more recently the economical crisis. It should be noted, at the same time, that enlarging the traditional research domain of discourse theory is not a unique contribution. A few other scholars have also applied discourse theory to study phenomena that traditionally are situated outside the confines of discourse theory. Jason Glynos has applied discourse theory (combined with Lacanian psycho-analysis) to study sexual identities (2000) and 'the ethics of mourning' (2014). And Anna Durnova (2013) has used discourse theory to analyse what she calls the 'politics of emotion', including for instance end of life politics and hygiene politics. In combination with the work of scholars like Glynos and Durnova, this dissertation contributes to the development of a new research line in the field of discourse theory, one that can be labelled as discourse-theoretical research into 'life-and body-political issues'. Discourse-theoretical research about 'life-and body-political issues' can include a variety of topics, including sexuality and relationships, health and illness, ageing, parenting and education, and the politics of beginnings and endings (pregnancy, birth, abortion, euthanasia, palliative care).

The visualisation below (table 13) gives a schematic overview of the key contributions this dissertation made to the fields of thanatology, discourse theory and media studies by bringing the cross-fertilisations between the three fields in view.

	Contribution to →	**Thanatology**	**Discourse theory**	**Media Studies**
Contribution of ↓				
Thanatology		/	Bringing the study of death and dying into the range of discourse theory	Bringing the study of death and dying into the research agenda of media scholars
Discourse theory		Insight into the master signifier of the good death: -the contingency of the articulation of the good death the embeddedness of the meaning of the good death in discursive struggle	/	A discourse-theoretical perspective of media as discursive machineries, a model of media reception
Media Studies		Insight into the meaning-making circuit of mass-media as key arena of meaning-making and struggle over the meaning of the good death	Contributing to the development of discourse-theoretical analysis into media material	/

Table 13: cross-fertilisation between thanatology, discourse theory and media studies.

3. Key theoretical, methodological and empirical insights

Re-introducing the basic components of this dissertation – the theoretical framework, the methodology and the empirical analysis – allows us to bring to the surface a selection of key insights the dissertation, with its discourse-theoretical perspective, enabled us to arrive at. The pages below zoom in on these insights, which should be seen in terms of the key lessons learned from the entire iterative research conducted in this dissertation. A first set of insights is located at the level of the theoretical framework, where the dissertation makes a contribution to existing literature on the medicalised death and end-of-life decision-making in that it sheds light on what can be marked as the discursive field of the medicalised end of life. A second set of insights is methodological in nature and above all gathers reflections about the analytical usability and applicability of the concepts of operationalisation and identification in discourse-theoretical analyses of media material as well as of other textual material. A third set of insights is located at the empirical level and is arrived at through the discourse-theoretical analysis of media representations of the medicalised end of life and their audience receptions.

3.1. The discursive field of the medicalised end of life

In theoretical terms, the dissertation adds to existing literature on the medicalised death and end-of-life decision-making in that it sheds light on what can be marked as the discursive field of the medicalised end of life.

The discourse theory of Laclau and Mouffe, in essence developed as a political theory, has largely remained within the confines of political research. When adopting a discourse-theoretical perspective to the issue of medical end-of-life decision-making, an obvious choice is to focus on the political debates about medical end-of-life decision-making and the permissibility of medical intervention in the dying process. The right to die movement, with its articulation of political demands of autonomy and self-determination, is an obvious actor to focus on, as are their (political) opponents that articulate a pro-life discourse. This dissertation indeed looked into the political project of the right to die, but theorised the movement – as well as the hospice movement – as political manifestations of a somewhat more stable discursive structure that has been identified as a 'medical revivalist' discourse. A discourse-theoretical perspective allowed us to situate debates about medical end-of-life decision-making (in which the right to die project indeed plays a crucial role) in a broader discursive configuration, where a relatively stable medical-revivalist discourse facilitates the emergence of a particular discourse of the good death, structured around autonomy and dignity as nodal points.

