Thesis submitted in fulfillment of the requirements for A joint PhD degree as
Doctor in Social Health Sciences (Faculty of Medicine & Pharmacy, Vrije Universiteit Brussel) &
Doctor in Health Sciences (Faculty of Medicine and Health Sciences, Ghent University)

Using a health promotion approach and behavioral theories to gain insight into factors related to palliative care behaviors among people confronted with serious illness

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2022

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This doctoral thesis is supported by a grant from the Research Foundation Flanders and the special research fund of Ghent University.

We all get dealt cards. Some of us get better cards than others. And while it’s easy to get hung up on our cards, and feel we got screwed over, the real game lies in the choices we make with those cards, the risk we decide to take, and the consequences we choose to live with. People who consistently make the best choices in the situations they’re given are the ones who eventually come out ahead in poker, just as in life. And it’s not necessarily the people with the best cards.

- **Mark Manson**

CONTENT

LIST OF CHAPTERS

Chapters 2-7 are based on the following publications

Chapter 2

Scherrens A, Beernaert K, Robijn L, Deliens L, Pauwels N, Cohen J, Deforche B. *The use of health behavior theories in end-of-life care research: a systematic review.* Palliative Medicine [2016 SCI impact factor: 4,22; journal ranking Q1; ranking n° 19/154 in Health Care Sciences and Services]

Chapter 3

Scherrens A, Deforche B, Deliens L, Cohen J & Beernaert K. *Using behavioral theories to study health-promoting behaviors in palliative care research.* [Submitted]

Chapter 4

Scherrens A, Cohen J, Mahieu A, Deliens L, Deforche B & Beernaert K. *The perception of people with cancer of starting a conversation about palliative care: a qualitative interview study.* European Journal of Cancer care [2018 SCI impact factor: 2,421; journal ranking D1; ranking n° 5/120 in Nursing]

Chapter 5

Scherrens A, Beernaert K, Deliens L, Lapeire L, De Laat M, Biebuyck C, Geboes K, Van Praet C, Moors I, Deforche B & Cohen J. *Identifying the most important behavioral correlates of starting a conversation about palliative care with the physician: a cross-sectional structured interview study in people with cancer.* [Submitted]

Chapter 6

Scherrens A, Cohen J, Deliens L, Beernaert K & Deforche B. *Development of a theory-based behavioral intervention to help people with cancer to start a conversation about palliative care: combining intervention mapping with a participatory approach.* [Ongoing]

Chapter 7

Scherrens A, Beernaert K, Magerat L, Deliens L, Deforche B, Cohen J. *Palliative care utilisation: family carers' behaviours and determinants – a qualitative interview study.* BMJ Supportive and Palliative Care. [2018 SCI impact factor: 3,208; journal ranking Q1; ranking n° 21/98 in Health Care Sciences and Services]

ACKNOWLEDGEMENTS – DANKWOORD

Ik zou nooit, maar dan ook nooit doctoreren… Te saai, te uitdagend, te onzeker.
Dit doctoraat, dit traject van 6,5 jaar of 79 maanden, werd uiteindelijk een onvergetelijke reis.
Mede mogelijk gemaakt door de aanwezigheid en de steun van de vele mensen rondom mij.
Dus daarom “een grote dankuwel”.

Dankuwel aan mijn promotoren en co-promotoren. Benedicte en Joachim, bedankt om mij in de zomer van 2015 onverwacht te contacteren, mij deze kans te geven en mij vooral te overtuigen om deze kans te grijpen. Jullie expertise en begeleiding zijn van onschatbare waarde. Ook omarm ik jullie aandacht voor de mens achter elke onderzoeker en zijn/haar onderzoeksdoelen. Ik citeer Benedicte “iemand kan pas presteren, als hij/zij zich goed voelt”. Joachim, jouw geloofwaardigheid kan misschien nog net iéts beter… iets met No Sweat No Glory! Kim, ik mag in mijn pollekes wrijven dat jij bereid was om mijn supervisor te zijn. Ik ben mede de onderzoeker geworden die ik nu ben, dankzij dankzij jou en jouw support. Je zorgde steeds voor nieuwe (en soms uitdagende) ideeën; kwaliteitsinjecties; structuur in mijn onvoorziene momenten van chaos; rust; maar ook voor een turbopil indien nodig. Je zorgde ervoor dat ik bij jou terecht kon, hetzij voor werkgerelateerde, hetzij voor niet-werkgerelateerde zaken. Ook heb jij mij geleerd hoe belangrijk het is om tijdig een verwezenlijking te vieren. Al een geluk dat er nog de smilies is. Verwijzend naar één van onze avondjes uit, ik verwacht jou nog wel op een dag mét spandoek langs de zijlijn. Luc, bedankt om mij -die voetbalster- de kans te geven om mij te ontwikkelen als junior onderzoeker binnen jouw succesvolle onderzoeksgroep. Mede dankzij jou zit health promotion in palliatieve zorg onderzoek in de lift.

Dankuwel aan de artsen, verpleegkundigen en het medisch secretariaat van het UZ Gent, AZ Sint-Lucas, Palliatief Netwerk Gent-Eeklo, palliatieve dagcentra en huisartspraktijken om in mijn project te geloven en mij telkens opnieuw te helpen in mijn zoektocht naar geschikte deelnemers.

Een warme dankuwel aan alle mensen die hebben deelgenomen aan mijn studies. Wat een verrijking om deze mensen één voor één te leren kennen en naar elk uniek levensverhaal te mogen luisteren. Dé boost om door te gaan met mijn onderzoek, en te blijven doorgaan.

Dankuwel aan alle collega’s. Voor de vele leermomenten; maar vooral voor het creëren van zo een warme en leuke werksfeer. Alle mensen van de eerste verdieping van gebouw K te Jette, de zesde en vierde verdieping van gebouw K3 te Gent. Waar ik mijn laptop ook opendeed, jullie zorgden telkens voor dat welkom-op-het-werk gevoel. Jeanny zou nooit meer hetzelfde klinken. En ook Bring sally up zou nooit meer hetzelfde klinken. Twee zo een onderzoeksgroepen, is als het beste van de twee werelden. Een bijzondere dankuwel aan de volgende mensen. Laure en Isabel, van het delen van PhD vreugde en stress, tot het delen van (te) spannende privéverhalen, tot het delen van een kamer op congres. Mijn volgende boek gaat over "het (PhD)leven zoals het is" en jullie zijn de trotse co-auteurs. Mijn bureaugenootjes, Plant A, Anneke & Annelies: het is een voorrecht om elke dag door mensen als jullie omringd te zijn. Jullie verzorgden al die jaren mijn constante aan motivatie en inspiratie. Jullie bom aan energie zorgt er voor dat ik zelf een dag na een pittig avondje Charlatan kan overleven. In naam van ons allen, bied ik bij deze mijn excuses aan aan de andere collega's op de gang voor de decibels van onze aanwezigheid. En om nu eindelijk op de onderzoeksvraag "kunnen collega's vrienden zijn?" te antwoorden… een significante absoluut! Maar… ik raad daarom niet onmiddellijk aan als één collega jumpt in de sky, om mee te jumpen in de sky. Dat zou wel eens kunnen tegenvallen. Gelukkig is er zoals steeds de sorry-poes ter troost. Subtiele knipoog.

Dankuwel vrienden, familie en gezin. Om mij -als die eeuwige studente- te steunen bij het schrijven van deze "grote thesis". Om elk op jullie eigen manier een beetje extra kleur te geven aan mijn leven en een beetje stress weg te nemen tijdens het afgelopen stressvolle jaar. Voske, Sofie, Lotte, Bruneel, Ilse, Capi, Summer, Romy alsook al mijn voetbalteamies. Eén voor één verdienen jullie een medaille voor beste regisseur van Plezier, Ontspanning, Beweging en Verbondenheid in het Leven van Lorie. Het leven is een… Welja, laat het ons houden op het leven is een feest! Voske, nu ik de kans krijg om het te vereeuwigen in mijn dankwoord. Je bent een ge-wel-dige madam, die quasi elke dag zoveel gemakkelijker en leuker maakt. Ook Lotte en gezin, als misschien wel onverwachte grote supporter(s). Om mee te leven, om stillekes te zijn en voor al het lekkers op mijn bord. De Sugarnurses & High School Chicks, voor de talrijke etentjes en vooral voor jullie flexibiliteit bij het inplannen van deze etentjes. In mijn vertelronde, kan de PhD update nu alvast geschrapt worden. Mama, papa, broer en gezin, allereerst om mij te doen geloven dat ik in staat was om deze unieke kans te grijpen. Om mij vervolgens telkens opnieuw van relevante krantenartikelen of jullie eigen ongezouten mening te voorzien. Om het nest warm te houden en toe te laten dat ik -die rooier- af en toe terugkom voor wat extra energie. Hetzij in de vorm van lekker eten, hetzij in de vorm van een goed gesprek. En nee broer, ik heb niets extra nodig van hen… Dat ik een ongelofelijke geluksvogel ben.

Zo gekeken naar de lengte van dit dankwoord, is er blijvende ruimte voor verbetering wat betreft het kort en bondig schrijven…

Kort en bondig: dankuwel ELK, voor ALLES.

- ***'Belangrijk'*** **door Annelie Scherrens**

LIST OF ABBREVIATIONS

- ACP Advance Care planning
- IMP Intervention Mapping Protocol
- TPB Theory of Planned Behavior
- WHO World Health Organization

PART I

GENERAL INTRODUCTION

CHAPTER 1

GENERAL INTRODUCTION

1.1 Introduction

People with cancer and their families develop palliative care needs well before the terminal phase of the disease[1,2]. If palliative care is timely discussed and initiated, problems other than those related to the cancer or tumor i.e. physical, psychological, social or spiritual problems, can be timely identified and addressed. Timely communication about palliative care creates opportunities to hear the patient and their families, to discuss (upcoming) needs and wishes and to plan the care of the patient. Timely initiation of palliative care leads to improved quality of care and quality of life in people with incurable cancer and their families[3–6]. Although evidence emphasizes the importance of timely initiation of palliative care for people with incurable cancer and their families, palliative care is often initiated too late or not at all[3,7]. This often leads to unmet palliative care needs and suboptimal care in the final months and weeks of life[8]. Efforts have been made to increase the proportion of people for whom palliative care is timely initiated[3,4]. However, palliative care research and practice is predominately approached as professional carers guiding care discussions and making care decisions[9]. Lack of attention is paid to the pertinent role that patients themselves and family carers[10] can play in timely initiation of palliative care[9]. Health promotion is a possible approach to empower patients and family carers in actively taking up these roles. Using a health promotion approach and behavioral theories in palliative care research can help to better understand palliative care behaviors, in order to develop effective and sustainable interventions aimed at improving these behaviors[11,12].

This dissertation is approaching the issue of timely initiation of palliative care through a health promotion lens. Using behavioral theories[11], the aim is to better understand and explain the behavior of starting a conversation about palliative care with the physician in people with incurable cancer. To better understand this patient behavior, its determining factors are identified. Following, the aim is to develop a theory-based behavioral intervention that is targeting these determining factors to help people with incurable cancer in taking the initiative in communication about palliative care with the physician[9,11]. The promotion of such patient behavior can contribute to more timely communication about palliative care between people with cancer and physicians, improvement of patient-empowerment, patient-centred care and thus a timelier initiation of palliative care and better quality of care and quality of life for the patient and his/her family. Additionally, this thesis focusses on family carer behaviors contributing to the initiation of palliative care for people suffering from a life-threatening disease (people with cancer and non-cancer diseases). Although behavioral theories have proven their worth in other domains of health promotion research, the use of a theoretically grounded focus on the role of palliative care behaviors of people confronted with serious illness is highly innovative and almost unexplored.

This introduction chapter provides a background to define and clarify central concepts such as patient-centred care, palliative care, palliative care needs, health promotion, behavioral theory and patient empowerment. Next, it will describe the state of the art of palliative care practice and research. Further, it will explain the methodology of using a health promotion approach and behavioral theories to improve timely communication and initiation of palliative care. Lastly, the research objectives, study design and methodologies used and the further outline of this dissertation are specified.