A key theoretical contribution of the dissertation is that it illustrates how the contemporary debates on medical end-of-life decision-making are not only to be understood in terms of, for instance, attitudes towards particular end-of-life decisions, dominant political ideologies and/or (good) medical practice, but that there is another way of understanding these debates. A discourse-theoretical (re-)interpretation and reading of existing literature, embedded in an iterative research process, has shed light on what can be labelled as the discursive field of the medical death, which is essentially characterised by contingency, dynamics of stability and discontinuity and discursive struggle at a variety of levels. A first level is situated at the very taken for granted nature of a Western discourse of death, where contingency becomes visible only when taking enough distance from its hegemonised nature. A second level is that of the medical-revivalist discourse of death and dying, where a certain openness and acceptance of death as part of life have achieved a certain degree of discursive stability, but where this stability is nonetheless challenged by descendants of a more rationalist approach to death and dying. A third level is the level of the good death, where autonomy and dignity function as nodal points but at the same time remain floating signifiers – especially when they become articulated in the political projects of the right to die movement and the hospice movement and in the right to die discourse and the hospice discourse.

3.2. Operationalisation and identification as analytical concepts in the discourse-theoretical study of death and dying

In methodological terms, this dissertation illustrated the applicability of discourse-theoretical analysis at the intersection of thanatology and media studies. It has been demonstrated that discourse-theoretical analysis is a flexible method of textual analysis; one in which a variety of analytical tools – including those of more linguistic traditions of discourse analysis - can be imported on the condition that the way of looking at the empirical material under analysis is compatible with DT's ontology as well as on the condition that a well thought-out methodological framework is created in which analytical concepts are connected to theoretical concepts. Supported by sensitizing concepts, looking at textual material in a discourse-theoretical way involves tracing down the usage of discourses in textual material and being attentive for the way texts function as places where discursive elements are articulated and where the discursive struggle over meaning takes place. This dissertation adopted discourse-theoretical analysis to look into the meaning-making circuit of mass media representations and their audience receptions by means of a discourse-theoretical analysis. To ensure that the discourse-theoretical analysis of media representations and their audience receptions reaches the level of a discourse-theoretical analysis, the relation between media and discourse needed to be theorised, which was done with the concepts of operationalisation and identification (and later the concept of recognition, brought to the surface during the reception analysis). These concepts are not merely theorisations of the relationship between discourse and the meaning-making circuit of mass media, however. They also actually served, supported and facilitated the identification of discourses in media representations and their audience receptions. The notion of operationalisation has proven its usability in drawing attention to the way discourses are materialised and imported in media contents, according to a number of media-specific logics of representations. These logics (e.g. dramatisation, personification, publicness) facilitate and support the importation of particular discourses and privilege certain ways of articulating signifiers while hampering the importation of other discourses and other ways of articulating signifiers. The notion of identification has proven to be a particularly relevant concept when analysing talk from a DT perspective in that it makes the researcher attentive for the way individuals, when engaging in talk, identify with particular discourses and subject positions. Given that qualitative interviews often face the problem of social desirability, identification is a crucial concept because it helps drawing attention to subtle, latent and implicit ways of putting things that – sometimes despite of what is said in more explicit terms – point in the direction of a certain way of subscribing to, negotiating or contesting discourses.

The concepts of operationalisation and identification have been deployed here in the light of an analysis of print media representations and their audience reception, where a number of other concepts (including DT concepts, concepts arrived at through a DT-reading of existing literature on death and dying (in the media) and a number of discourse-analytical and linguistic concepts) supported the analysis. But the notions of operationalisation and identification can also be used to conduct a discourse-theoretical analysis of other textual material, where texts – as should be clear by now – are defined in terms of the materialisation of meaning.

Different textual entry points for the analysis of the construction of the good death demand for a different implementation of DTA. While similar research questions are formulated, a DTA of media material and conversations, in which scholars integrate linguistic concepts into a DT framework, demands a different approach than, for instance, a DTA of architecture and interior design, which would urge scholars to - amongst others - engage with the notion of space (see part 4 of this general conclusion). One of the things the discourse-theoretical analysis conducted in this dissertation has learned us is indeed acknowledging that the circulation and construction of meaning in textual material cannot be seen in isolation from the very logics inherent to that material. Taking along logics of media-representation as contextual information allowed us to reach a more in-depth understanding of the discursive construction of the good death in mass media and the differences in these constructions between the different media genres that were analysed. It also prevented us from lapsing into a view where media are merely sites for the circulation and reproduction of existing discourses.

3.3. The circuit of mass media and the construction of the good death

At the empirical level, the discourse-theoretical analysis of media representations of the medicalised death and their audience receptions allowed us to generate insight into the way the meaning-making circuit of mass media is part of a broader discursive configuration, but is at the same time a specific meaning-making circuit that is marked by specific logics of representation and identification.

In both media representations and audiences' talk about these representations, we found materialisations of the meaning of the good death. The nature of these materialisations illustrates how media representations and the moment of media reception are embedded in a particular discursive configuration, where a medical-revivalist discourse on death is dominant. The analysis of media representations and their audience receptions has pointed in the direction of a relatively stable basis on which the more contingent level of the meaning of the good death builds. More concretely, the analysis bears witness of the hegemony of a number of basic ingredients of the good death, including the importance of quality of life and well-being and the right to participate in end-of-life decision-making. On top of this more stable foundation, contingency emerges as the signifiers of autonomy and dignity become articulated with a number of other concepts (of which care is probably the most important one) in a variety of ways – illustrating how the construction of the good death is still very much embedded in an atmosphere of struggle over meaning.

The main lessons learned from the discourse-theoretical analysis are tied to the ‘how’, the ‘where’ and the ‘why’ of the construction of the good death in the analysed media products and their audience receptions. First of all, the discourse-theoretical analysis provided insight into the way constructions of the good death come into being in both media representations of the medicalised death and in audience receptions of these representations. In media representations, constructions of the good death emerge through the operationalisation of discourses through specific mechanisms of representation. During the moment of media reception, constructions of the good death come about through practices of identification during which audience members subscribe to, negotiate or contest discourses operationalised in media representations of the medicalised death.

In the construction of the good death in the meaning-making circuit of media representation and audiences’ receptions, coverage of personal cases has shown to be particularly relevant. One of the main empirical insights arrived at in this dissertation is indeed the discursive and political significance of case coverage and its human-interest focus on the personal, the emotional and the intimate. More concretely, the analysis has demonstrated the significance of personal case coverage (embedded in a broader tradition of human-interest journalism) both in terms of media representation and in terms of audience receptions. Importing medical end-of-life decision-making into the realm of a personal case by means of logics and mechanisms of dramatisation and performativity, personification and intimisation, personal case coverage has shown to contain discursively very rich material. As mentioned, this type of coverage is not only significant in terms of media representation, it is also the type of journalism that triggered audiences the most during the interviews. More than in so-called harder genres, it is both in the representation of the end of life in human-interest journalism as in audiences’ receptions of these representations that a variety of specific articulations of the good death emerge.

Constructions of the good death not only emerge in personal case coverage and their audience receptions, but this coverage (very often appealing to human-interest techniques) is a place where they derive in-depth meaning. This in-depth meaning is achieved precisely by bringing the medical-political reality of medical end-of-life decision-making into the realm of a personal case. With this observation, I want to highlight the discursive richness and the political relevance of human-interest journalism, arguing that this type of coverage with its focus on the personal and the intimate is anything but trivial. Rather, human-interest coverage of the end of life provides a very fertile entry point for the discursive construction of the good death.

Emphasising the political relevance of human-interest journalism does not equal an unambiguous plea for this type of coverage, however. If anything, indeed, the analysis conducted here demonstrated that coverage focussing on a personal case has a democratic and emancipatory potential as well as a disciplining one (see also Harrington, 2008; Meijer, 2001). More concretely, a number of factors seem to enhance the possibility that human-interest journalism on the medical end of life becomes disciplining and limiting in its construction of the good death. A first factor is the type of actor around which the coverage revolves. First, when the article deals with the death of a prominent individual, like a politician or a writer, this encourages the importation of certain discourses (like a discourse of independence) and the setting in motion of certain media-logics (like heroisation). These dynamics, in turn, facilitate a particular construction of the good death; one that defines euthanasia as the only possibility to die well. A second factor that enhances the possibility of human-interest journalism to be disciplining in nature is the embeddedness in an explicit political project, like the right to die project. Human-interest journalism has shown to be a very fruitful carrier of a right to die discourse, but combined with media-logics of representation, like the tendency to create ‘heroes’, its political embeddedness tends to result in a construction of the good death in terms of an antagonistic euthanasia versus palliative care opposition.

When attempting to describe what it is that makes human-interest journalism potentially emancipatory, we arrive at a less politicalised focus on the dying individual, who is generally an ‘ordinary’ person, and his experiences with the dying process and/or preferences in death and dying. Being detached from an explicit right to die (or contra-right to die) political project as well as a focus on 'ordinary' people, then, seem to optimise chances of a democratic and emancipatory construction of the good death, where a plurality of possible ways of encountering the end of life become visible. It is above non-prominent case coverage where this emancipatory alternative of human-interest journalism was found.