1.2 Background

Before 1950, death was typically sudden and caused by infections and injuries. In the meantime, patterns of population age distributions, mortality, fertility, life expectancy and causes of death changed[13]. Health care, treatments and public health improved[14]. Nowadays, more people live to old age, so life expectancy is increasing and death is more likely to occur non-suddenly[13]. People dying non-suddenly (e.g. people suffering from chronic diseases such as cancer, organ failure or frailty) experience a long trajectory of functional and cognitive decline[15]. Serious chronic and life-limiting diseases accounted for 73.6% of all global deaths in 2019[13]. Following heart diseases, cancer is the most prevalent chronic disease[16].

1.2.1 Cancer

Cancer is a general term for a broad family of diseases that can affect any part of the body. By developing cancer, abnormal cells are growing beyond their usual boundaries. Metastasis is the process of abnormal cells spreading to other parts of the body, which is the primary cause of death from cancer[16]. People with advanced incurable cancer are suffering from cancer that has spread to other parts of the body and usually cannot be cured or controlled with curative treatment[16].

Incidence and mortality rates

Globally, cancer is the second leading cause of death[16]. The Global Cancer Observatory data from 2020 shows that about 19.3 million new cancer cases occurred with female breast cancers as the most commonly diagnosed cancer (2.26 million cases, 11.7% of all new diagnosis) followed by lung (2.21 million cases, 11.4%) and colorectal cancer (1.93 million cases, 10%). Cancer caused nearly 10 million deaths. Lung cancer is the leading cause of cancer death (1.18 million deaths, 18% of all cancer deaths) followed by colorectal (935 000 deaths, 9.4%) and liver cancer (830 000 deaths, 8.3%)[16,17]. The number of new cancer cases is expected to increase with 47% i.e. from 19.3 million in 2020 to 28.4 million in 2040. This number will keep increasing mainly due to demographic changes. In Belgium, 83 267 new cancer cases occurred in 2020[18]. Possibly, this incidence rate is lower due to the COVID-19 pandemic as a reduction of 44% in total diagnoses of invasive cancers was observed in April 2020 compared to April 2019 (the first wave of the COVID-19 pandemic). There were an estimated 4000 fewer new cancer diagnoses[19]. In Belgium, cancer and heart diseases are the main groups of causes of death, accounting for more than half of all deaths (2018). Cancer caused 28% of all deaths (2018)[18].

Cancer trajectory

The trajectory of functional decline of people with cancer differs from other major types of chronic diseases such as organ failure and physical and cognitive frailty[20]. Figure 1 illustrates that people with cancer mostly maintain comfort and functioning for a substantial period, followed by a short period of health status decline and usually a clear terminal phase. This trajectory of functional decline entails reasonable predictivity, with the substantial period of functioning maintenance creating opportunities to plan care in advance[21].

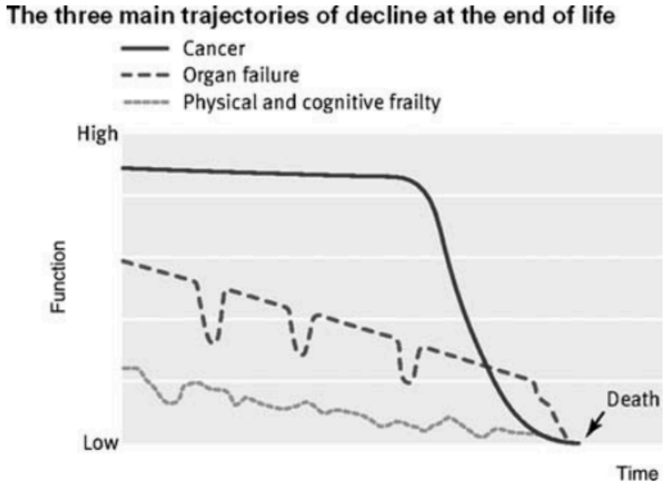

Figure 1. The three main trajectories of decline at the end of life, adapted from Lynn and Adamson (2003)[20]. With permission from RAND Corporation, Santa Monica, California, USA.

1.2.2 People with cancer and their palliative care needs

People diagnosed with cancer generally receive oncology care. Standard oncology care mainly focuses on cancer-directed therapy and aims to cure the cancer, improve symptom burden, reduce medical complications related to cancer or prolong life[6,22]. People with incurable cancer might experience high symptom burden, develop palliative care needs such as physical (e.g. pain), psychological (e.g. emotional support on fear or depression), social (e.g. social support in daily living activities such as domestic work or transport) or spiritual needs (e.g. dignity)[1]. They might also need health information and care planning[23,24]. They often experience a decline in their quality of life over the disease trajectory[1]. People with cancer are one of the largest populations among the chronic disease groups that potentially might benefit from palliative care[13,16,25]. Of the 40 million people in need of palliative care each year, 34% are people with incurable cancer[16]. The number of people with cancer with a combination of physical, psychosocial and/or spiritual problems and in need of palliative care will keep increasing, due to the growing number of people diagnosed with cancer, the elderly population and people with comorbidities[16,26].

People with cancer often experience that palliative care needs are unmet and not always well addressed[23,24,27,28]. Moreover, not only patients develop palliative care needs, but also their families supporting the care. For example, psychological distress highly occurs in family carers of people with incurable cancer[29]. A systematic review (2018) identifying the unmet care needs in people with incurable cancer and their family carers showed that emotional support was the most commonly unmet need in patients and information need in family carers.

People with cancer have various needs throughout their cancer trajectory. The trajectory of functional decline of people with cancer corresponds to a specific set of care priorities, including oncology care and palliative care[30]. Previous research shows that people with cancer have palliative care needs already and substantially present from diagnosis and well before the terminal phase of the disease[2,17,31,32].

This dissertation mainly focuses on people diagnosed with advanced, incurable cancer (potentially) developing palliative care needs and who might benefit from palliative care, now or in the future. Important to note, people with palliative care needs not necessarily have the preference or wish to utilize palliative care.

1.2.3 Palliative care for people with cancer

Palliative care: definition

Oncology care mainly focuses on the symptom-related problems, whereas palliative care in cancer focuses on relieving symptoms caused by cancer[33] and uses a holistic approach to the quality of life of both people with cancer and their families[3,4,6]. The World Health Organization (WHO) defines palliative care as *an approach that improves the quality of life of patients and their families facing the problems 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*[16].

The WHO states that '*palliative care is a crucial part of integrated and patient-centred health care*[16] and*:*

- *Provides relief from pain and other distressing symptoms;*
- *Affirms life and regards dying as a normal process;*
- *Intends neither to hasten or postpone death;*
- *Integrates the psychological and spiritual aspects of patients care;*
- *Offers a support system to help patients live as actively as possible until death;*
- *Offers a support system to help the family cope during the patients' illness and in their own bereavement;*
- *Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *Will enhance quality of life, and may also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'*

One possible way to understand the different levels of palliative care, is to distinguish generalist from specialised palliative care[34]. Generalist palliative care or primary-level palliative care refers to palliative care delivered by regular professional carers who apply basic competences and skills and for whom palliative care is not the main focus of their clinical practice (e.g. family physicians, oncologists, specialists or nurses). They should, in principle, recognize palliative care needs and meet them under ordinary circumstances and refer to specialist palliative care experts or services in more complex situations. Specialised palliative care refers to palliative care delivered by a multidisciplinary team of professional carers who are specially trained in palliative care (e.g. palliative care physicians or nurses). Specialised palliative care is recommended for people confronting a serious illness with more complex and challenging care needs that can no longer be met with primary care[34,35]. Considering the upcoming demographic change, i.e. aging population with high numbers of chronic diseases and comorbidity, and annual increase in death, a growing demand for specialised palliative care is expected[26].

In this dissertation, palliative care always refers to both generalist and specialised palliative care.

Shifting to a new model of palliative care

With the change from acute to chronic diseases causing death throughout the years, the initiation of palliative care has evolved and is still under debate. Its meaning and operationalization evolve continuously in both the scientific research field and health care services and depends on the patients' situation, needs and care wishes[36]. The old palliative care model (1960s), a 'Transition Model' (Figure 2), illustrated a clear cut-off between curative and palliative treatment and suggested that palliative care should be initiated when therapies are exhausted and in the terminal phase[37]. Currently, the lights are on a new paradigm of simultaneous curative and palliative care. The 'Trajectory Model' of palliative care by Lynn & Adamson (2003) (Figure 2), illustrates earlier integration of palliative care in the curative care for people confronting chronic, life-limiting diseases. Palliative care should become a part of the care from diagnosis to death, with gradually becoming the main focus as death approaches[20]. The importance of curative and life-prolonging care relatively decreases and the importance of palliative and comfort care increases over time. This 'Trajectory Model' considers the trajectories of these chronic diseases as complex, slowly-evolving and with a time-span from months up to a few years. A combination of curative and palliative care can better respond to patients' specific wishes and needs over time[20]. However, this care model might not suit to all people confronted with a life-threatening disease (e.g. those having a gradual, progressive decline with unpredictable exacerbations)[30]. Recent studies also suggested small adjustments to this model, e.g. according to key transition phases in end of life care[38] and palliative care modalities[39].

The WHO also highlights that palliative care can be initiated early in the disease trajectory, i.e. from the moment one develops palliative care needs, possibly in conjunction with other therapies that are intended to cure or prolong life (e.g. chemotherapy or radiotherapy)[16].

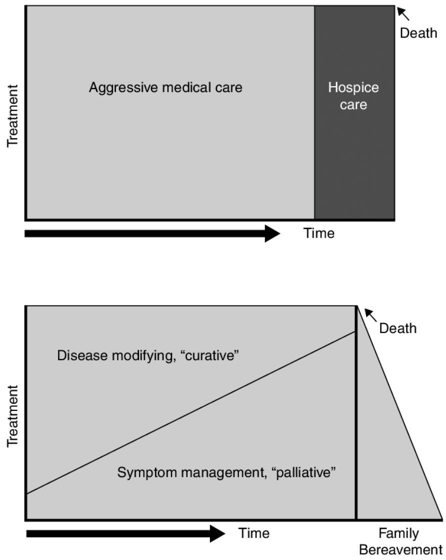

Figure 2. The older ‘Transition Model’ (above) vs. a ‘Trajectory Model’ of palliative care (below), reproduced from Lynn and Adamson (2003)[20]. With permission from RAND Corporation, Santa Monica, California, USA.

In this dissertation, the WHO vision is followed. The starting point is that a palliative care approach can be relevant from a chronic and life-limiting diagnosis and that it is compatible with any kind of care, whether goals involve disease-modifying (curative or palliative) treatments or whether the focus is exclusively on palliation of symptoms and suffering without disease modification[40]. However, palliative care should be initiated based on patients’ needs, preferences and wishes rather than on diagnoses, prognoses and the standard or curative care[41].

Timely palliative care: prevalence and health effects

Timely initiation of palliative care, i.e. timely and appropriately addressing the palliative care needs and not waiting until the terminal phase or the last weeks or days of life, should be promoted alongside standard oncology care[27,42]. Accumulating data from randomized controlled trials of early integrated palliative care models[3–6] as well as from quasi experimental and observational studies[43,44] show that timely initiation of palliative care leads to improvement of outcomes of both the patient and his/her family confronting life-limiting disease. At patient’ level, timely initiation of palliative care positively affected symptom intensity, mood and distress, aggressiveness of care, patient-centred care, satisfaction with care, survival time, quality of care and quality of life[3–6,43]. At family carer’ level, positive outcomes were related to mood and distress, burden, satisfaction with care, quality of care and resource use near end of life[3–6]. In addition to these study results, WHO data show that timely initiation of palliative care leads to more effective and efficient palliative care delivery, which reduces unnecessary hospitalization and use of health-care services and thus health care costs at society level[16].

Worldwide, access to palliative care is rather inconsistent as only 14% of people who need palliative care receive it[16,45]. Despite the beneficial effects of timely initiation of palliative care, (inter)national studies show that the older model of palliative care is still frequently used in oncology. Palliative care is often initiated too late, i.e. on average 15 days before death[7,46], or not at all[3,46]. Due to rather late initiation, the benefits of palliative care are not maximized[7,46]. It may result in suboptimal care in the final months and weeks of life[8] and a poorer quality of life in both the patient and his/her family[47]. Patients not timely receiving palliative care frequently receive aggressive and potentially avoidable treatments and interventions near death[48].

These findings emphasize that it should no longer be questioned whether palliative care should be initiated, but rather when the ideal time is to do so[23].

1.2.4 People involved in the initiation of palliative care for people with incurable cancer

Many people are involved in the care for people with incurable cancer and can potentially play a role in the initiation of palliative care for them. The most important are described below: the patients themselves, family carers, physicians, other professional carers, volunteers and community members.