Despite the differences between prominent-case coverage and non-prominent case coverage in terms of pluralistic constructions of the good death, both (mainstream) categories of media coverage build on a similar hegemonic medical-revivalist foundation where the right of individuals to plan their own death and to make their own end of life decisions is accepted. It is at this point that a second main insight arrived at through the discourse-theoretical analysis becomes particularly relevant: specialised media are arenas for the circulation of counter-hegemonic discourses. It is indeed in the medical and the religious newspapers that counter-hegemonic discourses, like a communitarian discourse through which autonomy is contested and/or denied, are operationalised. Here, a significant parallel between the discourse-theoretical representation analysis and the discourse-theoretical reception analysis can be drawn. Throughout the interviews with audience members, it became clear that a number of constructions of the good death as emerging in the prominent-case coverage are fiercely contested, not in the least the construction of the hedonic death. While this contestation is, generally speaking, shared by all audience categories, doctors, especially those with a religious background, not only contest the hedonic death, they also sometimes contest what is at the core of the mainstream and hegemonic construction of the good death in the analysed media representations: the right to make the own end-of-life decisions, even if this involves the choice for euthanasia. The parallel between counter-hegemonic representations in medical (and religious) media and the reception of these representations by doctors (with religious backgrounds) suggests the special status of the medical field. The medical field, more concretely, is at least partly detached from a mainstream (Belgian) acceptance of the right to die, which is challenged in the medical field by a series of counter-hegemonic forces – not in the least a discourse of care. Put in a broader perspective, this observation suggests the connection between social (sub)fields and discourses; particular discourses are indeed much more dominant in particular social fields than in others – a mainstream dominant discourse sometimes becomes counter-hegemonic in a particular social subfield. It is remarkable in a certain way that it is precisely in the field where euthanasia is factually performed (which inevitably comes with a certain power) that resistance against the right to die is most prominent. This, in turn, supports the thesis that discourses do matter and have a significant symbolic power. Indeed, a mainstream acceptance of the right to die – materialised in mainstream media representations but also in the existing Belgian legal framework – has in a way been imposed upon the media field, where doctors not always share this acceptance.

It is important to note here, once again, that the dynamics between hegemony and counter-hegemony cannot be isolated from the context in which they operate. The importance of the specificity of media and of the specificities of their subgenres has been emphasized several times throughout this dissertation. But at this point it is crucial also to highlight the importance of national context. It has been explained a number of times throughout this dissertation that Belgium is one of only a small number of countries where euthanasia, i.e. administering life-ending medication on the explicit request of the patient, is legal under certain circumstances. This specific national legal framework both contributes to and is a (material) outcome of a dominant acceptance of the right to die. When zooming out from the specificity of the Belgian context, however, it becomes very clear that this dominance is not a specific example of a more encompassing (international) hegemony. The most recent example that bears witness of the fact that the dominance of a Belgian right to die acceptance (embedded in a more encompassing discourse of the good death structured around autonomy and dignity as nodal points) is not part of an international hegemony is found in an essay published in The New Yorker (June 22, 2015), where euthanasia and the right to die are described in terms of an ‘out of control’ secularism and liberalism:

> Distelmans [oncologist, right to die activist and professor in palliative care], who wears leather coats and boots and artfully tossed scarves, has become a celebrity in Belgium for promoting a dignified death as a human right, a "tremendous liberation", and he gives talks at cultural centres, hospitals, and schools around the country […] In Belgium, euthanasia is embraces as an emblem of Enlightenment and progress, a sign that the country has extricated itself from its Catholic, patriarchal roots […] The right to a dignified death is viewed as an accomplishment of secular humanism, one of the seven belief systems that are officially recognized by the government

4. Directions and implications for further research

This dissertation hopes to inspire further discourse-theoretical research into death and dying as well as further research at the intersection of media studies and discourse theory.

The dissertation, first of all, aspires to trigger further discourse-theoretical research into audience receptions of media representations and provide them with a discourse-theoretical model of media reception that captures recognition and identification as two distinct processes of interpretation. Analyses of audience receptions of media representations of, for instance, issues of 'life-and body politics' (see section 1 of the general conclusions) can validate the applicability and accuracy of this discourse-theoretical model outside the field of thanatology. The dissertation also hopes to draw the attention of media scholars to the discursive richness and political relevance of human-interest journalism. The claim that human-interest journalism is politically relevant is of course not new (see e.g. Gripsrud, 2008; Harrington, 2008; Machin and Papatheoderou, 2002; Meijer, 2001). But this dissertation hopes to have interpreted and explained the disciplining and emancipatory potential of human-interest journalism at the intersection of discourse theory and media studies, precisely by drawing attention to the interplay between discourses and media logics. Again, research situated outside the field of thanatology can further validate the thesis about the political relevance of human-interest journalism. Think for instance of an analysis of media representations of imprisonment and their audience receptions. Here, an hypothesis would be that human-interest journalism, more than so-called harder and more objective news genres, allows for a specific interaction between the political reality of imprisonment with logics of representation – making a different kind of representation possible, one that for instance constructs the subject position of the prisoner potentially in a more human way and that gives access to stories of injustice, racism and poverty in a way that engages and involves audiences.

It is another aspiration of the dissertation to have released an impulse for further discourse-theoretical research into death and dying. It has been mentioned before that thanatology has remained largely unexplored by discourse theorists. One exception is discourse-theoretical research into death and killing in the context of war and (political) conflict – for instance through the theorisation of the discursive construction of the enemy and of killing as an ethical act (see for instance Carpentier, 2014). But most segments of death and dying are yet to be discovered by discourse theory. One example of possible further research at the intersection of discourse theory and thanatology is for instance a discourse-theoretical analysis of public rituals surrounding death and dying. Another example, closer to the issue of the right to die that was part of this dissertation's research focus, is the issue of suicide. The list of examples goes on, of course, but crucial to note is that a discourse-theoretical contribution to research into a wide variety of thanatological topics would be characterised by a critical distance from normative frameworks and guided by a research interest in shedding light on their contingent nature and the sphere of struggle and antagonism in which they are embedded.

At the more specific intersection of discourse theory and thanatological research into the medicalised death, it would be of interest for further research to explore textual material that has not been included in this dissertation. This research is indeed limited in that it is not entitled to produce claims about any other textual material than that of the analysed media representations and audience receptions of these representations. Complementing this research with analyses of other textual material is desirable to further validate the research findings of this dissertation.

In the field of media studies, scholars can turn their attention to a variety of media genres, including for instance documentary and popular fiction. At the intersection of thanatology and communication studies, examples of textual entry points are interpersonal communication between patients and their caregiver, where scholars can focus on the way both patients and caregivers identify with particular discourses on the good death and with particular subject positions like those of the empowered patient and the sensitive and/or serving doctor, and euthanasia request forms, where a discourse-theoretical analysis can focus on the way the writer of the letter identifies with and negotiates a right to die discourse. Outside the field of media- and communication studies, textual entry points can be policy documents and practices on end-of-life care – where scholars can focus on the way particular (shared) meaning systems surrounding death and the good death steering these documents and practices. Another, less obvious textual entry point, would be to study material artefacts like architecture and designs. As became clear throughout this dissertation, the notion of text encompasses much more than only written or spoken language in a discourse-theoretical tradition – which brings in a variety of analytical entry points that stretch away from 'language'. An option is to analyse the architecture and (interior) design of hospices and palliative care units, where discourse theorists would be interested in the way hospice architectures and designs operationalise and materialise a hospice end of life philosophy in a way that structures the physical ability of the dying patient (and his relatives) to move and to undertake certain (physical) activities.

By extension, further research adopting discourse-theoretical analysis can be done into other segments of death and dying like those mentioned above (death rituals, suicide). This would place the DTA of the construction of the good death in media conducted here in an even broader perspective, shedding light on the discursive configuration(s) in which the medicalised death and debates about medical end-of-life decision-making, suicide, and public rituals surrounding death and dying are embedded, and thus on an encompassing 'culture of death'.

For now, this dissertation hopes to have enhanced insight into the debates about medical end-of-life decision-making by drawing attention to the discursive construction of the good death in the meaning-making circuit of mass media. The dissertation, more specifically, aspires to have shed light on the contingent nature of discourses on death and the good death, and on the discursive struggle for meaning over the good death and the way mass media operate as specific discursive arenas where this struggle takes place. The dissertation indeed hopes to have generated insight in the specificity of mass media as discursive machineries and on the logics and mechanisms of media representation and audience reception at work in the discursive construction of the good death.

LIST OF PICTURES, TABLES, AND FIGURES

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