The main focus of this dissertation is on the patient and the family carers and physicians around the patient.

The patient

The patient being diagnosed with an advanced, incurable cancer is the central person. The main goal of quality oncology care should be to provide patient-centred care, which is defined by The Institute of Medicine (USE) as *providing care that is respectful of and responsive to individual patient's preferences, needs, and values and ensuring that patient's values guide all clinical decisions*[49]*.* Patients also have unique abilities to communicate about their preferences, (unmet) care needs and to be actively involved in the initiation of palliative care[50]. However, most patients expect their professional carer, whom they trust, to take initiative in the initiation of palliative care if needed[51,52], which shows that patient empowerment is still not well-established[52]. The European Patients Forum defines patient empowerment as *the process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important.* Patient empowerment enables patients to keep control over their disease, enhances their autonomy and improves patient-participation in care[52]. Autonomy is *the right to make autonomous decisions about their health care,* with autonomous decisions defined as *those made intentionally and with substantial understanding and freedom from controlling influences*[53]**.** Attention for patient empowerment is growing in public health research and health policies, but not in palliative care research and policies. Currently patients do not receive sufficient support to become equal partners in palliative care[54]. Nevertheless, experimental studies aimed at patient empowerment among patients with cancer have resulted in increased patient satisfaction and better health[56,57]. Using a patient empowerment approach in palliative care studies can increase the patients' knowledge, attitude and skills[57] necessary to stimulate them to be actively involved in communicating[58] and planning palliative care in advance. This can result in more patient-centred care[59], timely initiation of palliative care and higher quality of it.

This dissertation emphasizes the potential role of the patient in taking initiative in initiating palliative care and mainly focusses on the patient taking initiative in communicating about palliative care (needs and possibilities) with the physician.

Family carers

A family carer can be defined as a non-professional who continuously or regularly provides care support to a person with a significant need for care and with whom they not necessarily have a familial relationship but a close relationship. Family carers can be family (mainly spouses or children), but also friends or significant others. The combination of providing care and sharing the experience of illness with the patient[60], affects the family carers' physical and psychological health and wellbeing[61]. Evidence shows that family carers play a crucial role in providing physical, psychological and social support and in coordinating the care for people with cancer[10]. They also have the potential to play an important role in timely initiation of palliative care for the patient.[10,60,62,63]. Family carers actually have a twofold role in it. In addition to the care they provide to the patient, they also receive support (e.g. psychological support, practical support) as palliative care also focuses on family carers' outcomes[60].

Family care support depends from country to country and on the organization and culture of care. In Europe, the prevalence of family carers ranges from 13 to 29 percent[64]. In Belgium, about 24% of the population over 50 years of age is a family carer**.** Considering the long-term care system, the importance of family care will keep on increasing due to the growth and ageing of the population[65]. On the other side, several factors might negatively affect the availability of family care. The Flemish

Informal Care Plan (2016-2020) reported that the availability of family carers may decline because of societal changes (e.g. smaller family sizes, more women active in the labor market)[66].

Physicians

Various physicians are involved in the care for people with incurable cancer: the family physician, the oncologist and other specialists (e.g. the pulmonologist)[67]. Communication and collaboration between these physicians is necessary for ensuring continuous and quality oncology care. Physicians are involved in facilitating end-of-life discussions[68] and can play an important role in recognizing palliative care needs, communicating about palliative care and its possibilities, initiating generalist palliative care and referring to specialised palliative care in case of more complex and challenging situations[42].

The type of physician who takes responsibility for initiating palliative care, depends on the patient, the phase of cancer and other factors. Patients spending most of their time at home prefer their family physician as key figure[69]. In Belgium, and many other countries, family physicians are the responsible for palliative care at the primary care level[70,71]. Other determining factors, are the patient-physician relationship and physician' characteristics (e.g. palliative care training)[2,72].

Other people involved

Next to the patient, family carers and physicians, other people can play an important role in the initiation of palliative care for people with incurable cancer: other professional carers than physicians and volunteers. Their role is shortly described, as these people and their roles were not the main focus of this dissertation.

The multidisciplinary team around people with incurable cancer consists of various other professional carers such as nurses, support workers, paramedics, pharmacists, physiotherapists etc.[16]. Both professional carers from the primary care setting as the palliative care setting can play an important role in the initiation of palliative care[33]. Next, volunteers can be involved in supporting the care for people with incurable cancer and their families and can positively influence their quality of care[73,74]. Volunteers are people who are not family members nor friends, did not follow a formal training in health care and are unpaid. For example, their care support can include facilitating the access to high-quality information and providing psychosocial and existential support[75]. Volunteers are involved in palliative care provision in both institutional and community-based settings[76]. Trained volunteers will become more and more important in the future to fill the gap between the availability of professional palliative care services and the increasing demand for palliative care in people confronting a serious illness[26,74], partly due to increasing resource constraints in professional health care and the population growth and ageing[26].

1.2.5 Barriers and facilitators in the initiation of palliative care for people with cancer

Barriers and facilitators experienced among people who can play an important role in the timely initiation of palliative care affect its initiation. For example, the majority of patients, family carers and professional carers are not aware of the meaning of palliative care (e.g. beliefs such as palliative care being equal to terminal care) and its (potential) benefits[16,27]. Existing literature mainly focused on barriers and facilitators among professional carers and shows that they do not systematically assess non-acute care needs and recognize palliative care needs rather lately[2,42], experience lack of clarity about their role, the right time for referral and how to refer. Professional carers also perceived inadequate communication, limited experience, lack of knowledge and skills and lack of self-confidence as important barriers[70,77]. Luckily, evidence also shows that people involved in the care for people with incurable cancer frequently indicated that overcoming these barriers and strengthening the perceived facilitators helped them or could help them to contribute to timely initiation of palliative care. Knowledge, competences and skills, continuity of care, multidisciplinary collaboration and collaboration between professional carers and lay carers (family carers, volunteers), adequate and timely communication about palliative care were identified as facilitating factors in previous studies[78,79]. Information about the perceived barriers and facilitators related to the initiation of palliative care among all those involved in the care for people with incurable cancer creates opportunities to improve timely initiation of palliative care. Next to these experienced barriers and facilitators at patient, family carer and professional carer level, organizational and structural factors such as resources, time constraints, workloads and work environments are influencing the initiation of palliative care for people with cancer[80].

1.2.6 Using a health promotion approach that focuses on communicative behavior to improve timely initiation of palliative care for people with cancer

Increasing effort is put internationally in trying to increase timely initiation of palliative care for people with cancer[3–6]. Considering existing literature, palliative care research is mainly dominated by the paradigm of pathogenesis, i.e. focusing on assessing and improving the biopsychosocial factors causing problems and suffering[9]. Additionally, the focus is usually on the role of health services or professional carers in achieving this[59]. What seems to be completely lacking is a health promotion perspective targeting the behavioral aspects of timely initiation of palliative care. A health promotion approach can focus on the pertinent role that behavior[11] of the patient and important others involved in their care (e.g. family carers as well as physicians) can play. Patient behavior has an important influence on the quality of palliative care[2,8] and achieving change could improve the timely initiation of palliative care in the disease trajectory[12].

Communicative behaviors are one among other important palliative care behaviors that have been identified in a myriad of literature as positively influencing patient empowerment and patient-centred care and as crucial for quality palliative care[81–83]. Timely conversations about palliative care are needed prior to timely initiation of palliative care[78]. To accomplish this timely communication, all people involved and the health care system have to take their responsibility. Previous studies show that it occurs rather late in the disease trajectory and leads to unmet needs (e.g. information needs[84]) in people with cancer[85]. First discussions about palliative care are frequently postponed. For example, physicians often wait until the patient brings palliative care up because they fear that bringing it up themselves would be intrusive or discomforting[2], cause anxiety or stress or take the patients' hope away[86]. It is clear from previous literature that important barriers -and hence also opportunities- in initiating palliative care also exist at the level of the patient[78,84,85]. Qualitative research has indicated that patients often do not want to communicate about palliative care because they associate it with death, want to maintain hope and avoid emotional burden. They do not want to burden the professional carer with their psychosocial or existential needs but rather with purely physical and disease (as opposed to illness)-related problems[2,8]. Nevertheless, the majority of people confronted with a serious illness think about palliative care well before the terminal phase and would appreciate it if their physician starts a conversation about it[87]. Patients indicate that they want to be informed about palliative care well before the terminal phase[2,84], want their physician to know their palliative care wishes[88], and prefer an active role in decision-making at the end of life[89].

Of note, these barriers (and facilitators) were mostly identified by questioning professional carers' experiences instead of questioning patients themselves and almost exclusively focus on the perspective of professional carers and their role in starting a conversation about palliative care[9,72]. Therefore, there is a need for research that directly questions patients about starting a conversation about palliative care themselves.

This dissertation therefore focuses on people with incurable cancer starting a conversation about palliative care with the physician. This is a behavior that is assumed to be contributing to more timely communication about palliative care and more timely initiation of palliative care.

Health promotion approach: what's in a name

Following the Ottawa Charter of Health Promotion (1986), *health promotion is the process of enabling people to increase control over, and to improve their health*[90]. Only some of the empirical literature in palliative care research uses a health promotion or salutogenic approach that focuses on factors – such as psychological factors (e.g. empowerment, attitude, self-efficacy) and perceived socio-environmental factors – that stimulate health and wellbeing and on enabling people (e.g. patients, family carers, community members) to have control of these factors and to make healthy choices i.e. adopting behaviors that contribute to the timely initiation of palliative care[9]. Nevertheless, there is growing evidence showing that using a health promotion approach and focusing on promoting health behaviors in those confronted with serious illness can potentially improve their quality of life in their final days[91,92]. Theory-based behavioral research and interventions are needed to understand palliative care behaviors and to realize behavioral change. Health promotion research builds strongly on theoretical behavior theories[91,93]. The use of behavioral theories allows the identification of specific behavioral factors that contribute to the explanation of a behavior related to timely initiation of palliative care. Using behavioral theories makes it possible to understand why people confronted with serious illness do or do not perform certain behaviors. By developing interventions addressing the factors that most influence the behavior, a change in the behavior can be obtained[11,94]. Evidence shows that use of such models leads to more effective interventions and successful behavioral change[91,94]. Although many explanatory and intervention studies in end-of-life care and palliative care research focus on an end-of-life care behavior (e.g. advance care planning), not many appear to be guided by a behavioral theory that specifies how to understand the behavior and how to realize behavioral change[95].

Behavioral theories

Conceptualization and definitions

An exploratory behavioral theory is a theoretical framework or tool to understand why people perform certain health behaviors or why not, by identifying its behavioral factors. In scientific literature, depending on study aim and methodology, frequently used synonyms of behavioral factors are constructs, correlates, determinants or predictors. Behavioral factors are influenced by socio-demographic factors, but can be distinguished from these, because they are changeable whereas socio-demographic factors are not. A behavioral change theory can be used to change a specific behavior by using it as a framework for developing and implementing behavioral interventions targeting the specific behavior through its determinants[93,96]. There is a wide range of behavioral theories, which focus on various levels: individual, interpersonal, community or societal level. Multilevel theories focus on all levels[11,97]. These theories are by nature abstract and not content- or topic-specific. They can be generalized over behaviors and populations, but the weight of each factor can vary[11,98]. Behavioral theories can be used flexibly in research as factors can be added to a chosen behavioral theory [11].

In this dissertation, the Theory of Planned Behavior (TPB) is used as main theoretical framework to identify behavioral factors related to starting a conversation about palliative care with the physician and to explore behavioral factors related to family carer' behaviors contributing to the initiation of palliative care, but with the flexibility of adding behavioral factors from other behavioral theories.

Theory of planned behavior (TPB)

The TPB is an individual behavioral (change) theory, being the most widely used in health care research. The TPB incorporates three behavioral factors (attitude, subjective norm and perceived behavioral control) that influence a behavioral intention, which on its turn is the most important factor for the actual behavior[99] (see Figure 3). Attitude is the individual's positive or negative evaluation of performing the behavior. Subjective norm contains perceived social expectations[11,100]; i.e. the social pressure to perform or not to perform a given behavior. Perceived behavioral control is the subjective probability that a person is capable or has control over performing a behavior[100]. All these factors consist of population-specific beliefs about the behavior, e.g. attitude consists of outcome beliefs (outcome of the behavior, for example benefits) and evaluation beliefs (how important are these outcomes). Subjective norm can be divided into normative beliefs (what important people in the environment think about the behavior, for example the spouse of someone) and motivation to comply (how important is it to comply with these expectations). Perceived behavioral control is preceded by control beliefs[11,99].

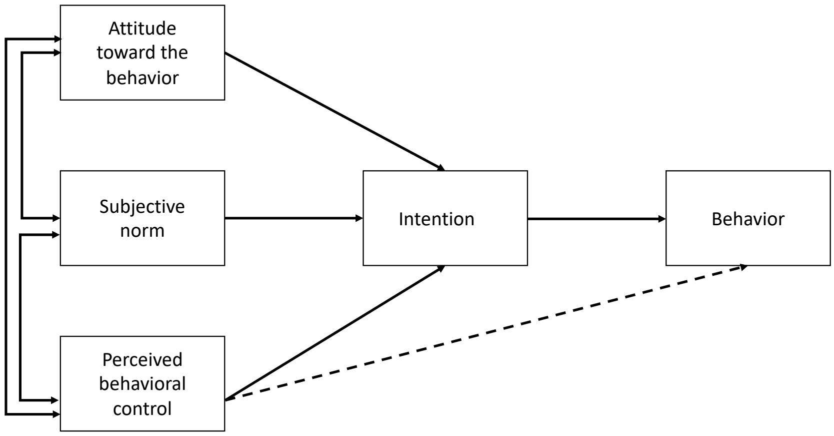

Figure 3. The TPB, redrawn from Ajzen (1991)[99]

1.3 Study objectives and research questions

This dissertation brings two research domains together, being health promotion research and palliative care research. Behavioral theories were used in order to better understand and explain palliative care behaviors in people confronted with incurable cancer and to develop a behavioral intervention aimed at patient behavior change. It has three main objectives, each with specific research aims.

1) **Objective 1:** To assess the end-of-life care studies that have used behavioral theories (*Chapter 2*) and to describe how behavioral theories can be used in the domain of end-of-life care research (*Chapter 3*). This objective has two specific research aims:

   1a. To assess what number of published end-of-life care and palliative care studies have used behavioral theories with the aim of understanding or changing an end-of-life care behavior; which theories were used; to what extent these studies did explore, operationalize, and measure all factors of the behavioral theory used; which behavioral outcomes were examined.

   1b. To describe how behavioral theories can be used to gain insight into critical factors of health-promoting behavior in seriously ill people, using the case example of 'starting a conversation about palliative care with the physician' for people with incurable cancer.

2) **Objective 2:** To better understand and explain starting a conversation about palliative care with the physician in people with incurable cancer in both the home care and hospital setting (*Chapters 4-5*) and to develop a theory-based intervention aimed at patient behavior change (*Chapter 6*). It has three specific research aims:

2a. To better understand the communicative behavior of starting a conversation about palliative care with a professional carer (e.g. (family) physician) among people with incurable cancer. This will be done by identifying the behavioral factors based on the TPB and by developing a palliative care behavioral model for the defined communicative behavior.

2b. To quantitatively test the palliative care behavioral model developed and to examine which factors (i.e. psychological and perceived social environmental factors) are associated with people with cancer starting or intending to start a conversation about palliative care with the physician (i.e. the family physician, the oncologist, the specialist).

2c. To develop a theory-based behavioral intervention that aims to help people with incurable cancer to start the conversation about palliative care with the physician and to support physicians in reacting appropriately. A participatory approach, involving end-users and potential stakeholders, was used. As this study is still ongoing, only the methods and results will be described.

3) **Objective 3:** To explore family carers' behaviors and its factors from the perspective of family carers (*Chapter 7)*. This third main objective has three specific aims:

3a. To identify what individual behaviors family carers perceive as influencing the seriously ill persons to start using palliative care

3b.To better understand these behaviors by identifying factors perceived by family carers as influencing their behaviors contributing to the start of palliative care

3c. To develop a preliminary behavior model that provides an overview of factors explaining why family carers do or do not display behaviors that might contribute to seriously ill persons starting to use palliative care.

1.4 Methods

The abovementioned objectives were addressed through different study designs including a systematic review, three qualitative interview studies and a cross-sectional survey study. We performed a systematic review to gain insight into the number of end-of-life care and palliative care studies that have used behavioral theories (Chapter 2). We described step-by-step how we used behavioral theories to gain insight into the patient behavior of starting a conversation about palliative care with the physician (Chapter 3). We used qualitative interviews to identify the factors related to the behavior of starting a conversation about palliative care with the physician or having the intention to do so in people with incurable cancer (Chapter 4). We used a quantitative cross-sectional survey design based on interviews to examine which factors were quantitatively associated with the behavior of starting a conversation about palliative care with the physician or having the intention to do so in people with incurable cancer (Chapter 5). Based on the study findings described in Chapters 3 and 4, we used qualitative interview and group discussion sessions to develop a theory-based behavioral intervention that aims to help people with cancer in starting the conversation about palliative care with the physician and to support physicians in reacting appropriately (Chapter 6). Finally, we used qualitative interviews to identify family carers' behaviors and related factors that contribute to the patients' initiation of palliative care (Chapter 7). The methods are explained below.

1.4.1 Systematic review

We conducted a systematic review by searching in the databases MEDLINE (PubMed), PsycINFO, EMBASE, Web of Science and CINAHL from date of inception to June 2017 and by screening the reference lists of the included studies. Theory-based studies aimed at understanding or changing end-of-life care behaviors that explicitly referred to individual or interpersonal behavioral theories were included. Considering the study design criteria, quantitative, qualitative and mixed method design studies were included. The studies had to involve participants who had experience with end-of-life care such as patients, family carers and professional carers or had to focus on the general public (e.g. advance care planning). The following study information was extracted: the aim, study method, study participants, behavioral theory, behavioral factors identified, behavioral outcomes and the main findings. In addition, the quality assessment score of each included study was added. The methodology is described in detail in Chapter 2.

1.4.2 Step-by-step description of the use of behavioral theories in palliative care research

We detailly described the process – in four steps – of how behavioral theories can be used to gain insight into critical factors of health-promoting behavior in seriously ill people, using our case example of people with incurable cancer starting a conversation about palliative care with the physician. In step one, we chose a theory. In step two, we applied and adapted the selected theory by performing 25 interviews with the target population which resulted in a new behavioral model (Chapter 4). In step 3, we operationalized the factors of this model. An expert group (n= 14) checked content validity. We tested the questionnaire cognitively (n=8). In the last and fourth step, we conducted a survey study (n=80) and performed logistic regression analyses to identify the most important factors (Chapter 5). More details are described in Chapter 3.

1.4.3 Qualitative interviews with people with incurable cancer

We performed qualitative face-to-face in-depth interviews using a semi-structured interview guide (Appendix 1) with adults with incurable cancer. Interviewees were patients receiving as well as not receiving palliative care. We wanted to better understand the behavior starting a conversation about palliative care with a professional carer (e.g. the physician) by identifying its influencing factors. After behavioral factors were identified, a preliminary palliative care behavior model for starting a conversation about palliative care was developed. People with incurable cancer were recruited via physicians and nurses from different hospitals, the regional palliative care network, or Flemish palliative care day centres. All interviews were conducted in Dutch (the native tongue of the participants as well as the researchers) between February and June 2018 at the participants' home, hospital unit, or palliative care day centre. The semi-structured interview guide was developed based on the TPB and covered three major themes (1) perception of starting a conversation about palliative care, (2) facilitating factors and (3) hindering factors. More details on the methods are described in Chapter 4.

Ethical considerations

The study was approved by the ethics committee of Ghent University Hospital (registration number B670201734263) and AZ Sint-Lucas Ghent (2017/1465). We obtained written informed consent from all study participants.

1.4.4 Quantitative cross-sectional survey study based on interviews with people with incurable cancer

We conducted a quantitative cross-sectional survey study based on interviews with people with incurable cancer to assess which factors of the newly developed palliative care behavioral model (cfr. Chapter 4) were quantitatively associated with starting or intending to start a conversation about palliative care with the physician. People with incurable cancer were recruited through oncologists, palliative care nurses and study nurses who frequently came into contact with this target group in hospitals or the palliative care network. All data was collected at the hospital or the participants' home in Flanders, between August 2019 and March 2020. A patient questionnaire (Appendices 3 and 4) assessing the psychological and perceived environmental factors related to palliative care and the behavior of starting a conversation about palliative care with the physician was developed. This questionnaire was based on existing questionnaires from other health behavior domains as well as the findings from the qualitative study (Chapter 4), and was cognitively tested and face validated. More details on the methods are described in Chapter 5.

Ethical considerations

The study protocol was approved by the Ethical Review Board of Ghent University Hospital (Belgian registration number: B670201940338). We obtained written informed consent from all study participants.

1.4.5 Qualitative interactive sessions with people with cancer, physicians and other potential stakeholders

We systematically developed a behavioral intervention following the Intervention Mapping Protocol (IMP)[11], i.e. an iterative stepwise approach for developing theory-based and evidence-based health promotion interventions and by using a participatory approach for the creation and design of the intervention (Chapter 6). We composed a planning group based on the various perspectives needed: people with cancer, physicians, family carers of people with cancer, other potential stakeholders and (inter)national researchers with relevant expertise. Planning group members were recruited through patient committees and organizations, Ghent University Hospital, general practitioner practices, palliative care network Gent-Eeklo, family care associations, universities and other relevant health organizations. During three, two individual and one group, semi-structured face-to-face or online sessions the planning group went through the first four steps of the IMP. The sessions took place between October 2020 and May 2021. The acceptability of the intervention materials developed are currently being tested.

Ethical considerations

The study was conducted in Flanders, Belgium, and approved by the ethics committee of Ghent University Hospital (registration number B6702021000308). We obtained written informed consent from all study participants.

1.4.6 Qualitative interviews with family carers of people with incurable cancer

We performed qualitative face-to-face in-depth interviews using a semi-structured interview guide (Appendix 5) with family carers of deceased persons who used palliative care. Behaviors that influenced patients to start using palliative care and related factors were identified and a preliminary behavioral model was developed. Family carers were recruited through professional carers who frequently dealt with family carers for seriously ill people using palliative care and the researchers‘ personal networks. All interviews were conducted in Dutch between March and December 2017 at the participants’ home. A semi-structured interview guide was developed based on the TPB. More details on the methods are described in Chapter 7.

Ethical considerations

The study was conducted in Flanders, Belgium, and approved by the ethics committee of Ghent University Hospital (registration number B670201731675). We obtained written informed consent from all study participants.

1.5 Dissertation outline

Following this introduction, Chapters 2-5 and 7 of this dissertation are based on articles which have been published, accepted or submitted for publication. Chapter 6 is based on an ongoing study. All Chapters can be read independently.

This dissertation includes five parts, with three parts consisting of different chapters to address the main research objectives with specific research aims. In **PART I**, the **GENERAL INTRODUCTION** describes the rationale for this dissertation as well as its objectives and methodology.

PART II focusses on the use of a health promotion approach and behavioral theories in end-of-life care research and palliative care research. This part covers the first objective of this thesis.

PART III zooms in on one specific palliative care behavior, being starting a conversation about palliative care with the physician from the perspective of people with incurable cancer. This part covers the second objective of this thesis.

In **PART IV,** the family carers' behaviors that may contribute to the initiation of palliative care and its factors were explored. This part covers that last and third objective of this thesis.

The final chapter of the dissertation**, PART V**, the **GENERAL DISCUSSION**, consists of the main findings of each study, reflections on its strengths and limitations, discussion of the findings in comparison with international literature and the implications of the findings for practice, policy and future research.

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PART II

THE USE OF HEALTH BEHAVIOR THEORIES IN END-OF-LIFE CARE RESEARCH

CHAPTER 2

THE USE OF HEALTH BEHAVIOR THEORIES IN END-OF-LIFE CARE RESEARCH: A SYSTEMATIC REVIEW

Scherrens A, Beernaert K, Robijn L, Deliens L, Pauwels N, Cohen J, Deforche B. The use of health behavior theories in end-of-life care research: a systematic review (2018). *Palliative Medicine;* 32(6):1055-1077.

[Published]

Abstract

Background – It is necessary to understand behaviors that contribute to improvement in the quality of end-of-life care; use of behavioral theories allows identification of factors underlying end-of-life care behavior, but little is known about the extent to which, and in what manner, these theories are used in an end-of-life care research context.

Aim. To assess the number of end-of-life care studies that have used behavioral theories, which theories were used, to what extent main constructs were explored/measured and which behavioral outcomes were examined.

Design – We conducted a systematic review. The protocol was registered on PROSPERO (CRD42016036009).

Datasources – The MEDLINE (PubMed), PSYCinfo, EMBASE, Web of Science & CINAHL databases were searched from inception to June 2017. We included studies aimed at understanding or changing end-of-life care behaviors and that explicitly referred to individual behavioral theories.

Results – We screened 2,231 records by title and abstract, retrieved 43 full text articles and included 31 studies – 27 quantitative (of which four (quasi-) Randomized Controlled Trials) and four qualitative – for data extraction. More than half used the Theory of Planned Behavior (9), the Theory of Reasoned Action (4) or the Transtheoretical Model (8). In nine of 31 the theory was fully used and 16 of the 31 focused on behaviors in advance care planning.

Conclusion – In end-of-life care research the use of behavioral theories is limited. As many behaviors can determine the quality of care, their more extensive use may be warranted if we want to better understand and influence behaviors and improve end-of-life care.

Keywords

Palliative care, terminal care, withholding treatment, advance care planning, health promotion, behavior, behavioral theory, review

Key statements

What is already known about the topic?

- Behavioral theories are useful to understand health care behaviors and to develop effective intervention
- Behavior (eg initiating advance care planning conversations) is an important factor influencing the quality end-of-life care
- Hitherto, it is not known to what extent and in which manner behavioral theories are used in end-of-life care research

What this paper adds

- This systematic review shows that the use of behavioral theories in end-of-life care research is scarce
- Only 31 studies (and only 1 RCT) used a behavioral theory to understand or change a behavior related to end-of-life care
- The end-of-life care behavior focussed on is advance care planning in a majority of studies

Implications for practice, theory or policy

- There is evidence that behavioral theories do form a suitable theoretical framework to examine end-of-life care
- The adequate use of behavioral theories prior to interventions to improve end-of-life care may increase their success
- Researchers in end-of-life care may need to use behavioral theories more often and more adequately in order to better understand and change behaviors in end-of-life care

2.1 Background

There is a growing interest in behavioral theory, resulting in its widespread use within health care[1]. A behavioral theory is used as a tool to understand who performs certain targeted behaviors (e.g. smoking cessation, adherence to medication intake, contacting the palliative home care team etc.) and why people perform these behaviors[2,3]. A behavioral change theory has been used widely as a tool to change a specific behavior and is used for the development and implementation of interventions targeting specific behaviors[1,4–8]. Understanding and changing a specific behavior by using a behavioral theory are two complementary functions[9]. Targeted behavioral interventions can help people make health-promoting choices and improve their quality of life[10]. There is also evidence that health care intervention studies are more likely to be effective if they are supported by behavioral theory[11,12].

Research into end-of-life care not only tried to gain insight into practice but, in recent years, has been endeavoring to improve practice and the patients' and families' quality of life as much as possible. Targeting health behaviors, such as completing advance directives, having a conversation with the patient about wishes and needs and advance care planning[2,7] and having a better understanding of health behaviors at the level of patients, family carers and professional caregivers seems to be essential for the improvement of the quality of end-of-life care[7,13].

Hence, in order to improve end-of-life care a better understanding and eventually changing targeted behaviors, the use of behavioral theories is warranted[14,15]. There are strong indications from other scientific fields that the use of behavioral theories is relevant and would form an essential step towards the development of more effective interventions in end-of-life care research[11]. Although many explanatory and intervention studies focus on an end-of-life care behavior (eg studies focussing on advance care planning), not many behavioral studies appear to be guided by a behavioral theory that specifies how to understand end-of-life care behavior and how to elicit behavioral change[9]. However, to date end-of-life care studies using behavioral theories have not yet been systematically identified. It is unclear to what extent behavioral theories are used in end-of-life care research nor how they are used. This review will be to our knowledge the first to explore the use of behavioral theories in end-of-life care.

A systematic review was undertaken to answer the following research questions:

1. to what extent did studies use behavioral theory in end-of-life care research with the aim of understanding or changing an end-of-life care behavior?
2. which behavioral theories have been used in end-of-life care research?

3. what and how many constructs of the behavioral theories were operationalised/not operationalised?
4. what were the targeted end-of-life care behavioral outcomes?

2.2 Methods

A systematic review was conducted. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement, an evidence-based minimum set of items for reporting systematic reviews, was used. The review protocol was registered on PROSPERO (CRD42016036009) before screening and data-extraction and is available in full on the PROSPERO website (https://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016036009).

2.2.1 Study eligibility criteria

We used predefined criteria to select eligible studies (see inclusion and exclusion criteria in **Table 1**). For the inclusion and exclusion criteria, we focused on the broad function of an individual behavioral theory: the studies had to use an individual behavioral theory as conceptual framework, independent of the degree of use and the extent to which theoretical main constructs were explored/operationalised/measured (**Table 1**). By doing so, we could identify both studies aimed at understanding or changing an end-of-life care behavior. We included articles written in English, French or Dutch. There was no date limit. If no full text was available, studies were purchased.

Table 1. Inclusion and exclusion criteria

Inclusion	Exclusion
Substantive criteria	*Substantive criteria*
• Behavioral theory All studies aimed at explaining or improving end-of-life care (terminal care, palliative care, hospice care, respite care, advance care planning etc.)[a] explicit[b] referring to or operationalising[c] an individual behavioral theory[d];	• Other theories Studies using environment-oriented theories (e.g. systems theory, theories of power, coalition theory etc.), theories in which understanding and changing environmental determinants of behavior are the major processes of interest. Also, studies using other health models such as the Chronic Care Model.
	• Population Professional caregivers or other (allied) health professionals whose job made them unlikely to care for end-of-life patients (e.g. rehabilitation, plastic surgery etc.) were excluded.
	• Outcome Articles whereby the outcomes are not associated with end-of-life care.
Technical criteria	*Technical criteria*
• Primary research Studies reporting original data.	• Nonpeer-reviewed studies, editorials, narrative reviews, comments and expert opinion.
• Study design No restrictions by study design. Both qualitative, quantitative and mixed method studies.	
• Language Articles written in English, French, and Dutch	
• Date No restrictions by date.	

a *Improving aspects of* end-of-life care*, such as communication about end-of-life wishes, patient satisfaction with* end-of-life care *as well as health outcomes*

b *Explicit reference implies that the authors mentioned in the introduction, methods or abstract that they had used a behavioral theory.*

c *Referring and operationalising a behavioral theory can be defined as use of this theory as conceptual framework, independent of the degree of use, the extent to which theoretical main constructs were explored/measured/operationalised*

d *behavior-oriented theories in which understanding and changing human behavior are the major processes of interest.*

Types of studies

We included both qualitative and quantitative studies reporting original data. In addition, we included both studies partially or fully exploring/measuring the theoretical main constructs[12,15].

Types of theories

We focused on studies that used behavioral theories to understand or to change end-of-life care behaviors. Each theory consists of different constructs (e.g. the Theory of Planned Behavior consists of ‘attitude’, ‘subjective norm’ and ‘perceived behavioral control’), which are the key concepts. These constructs can be explored, operationalised or measured in order to define the structural and psychological determinants of the specific behavior[2,3,12,15]. In addition, behavioral theories can relate to various levels (individual, interpersonal and ecological), but we only included those on the individual level focussing on understanding and changing individual behaviors and not those focussing on environmental levels[3,16] (**Table 2**). We specifically mentioned all existing and known individual behavior theories in the search string (**Appendix 1**). In addition, we included behavior-oriented multilevel theories centralising individual behavior (**Table 2**) as well as those specifically mentioned in the search string. As lesser known theories might be missing from this list, we used umbrella terms such as ‘behavior theory’ and ‘ecological theory’ as well.

Table 2. Included behavioral theories, specifically mentioned in the search string

Level	Included behavioral theories
Individual theories	The Social Learning Theories (classical conditioning and operant conditioning) and the Social Cognitive Theory; the theories of Information Processing (the Information Processing Theory, Semantic Network Theory, Mental Model Theory, Elaboration Likelihood Model and Persuasive-communication Model); the Health Belief Model; the Protection Motivation Theory and Extended Parallel Process Model: the Theory of Reasoned Action, Theory of Planned Behavior and the Integrated behavioral model; Information-motivation-behavioral-skills Model; Goal-setting Theory, theories of goal-directed behavior, theories of automatic behavior, impulsive behavior, and habits; the Transtheoretical Model of behavior change; Precaution Adoption Process Model and Risk Communications; Attribution Theory and Relapse Prevention Theory; Theory of Self-Regulation; theories of Stigma and Discrimination; Diffusion of Innovation Theory and the ASE-model[3,16–18].
Interpersonal theories	Socio-Ecological Theory, the Social Networks Theory, the Social Support Theory and the Social Norm Theory

Types of outcomes

We considered both the intention to perform a behavior (e.g. the intention to plan end-of-life care) and a behavior itself (e.g. planning the care) as behavioral outcomes, because ‘intention’ is one of the most important direct predictors of a behavior[19,20]. We excluded articles with outcomes not associated with end-of-life care. We have not included the behavioral outcomes in the search string because identifying behaviors was one of the research goals of this systematic review.

Types of participants

We included studies when the participants (patients, family carers and professional caregivers) had experience with end-of-life care. We decided not to include the population in the search string, since it was assumed that a combination between ‘end-of-life care’ and ‘an individual behavioral theory’ would largely cover a group of people/services concerned with end-of-life care. Where this was not the case, study populations consisting of professional caregivers or other allied health professionals whose job made them unlikely to care for people at the end of life (e.g. rehabilitation, plastic surgery etc.) were excluded.

2.2.2 Search Strategy

We identified studies by searching in five electronic databases: MEDLINE (using the PubMed interface), PsychINFO (using the EBSCOhost interface), EMBASE, Web of Science & CINAHL, from date of inception till 16 June 2017. We modified a basic search strategy for each database. In an additional file (**Appendix 1**) we provided the full electronic search strategies for the different databases.

2.2.3 Study selection

Electronic search

We based the process of identifying studies on the methodology described in the Cochrane Handbook for Systematic Reviews of Interventions guidelines[21]. Once we completed the literature search, we exported all records to the reference management software tool Endnote (Version X7.1). We removed duplicated records and non-original studies. We screened the titles and abstracts of remaining studies and analysed them independently by two authors (ALS & LR). Afterwards, the same authors independently performed the whole process of full-text screening and discussed the discrepancies. In cases of disagreement, a third reviewer was available for arbitration (KB).

Additional search resources

Additionally, we screened the reference lists of the included studies.

2.2.4 Data extraction

The data extraction and quality assessment was done independently by each of the researchers (ALS, LR & KB) using a data extraction tool and the QualSyst quality rating tool[22]. We extracted study information in a Microsoft Office Excel spreadsheet regarding the aim, study method, study participants, behavioral theory, the theoretical constructs of the behavioral theory identified, behavior and the main findings. We also added information on whether a theory has been fully used or not. For quantitative studies, fully used is defined as operationalisation and measurement of all theoretical main constructs. For qualitative studies, fully used is defined as the exploration of all theoretical main constructs. An overview of all main constructs per theory is shown in **Table 3.** We have not taken into account the research question to determine the degree of use.

Table 3. Behavioral theories used, their degree of use and the theoretical constructs explored/measured within the included studies

Behavioral theory (total N= 35 studies[a])	**Description**	**Constructs explored/measured (N=)**	**Constructs not explored/measured (N=)**
Theory of Planned Behavior (N= 9)	This is a theory which predicts deliberate behavior, behavior that can be deliberative and planned. It links beliefs and behavior[23]. *Main constructs*: behavioral intention, attitude, subjective norm, perceived behavioral control.	'Intention' (N=4), 'attitude' (N= 9), 'subjective norm' (N= 9), 'perceived behavioral control' (N= 9)	'Intention (N=5), 'attitude' (N= 0), 'subjective norm' (N= 0), 'perceived behavioral control' (N= 0)
Transtheoretical Model (N=8)	This model describes an individual's motivation and state of readiness to change behavior[24]. *Main constructs*: stages of change, processes of change, decisional balance, self-efficacy and situational temptation.	Stages of change (N=7), processes of change (N=6), decisional balance (N=6), self-efficacy (N=2) and situational temptation (N=0).	Stages of change (N=1), processes of change (N=2), decisional balance (N=2), self-efficacy (N=6) and situational temptation (N=8).
Theory of Reasoned Action (N=4)	This is an expectancy-value theory. This theory centralizes the relationship between motivation, expectations about one's own abilities and the value of the result to be achieved[25] *Main constructs*: behavioral intention, attitude, subjective norm.	Intention (N=4), attitude (N=4), subjective norm (N=3)	Intention (N=0), attitude (N=0), subjective norm (N=1)
Social Cognitive Theory (N=2)	The social cognitive theory is an interpersonal theory that includes both determinants of behavior and the processes of behavioral change. Behavior, cognitive, personal and environmental factors are factors that are related to each other[26].	Outcome expectations(N=2), self-efficacy(N=2), perceived behavior of others(N=1), behavior capability(N=1).	Outcome expactancies (N=2), environment (N=2), perceived behavior of others(N=1) and behavior capability(N=1).
Health Belief Model (N=4)	This model focuses on observations of individuals of a threat posed by a health problem. The focus is on health and riskrelated behavior. *Main constructs:* perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy.	Perceived susceptibility (N=2), perceived severity(N=2), perceived benefits(N=3), perceived barriers(N=3), cues to action(N=0), self-efficacy(N=0)	Perceived susceptibility (N=1), perceived severity(N=1), perceived benefits(N=0), perceived barriers(N=0), cues to action(N=3), self-efficacy(N=3).
	Main constructs old version; cues, beliefs, barriers	Cues (N=1), beliefs (N=1), barriers (N=1)	Cues (N=0), beliefs (N=0), barriers (N=0)

Behavioral theory (N= # studies)	**Description**	**Constructs explored/measured (N=)**	**Constructs not explored/measured (N=)**
Self-determination Theory (N=1)	Central to this theory is the difference between autonomous and controlled motivation[27]. *Main constructs*: competence, autonomy, relatedness.	Competence (N=0), autonomy (N=0), relatedness (N=0)	Competence (N=1), autonomy (N=1), relatedness (N=1)
Self-regulation Model of Leventhal (N=1)	Based on desired goals, appropriate strategies are chosen in order to realize behavioral change. [(!) An old Self-Regulation Model of Leventhal was used]. *Main constructs:* representation of danger, situational stimuli, coping procedures, action plans, representation of fear and appraisal.	Self-Regulation Model of Leventhal was used: representation of danger(N=1), situational stimuli(N=0), coping procedures(N=0), action plans(N=0), representation of fear(N=0) and appraisal(N=0).	Self-Regulation Model of Leventhal was used: representation of danger(N=0), situational stimuli(N=1), coping procedures(N=1), action plans(N=1), representation of fear(N=1) and appraisal(N=1).
Self-regulation Theory (N=1)	Not clear[b].	Not clear[b]. Goals, value and expectancy.	Not clear[b].
Self-efficacy Theory (N=1)	This theory includes social learning analysis, whereby expectations of personal efficacy stem from some main sources of information such as performances and personal experiences, vicarious experiences of observing others succeed through their efforts, verbal persuasion and states of physiological arousel[28]. *Main constructs*: Efficacy expectations, performance accomplishments, vicarious experience, verbal persuasion and emotional arousal.	Efficacy expectations (N=1), performance accomplishments (N=1), vicarious experience (N=1), verbal persuasion (N=1) and emotional arousal (N=1)	Efficacy expectations (N=0), performance accomplishments (N=0), vicarious experience (N=0), verbal persuasion (N=0) and emotional arousal (N=0)
Protection Motivation Theory (N=1)	Threatening messages incite cognitive processes. These elicit responses. This theory contains the same basic elements as the Health Belief Model. *Main constructs*: threat appraisal, coping appraisal, threat seriousness, personal suceptibility, response efficacy, self-efficacy, protection motivation, rewards-reinforcement, costs-punishment and fear-arousal[29].	Threat appraisal(N=1), coping appraisal(N=1), threat seriousness(N=1), personal suceptibility(N=1), response efficacy(N=1), self-efficacy(N=1), protection motivation(N=1), rewards-reinforcement(N=1), costs-punishment(N=1) and fear-arousal(N=0).	Threat appraisal(N=0), coping appraisal(N=0), threat seriousness(N=0), personal suceptibility(N=0), response efficacy(N=0), self-efficacy(N=0), protection motivation(N=0), rewards-reinforcement(N=0), costs-punishment(N=0) and fear-arousal(N=1).

Behavioral theory (N= # studies)	**Description**	**Constructs explored/measured (N=)**	**Constructs not explored/measured (N=)**
Integrated Behavioral Model (N=1)	This Model is a combination of the Theory of Reasoned Action and the Theory of Planned Behavior. This model states that behavior is determined by variables besides intention and that intention is determined by a number of variables including attitude, subjective norm and perceived behavioral control. It includes a two-step idea in which various factors determine intention and then various factors determine behavior[15]. *Main constructs:* attitudes (experiential attitude & instrumental attitude), perceived norms (subjective norm & descriptive norm), personal agency (self-efficacy & perceived behavioral control)	Behavioral intention, attitudes (direct & indirect attitude) (N=1), perceived norms (direct & indirect perceived norm) (N=1), personal agency (self-efficacy) (N=1);	IBM: personal agency: (perceived behavioral control) (N=1).
The Precaution Adoption Process Model (N=1)	The adoption of a new precaution to avoid risky behavior requires deliberate action. The Precaution Adoption Process Model includes seven stages of action[10]. *Main constructs/stages*: Unaware of issue, unengaged by issue, deciding about acting, decided not to act, decided to act, acting, maintenance.	Stage of readiness (unaware, unengaged, undecided, decided not to act, decided to act, process of acting, maintenance) (N=1).	Stage of readiness (N=0)
Social Learning Theory (N=1)	The Social Learning Theory states behavior is learned from the environment through the process of observational learning[26]. *Main constructs*: expectations, observational learning, behavioral capability, self-efficacy, reciprocal determinism and reinforcement.	Observational learning (N=1)	Expectations (N=1), behavioral capability(N=1), self-efficacy(N=1), reciprocal determinism(N=1) and reinforcement(N=1).

N= Number of times used

[a] The number of behavioral theories used (N=35) differs from the total number of studies (N=31), because some studies have combined two theories.

[b] It is not clear on what self-regulation theory this study is based on. It seems to be a combination of the self-regulation theory, the expectation-value theory and the goal-setting theory

In addition, we added the quality assessment score of each included study. We used the quality assessment tools called the QualSyst tools, constructed by researchers from the Alberta Heritage Foundation, for assessment of the quality of both qualitative and quantitative studies[22]. For assessing the quality of qualitative studies, ten standard criteria had to be scored while for quantitative studies there were 14 criteria. The criteria for qualitative studies relate to the research question, study design, context, theoretical framework, sampling strategy, data collection method, data analysis, verification procedure, conclusion and reflexivity of the account. The criteria for quantitative studies relate to the research question, study design, method of subject selection, subject characteristics, outcome measures, sample size, analytic methods, estimate of variance, confounding, results, conclusions and, in cases of intervention studies, to the allocation and blinding. The scores range from 0.0 to 1.0. We have not defined a minimum quality threshold for study inclusion. These quality scores do not say anything about the quality of behavioral theory used in these studies, but only indicate the extent to which the design, conduct and analyses minimise errors and biases. We have not performed any quality analyses to assign an evidence label to the body of evidence of the included studies.

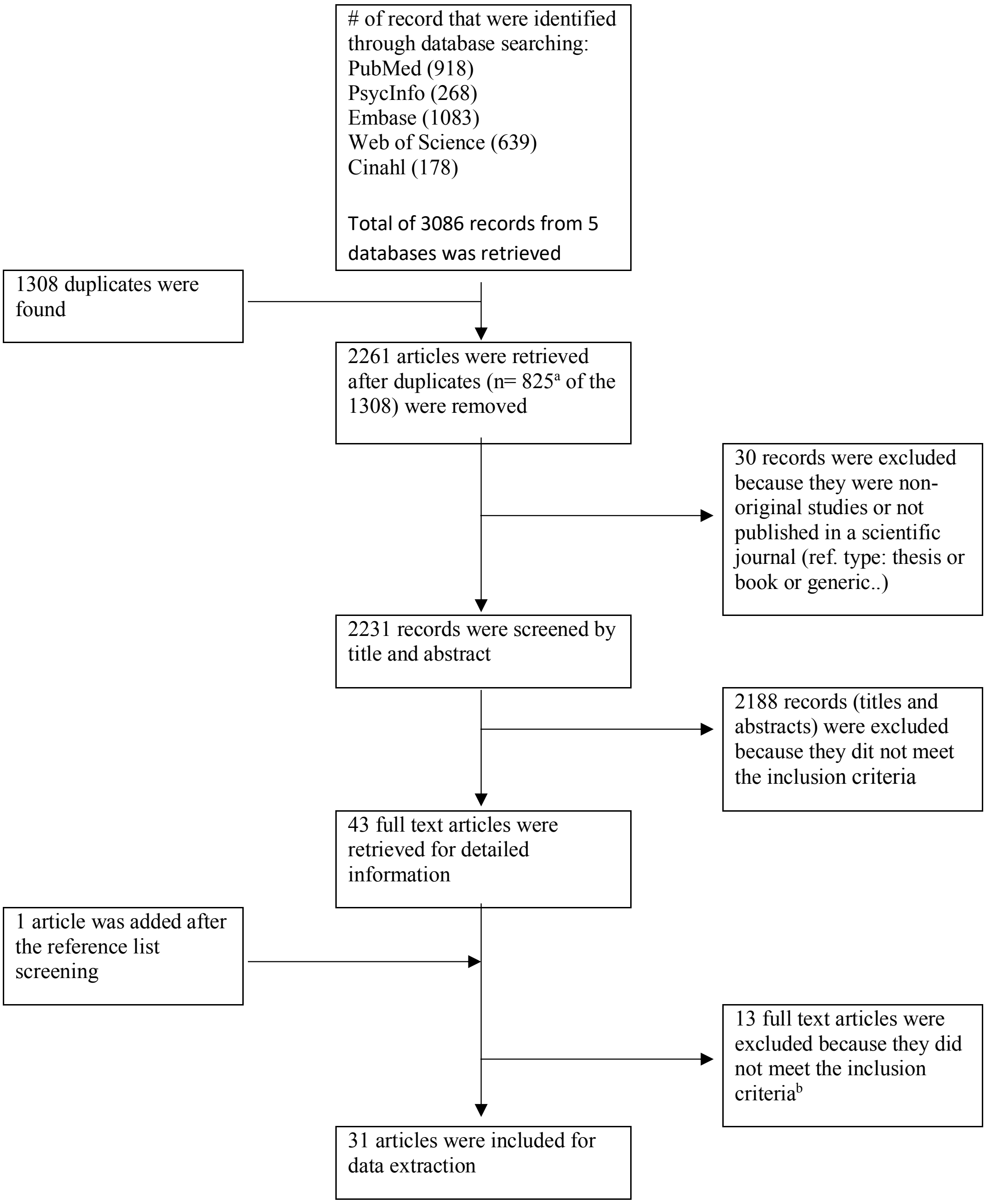
2.2.5 Data analysis

We carried out a narrative synthesis for systematically describing the characteristics of the studies included, as well as to highlight the most important findings[30].

3 Results

3.1 Selection of relevant studies

Figure 1 presents a PRISMA Flow Diagram[31] that summarises the review process and a selection of the studies.



a More than half of the total number of duplicates was removed, because of some articles were traced two or more times in the various databases
b Two main reasons for exclusion: 7 studies are non-original studies collecting no original data, 3 studies did not use a theoretical framework or did not measure one of the main constructs of the theory, while the use of a behavioural theory was indicated in the abstract.

Figure 1. The flow diagram of literature search and selection of articles

Overall, we retrieved 3,086 records from systematic searches in five databases. After exclusion of duplicates and non-relevant articles, a total of 30 studies remained. We added one more after screening of the reference lists of all included studies. This resulted in 31 articles for data-extraction. Characteristics of the included studies are presented in **Table 4.**

We included twenty-seven quantitative and four qualitative studies, all published between 1990 and June 2017, on behavioral theories in an end-of-life care context. These were all written in English. The quantitative studies included 22 cross-sectional survey studies, three quasi-Randomized Controlled Trials (RCTs) and one RCT. The qualitative studies included one using a combination of focus groups and individual interviews, two individual interview studies, one focus group study and one case study.

The populations studied could be divided into four groups: health care professionals (11 out of 31 studies), family carers (two out of 31 studies), patients (four out of 31 studies) and the general public (14 out of 31 studies). The health care professionals were from different specialties, most of them were physicians or nurses caring for seriously ill or terminal patients. The family carers included caregivers of people with dementia, pancreatic cancer or amyotrophic lateral sclerosis. The patient populations suffered from a diabetic or endocrinological disease or end-stage cancer. The general public mostly covered people of 60 years or more. No studies were excluded because the population consisted of professional caregivers or other allied health professionals whose jobs made them unlikely to care for end-of-life patients. Regarding the subjective quality assessment (quality score range 0.0 – 1.0), the qualitative studies scored between 0.45 – 0.85 and the quantitative studies between 0.61 – 1.00.

Behavioral theories

In total, we identified thirteen different behavioral theories (**Table 3)**. Nine studies used the Theory of Planned Behavior[2,32–39], eight the Transtheoretical Model[23,40–46], four the Theory of Reasoned Action[47–50], four the Health Belief Model[51–54], one a combination of the Integrated Behavioral Model and the Precaution Adoption Process Model[55], one the Self-determination Theory[56], one the Self-Regulation Model of Leventhal[57], one a variant of the Self-Regulation Theory[58], one the Protection Motivation Theory[29] and one the Self-efficacy Theory[59]. Most studies used only one theory. Three studies combined the Social Cognitive Theory with another theory, one in combination with the Transtheoretical Model and the Social Cognitive Theory[45], a second a combination of the Theory of Reasoned Action and the Social Learning Theory[50] and a third a combination of the Theory of Planned Behavior and the Social Cognitive Theory[35].

Constructs

In nine studies the theory used was fully used, meaning that all the main theoretical constructs were explored, operationalised and/or measured. All studies using the Theory of Planned Behavior explored or measured three of the main constructs i.e. ‘attitude’, ‘subjective norm’ and ‘perceived behavioral control’, but not the fourth, ‘intention’. Four studies also measured ‘intention’. In none of the eight studies using the Transtheoretical Model was the theory fully used. In seven of them, some of the stages of change (precontemplation, contemplation, preparation, action, maintenance, termination) were measured. However, two out of the eight studies using the Transtheoretical Model did not use the full theory. Two studies using the Transtheoretical model and measuring only a few constructs included enough main constructs to answer the research question[43,46]. For an overview of the explored and measured constructs of the other theories see **Table 3.**

Health behaviors

Sixteen studies focused on behaviors related to advance care planning from the perspective of patients, the general public and health care professionals; these were to complete a durable power of attorney for a health care document, to complete/revise advance directives, to complete a living will, to document end-of-life wishes using an advance directive, to engage in advance care planning, to communicate about and to discuss end-of-life preferences, and to facilitate advance care planning in nursing homes[14,23,29,39–46,51–55,57]. The targeted behaviors within the other fifteen studies were rather different from each other. They were, from the patient's perspective: to search for information on end-stage cancer, and to manage the uncertainty and distress associated with end-of-life care; from the general public's perspective: to enroll in a hospice; from the family carers' perspective: to use residential respite care and to participate in decision-making in end-of-life care; from the health care professionals' perspective: to perform euthanasia, to refer palliative care patients for physiotherapy, to support patients in decision-making about place of care at the end of life, to care for the person who was dying and their family, to decide whether to disclose bad news, and to disclose a diagnosis of dementia.

Table 4. Characteristics of included studies ordered on the basis of behavioral theory, the extent of constructs explored/operationalised/measured and behavior.

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
1	Lavoie et al.[33] Psychosocial determinants of physicians' intention to practice euthanasia in palliative care. (2015) QualSyst score: 0.95	1. To identify the psychosocial determinants of physicians' intention to practice euthanasia in palliative care 2. verifying whether respecting the patient's autonomy is important for physicians.	Physicians (N=445) of different specialties from the province of Quebec, Canada.	Quantitative: questionnaire (cross-sectional)	Theory of Planned Behavior	Intention, attitude, subjective norm, perceived behavioral control Additional: professional norm and moral norm (+beneficence and justice)		The intention to practice/to perform euthanasia	Physicians had a low intention to practice euthanasia in palliative care if this practice was legal. Determinants of the intention among physicians were knowing patient's wishes, perceived behavioral control, moral normal and cognitive attitude.
2	Lavoie et al.[34] Psychosocial determinants of nurses' intention to practise euthanasie in palliative care. (2016) QualSyst score: 0.90	To identify the psychosocial determinants of nurses' intention to practise euthanasia in palliative care if it were legalised.	Nurses (N= 445) of different specialties from the province of Quebec, Canada.	Quantitative: questionnaire (cross-sectional)	Theory of Planned Behavior	Intention, attitude, subjective norm, perceived behavioral control Additional: professional norm and moral norm (+beneficence and justice)		The intention to practice/to perform euthanasia	Most nurses had a positive intention to practice euthanasia in palliative care if it was legal. Determinants of the intention were the subjective and moral norms.
3	Lavoie et al.[32] Effect of Knowing Patients' Wishes and Health Profession on Euthanasia. (2014) QualSyst score: 0.86	To experimentally test whether knowing patients' wishes and profession can affect health professionals' intentions and beliefs regarding performing euthanasia.	Physicians (N=117) and nurses (N=153) caring for end-of-life patients from the province of Quebec, Canada.	Quantitative: factorial experiment – questionnaire + vignette with experimental conditions (patient's wishes known or not/profession)	Theory of Planned Behavior	Intention, attitude, subjective norm, perceived behavioral control Additional: professional norm and moral norm (+beneficence and justice)		The intention to practice/to perform euthanasia	There was a significant known wishes x profession interaction for intention. Knowing patient's wishes regarding euthanasia appears to influence physicians, but not nurses.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
4	Foy et al.[35] Which factors explain variation in intention to disclose a diagnosis of dementia? A theory-based survey of mental health professionals. (2007) QualSystscore: 0.95	To identify factors that predict the intentions of members of older people's mental health teams to perform key behaviors involved in the disclosure of dementia.	Mental Health Professionals (N=399)	Quantitative: questionnaire (cross-sectional)	Theory of Planned Behavior & Social Cognitive Theory [c]	TPB: intention, (emotional) attitude, subjective norm, perceived behavioral control; SCT: self-efficacy; outcome expectancies ADDITIONAL: Team role (perceived reliability/role of colleagues + role responsibility), number of professional groups	TPB: / ; SCT: perceived behavior of others, behavior capability, outcome expectations, the environment	To disclose a diagnosis of dementia (3 key behaviors: to determine what patients already know or suspect about their diagnosis; to use explicit terminology when talking to patients; to explore what the diagnosis means to patients.	Overall, the TPB best explained behavioral intention. For determining what patients already know, subjective norm, perceived behavioral control and attitude explained 29,4% of the variance in intention. The same variables explained 53,7% of the intention to use explicit terminology. For exploring what the diagnosis means to patients, subjective norm and perceived behavioral control explained 48,6% of intention.
5	Nelson et al.[36] Exploring disctrict nurses' reluctance to refer palliative care patients for physiotherapy. (2012) QualSyst score: 0.55	To investigate district nurses' beliefs regarding referral of a patient receiving palliative care for physiotherapy.	Nurses (N=16) - District nurses enrolled in two postgraduate courses at a university in Northern Ireland	Qualitative : focus groups (N=3)	Theory of Planned Behavior	Attitude (control beliefs), subjective norm (normative beliefs), perceived behavioral control (behavioral beliefs)	Intention	To refer palliative care patients for physiotherapy	Nine beliefs were identified as influencing referral decisions, the majority of which were negative , such as the belief that physiotherapists lack palliative care skills and could foster false hope.
6	Murray et al.[2] Nurses perceptions of factors influencing patient decision support for place of care at the EoL. (2009) QualSyst score: 0.85	To investigate nurses' perceptions of behavioral factors that affect patient decision support in the context of place of end-of-life care.	Nurses (N=22) – Oncology and Palliative Care nurses from 3 health networks in Canada.	Qualitative: individual interviews (N=22)	Theory of Planned Behavior	Attitude, subjective norm, perceived behavioral control	Intention	To support patients in decision-making for place of care at the end-of-life	Nurses held favorable attitudes toward providing decision support for place of care at end of life. Overlap between other professional's roles and nurses' clinical experience affected nurses' decision support behaviors. Nurses reported a lack of skills, confidence and tools to help them provide it.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
7	Philipson & Jones[37] Residential respite care: the caregiver's last resort. (2011) QuaSyst score: 0.80	To improve understanding of the beliefs that may influence the use and non-use of residentional respite care by caregivers of people with dementia.	Primary caregivers (N=36) from Australia.	Qualitative: focus groups (N=5) and individual interviews (N=10 + 2 dyads)	Theory of Planned Behavior	Attitude, subjective norm, perceived behavioral control	Intention	To use residential respite care (RRC)	The application of theory to identify the service beliefs of caregivers was useful to highlight the attitudinal and service barriers that exist for some caregivers regarding the use of RRC. The primary difference was in relation to the perceived need of service users, who held the behavioral belief that service use had become necessary to extend caregiving longevity.
8	Zhou et al.[38] Knowledge, Attitudes, and Practice Behaviors of Oncology Advanced Practice Nurses Regarding Advanced Care Planning for Patients with Cancer. (2010) QualSyst score: 0.80	1. To investigate initial reliability and validity of a Web-based survey focused on oncology advanced practice nurses' (APNs') knowledge, attitudes, and practice behaviors regarding advanced care planning 2. To obtain preliminary understanding of APN's knowledge, attitudes, and practice behaviors and perceived barriers to advanced care planning.	Nurses (N=300) – Oncology APN's from The eastern United States.	Quantitative: pilot study - questionnaire (cross-sectional)	Theory of Planned Behavior	Attitude, subjective norm, perceived behavioral control Additional: Knowledge	Intention	Practice behaviors within ACP	The attitudinal and practice behaviors portions of the survey demonstrated preliminary construct validity and test-retest reliability. Regarding advance care planning, respondents were moderately knowledgeable, but their advanced care planning practice was not routine.The most common reported barriers were from patients' and families' as well as physicians' reluctance to discuss advanced are planning.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
9	Beck et al.[39] Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: a cross-sectional study (2016) QualSyst score: 0.95	To examine nursing home managers' knowledge, attitudes, beliefs and current practice regarding advance care planning for people with dementia in long-term care settings informed by the Theory of Planned Behavior.	Nursing home managers (N=116) – working in a nursing home in a region in the UK	Quantitative: questionnaire (cross-sectional) As part of a larger scale sequential explanatory mixed-methods study.	Theory of Planned Behavior	Attitude, subjective norm, perceived behavioral control Additional: Understanding Knowledge Current practices	Intention	To facilitate ACP in nursing homes.	Nursing home managers demonstrated a lack of knowledge of advance care planning, with negative attitudes underpinned by concerns regarding the capacity and lack of perceived benefits to the person with dementia. Currently, they do not view advance care planning as part of their role.
10	Jezewski[40] Psychometric Testing of Four Transtheoretical Model Questionnaires for the Behavior, Completing Health Care Proxies. (2009) QualSyst score 0.90	To develop four questionnaires to assess the behavior, completing a health care proxy: 1. To operationalize the four Transtheoretical constructs for completing a HCP 2. To evaluate the psychometric properties of the questionnaires.	General public (N=566) – Members of two health insurance providers in western New York	Quantitative: questionnaire (cross-sectional)	Transtheoretical Model	5 Stages of change (precontemplation, contemplation, preparation, action, maintenance), processes of change (experiential and behavioral)[d], decisional balance, self-efficacy.	1 stages of change (termination); situational temptation	To complete a health care proxy (HCP) - a type of advance directive	The data support validity and reliability of the TTM questionnaires related to HCP completion.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
11	Finnell et al.[41] Applying the Transtheoretical Model to Health Care Proxy Completion. (2011) QualSyst score: 0.90	To investigate the applicability of the TTM for completing a health care proxy.	General public (N=566) – Members of health insurance providers in western New York	Quantitative: questionnaire (cross-sectional).	Transtheoretical Model	4 stages of change (precontemplation, contemplation, preparation, action), processes of change[d], decisional balance, self-efficacy	2 stages of change (maintenance, termination); situational temptation	To document end-of-life wishes using an advance directive	Both the experiential and the behavioral processes of change revealed the lowest scores in the precontemplation stage, peaking in the preparation stage. Self-effiacy scores incrementally increased across the stages of change with the largest effect from the precontemplation to preparation stage.
12	Moorman & Inoue[42] Persistent problems in EoL planning among young- and middle-aged american couples. (2013) QualSyst score: 0.85	To explain why 1. rates of advance care planning remain low in the general population 2. surrogate decision makers are often inaccurate about patients' end-of-life preferences.	General public (N=2150) of 18-64y. – Members of a nationally representative internet panel and a convenience sample from online advertisements.	Quantitative: questionnaire (cross-sectional)	Transtheoretical Model [b]	5 stages of change (precontemplation, contemplation, preparation, action, maintenance), processes of change[d], decisional balance,	1 stage of change (termination), processes of changed, self-efficacy and situational temptation.	To plan for end-of-life (ACP) – To complete an AD and informal discussion	Both older age and poorer health were independently associated with the greater likelihood of heaving discussed end-of-life health care treatment preferences.
13	Medvene et al.[43] Advance Directives: Assesings stage of change and decisional balance in a community-based educational program. (2007) QualSyst score: 0.68	1. To increase understanding of attitudes and behaviors regarding the completion of AD. 2. To investigate the applicability of two imporant constructs from the Transtheoretical Model.	General public (N=97) of 34-91y. old from churches in a midsized city in the Midwest of the United States.	Quantitative: quasi RCT (educational meeting, pre-questionnaire + intervention + post-questionnaire)	Transtheoretical Model[a]	5 stages of change (precontemplation, contemplation, preparation, action and maintenance); decisional balance	1 stage of change (termination), Processes of change, self-efficacy and situational temptation	To complete/to revise advance directives (AD's)	The findings provided support for the applicability of the TTM to completing/revising ADs. The cons outweighed the pros among participants in the precontemplation stage, while the pros outweighed the cons among those in the action stage.

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
14	Havens[44] Differences in the Execution/Nonexecution of Advance Directives by Community Dwelling Adults. (2000) QualSyst score: 0.65.	To investigate differences related to the execution or nonexecution of ADs by community dwelling adults with decisional capacity.	General public (N=38 for executed) – Community dwelling adults resided in Vermont at least 6 months of each year.	Quantitative: questionnaire (cross-sectional).	Transtheoretical Model	5 stages of change (precontemplation, contemplation, preparation, action and maintenance); 8 processes of change (helping relationship, socially liberation, consciousness raising, social reevaluation, dramatic relief, self-liberation, reinforcement management, self-reevaluation.	1 stages of change (termination), 2 processes of change (decisional balance, self-efficacy) and situational temptation.	To execute/to not execute an advance directive	There are significant differences between AD executors and nonexecutors (age, participation in discussions, AD educational experience, personal experience with terminal illnesses or critical injuries and so on)
15	Sudore et al.[45] A Novel Website to Prepare Diverse older Aults for Decision Making and Advance Care Planning: a Pilot Study. (2014) QualSyst score: 0.90	To pilot-test an ACP website, based on a theoretical framework of behavior change, to engage older adults in ACP.	General public (N=43) of 60y. or older from three low-income senior centers in San Francisco.	Quantitative: quasi RCT – pilot-study (pre-questionnaire + website-intervention + post-questionnaire;.	Transtheoretical Model + Social Cognitive Theory [c]	5 stages of change (precontemplation, contemplation, preparation, action, maintenance), decisional balance, processes of change[d] ADDITIONAL: beliefs, goal-setting, knowledge, training, perceived barriers (< behavior change theory in general) SCT: outcome expectations, self-efficacy, perceived behavior of others, behavior capability;	1 stage of change (termination), processes of change[d], self-efficacy, situational temptation. SCT: outcome expectancies, environment;	To engage in ACP	The website improves engagement in the process of ACP and behavior change.

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
16	Fried et al.[23] Promoting ACP as health behavior change: development of scales to assess decisional balance, medical and religious beliefs, and processes of change. (2012) QualSyst score: 0.90.	1. To develop measures representing key constructs of the Transtheoretical model of behavior change as applied to (ACP) 2. To examine whether associations between these measures replicate the relationships posited by the Transtheoretical model.	General public (N=304) of 65y. or older from two primary care practices and one senior center.	Quantitative: questionnaire-pilot-study (cross-sectional).	Transtheoretical Model	5 processes of change (behavioral and cognitive processes 5 van de 10: consciousness raising, self reevaluation, helping relationships, stimulus control and self liberation), decisional balance,; ADDITIONAL: values/beliefs (religious beliefs and medical misconceptions)	6 stages of change, 5 processes of change, self-efficacy, situational temptation.	6 Behaviors within ACP: health care proxy, living will, talking to loved ones-life sustaining treatment, talking to loved ones-quality vs. quantity, talking to MD-life sustaining treatment, talking to MD-quality vs. 55quantity.	The core constructs of the TTM as applied to ACP can be measured with high reliability and validity.
17	Fried et al.[46] Stages of change for the component behaviors of advance care planning. (2010) QualSyst score: 0.80	To develop stages of change measures for ACP.	General public (N= unknown) of 65y. or older from two primary care practices and one senior center.	Quantitative: questionnaire (cross-sectional)	Transtheoretical Model [a]	5 stages of change (precontemplation, contemplation, preparation, action, maintenance)	1 stage of change (termination), processes of change, decisional balance, self-efficacy, situational temptation.	Readiness to participate in ACP	Older persons show a range of readiness to engage in different aspects of ACP (for example: between 50% and 60% of participants were in the action or maintenance stage for communication with loved ones about life-sustaining treatment and completing a living will).

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
18	Waltman[47] Attitudes, Subjective Norms, and Behavioral Intentions of Nurses Toward Dying Patients and Their Families. (1990) QualSyst score: 0.90.	1. To develop and validate an instrument, "Attitudes, Subjective norms, and Behavioral Intentions of nurses toward the care of dying patients and their families" 2. to investigate the relationship among selected demographic variables, death anxiety, and social desirability response tendency on the behavioral intentions of nurses toward the dying.	Nurses (N=372) – Nurses caring for dying patients from the Board of Nurse Examiners in one Midwestern state.	Quantitative: questionnaire (cross-sectional)	Theory of Reasoned Action	Intention, attitude, subjective norm		To care for a dying patients (few behaviors within end-of-life care)	The core constructs attitudes and subjective norms were major determinants of intentions toward the care of dying patients and their families.
19	Natan et al.[49] Disclosing bad new to patients with life-threatening illness: Differences in attitude between physicians and nurses in Israel. (2009) QualSyst score: 0.78	1. To define factors influencing the process of caregivers in disclosing bad news to patients 2. To ascertain whether physicians and nurses behave differently.	Physicians (N=100) and nurses (N=200) of different specialties from several Israeli hospitals.	Quantitative: questionnaire (cross-sectional)	Theory of Reasoned Action	Intention, attitude, subjective norm		To decide whether to disclose bad news to patients (the behavior 'usually telling bad news' and the behavioral intention to routinely disclose bad news to terminal patients in the future)	Caregivers find it difficult to disclose terminal status information. Theory of Reasoned Action may help to predict disclosure of bad news. The main predictors among nurses were behavioral beliefs and prior experience, and among physicians' subjective norms and prior experience.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**		**Behavior**	**Most important results**
						Explored/measured	Not explored/measured		
20	Hainsworth[48] The effect of death education on attitudes of hospital nurses toward care of the dying. (1996) QualSyst score: 0.61	1. To investigate the effect of death education on attitudes and behavioral intentions of experienced nurses 2. To determine the influence of death education on nurses' self-perceptions regarding supervision or peer review of their behavior toward dying patients and their families.	Nurses (N=28) (experimental group N=14 & control group N=14) – Nurses of adult medical-surgical units in an urban teaching hospital.	Quantitative: RCT (pre-questionnaire + educational intervention/no intervention + post-questionnaire)	Theory of Reasoned Action	Intention, attitude, subjective norm		To care for dying patients and their family (especially focus on communication)	The educational intervention had a significant positive effect on subjective norms.
21	Enguidanos et al.[50] Use of role model stories to overcome barriers to hospice among African Americans. (2010) QualSyst score: 0.73	To test a brochure comprising hospice patient role model stories aimed at improving attitudes and knowledge of hospice among older African Americans.	General public (N=71) of 65y. or older – having two or more chronic conditions from community-based organizations (senior centers, community exercise programs, churches and senior care management services) in Los Angeles.	Quantitative: quasi RCT (pre-questionnaire + brochure intervention + post-questionnaire)	Theory of Reasoned Action + Social Learning Theory [c]	TRA: intention, attitude SLT: observational learning (modeling) ADDITIONAL: knowledge	TRA: subjective norm SLT: expectations, behavioral capability, self-efficacy, reciprocal determinism, reinforcement	To enroll in hospice	The exposure to a hospice brochure containing theoretically driven, role model stories was effective in improving knowledge of and attitudes toward hospice as well as intentions to enroll a family member or self in hospice care.

	Author **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**	**Behavior**	**Most important results**	**Author** **Title (Year)** **Quality (QualSyst Tool score range 0.00-1.00)**
						Explored/measured	Not explored/measured		
22	Stelter et al.[51] Living will completion in older adults. (1992) QualSyst Score: 0.75.	To investigate why the living will (LW) is not being completed: 1. to design to characterize the group that already had completed LW and 2. to identify the barriers people perceive in their completion of a LW.	General public (N=214) of 65-90y. old – older people who dined at 10 local nutrition sites in America.	Quantitative: questionnaire (cross-sectional)	Health Belief Model (old version)	Cues (informed via media, physician, health status), Beliefs (efficacy of living will, trust of physician, orientation of future, sense of personal control), Barriers (family issues, personal disabilities, access to form, form length, complexity)		To complete a LW	Two major barriers for completing a LW: family issues and a need for assistance in completing the form.
23	Ko & Lee [52] Completion of advance directives among korean american and non-hispanic white older adults. (2010) QualSyst score: 1.00	To investigate the role of culture in the completion of advance directives in terms of individuals' perspectives and beliefs pertaining to end-of-life care.	General public (N=217) of 65y/ or older from senior centers located in New York City.	Quantitative: questionnaire (cross-sectional)	Health Belief Model	Perceived susceptibility, perceived severity, perceived barriers, and perceived benefits	Cues to action, self-efficacy	To complete advance directives	More non-Hispanic White older adults completed advance directives compared to Korean American older adults. Health beliefs, but not knowledge, significantly mediated the relationship between ethnicity and completion of ADs.
24	Ko & Lee[53] EoL communications: Ethnic differences between korean american and non-Hispanic white older adults. (2009) QualSyst score: 0.80	To examine ethnic difference in end-of-life communication between Korean American and Non-Hispanic White older adults.	General public (N=217) – older adults rom senior centers located in a large eastern US City.	Quantitative: questionnaire (cross-sectional).	Health Belief Model	Perceived susceptibility, perceived severity, perceived barriers, and perceived benefits	Cues to action, self-efficacy	To communicate about end-of-life (ACP)	Higher knowledge, stronger beliefs about the perceived severity and barriers, and greater experience of illness were related to having end-of-life communication.

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**	**Behavior**	**Most important results**	**Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)**
						Explored/measured	Not explored/measured		
25	Vandecreek[54] Barriers that predict resistance to complete a living will. (1996) QualSyst score: 0.60.	To identify perceived barriers and benefits to complete living wills.	Patients (N=101) – medical outpatients with a diabetic or endocrinologic disease + family carers (N=75) from the USA.	Quantitative: questionnaire (cross-sectional)	Health Belief Model	Perceived barriers and benefits	Perceived susceptibility, perceived severity, cues to action, self-efficacy	To complete a LW	The major barrier to the completion of LWs is that they connote personal death.
26	Zanchetta et al.[56] Self-determination and information seeking in end-stage cancer. (2006) QualSyst score: 0.45	To investigate the unique situation of a woman with end-stage cancer and her continuous motivation to seek information about her illness.	Patient with end-stage cancer of 73y. old from Canada.	Qualitative: case study	Self-Determination Theory		Competence, autonomy, relatedness	To search information in end-stage cancer	The patient's motivation illustrates that the intention to maintain autonomy in the end stage of cancer can be expected among most individuals.
27	Jonnalagadda et al.[57] Racial and ethnic difference in beliefs about lung cancer care. (2012) QualSyst score: 0.85.	To evaluate racial and ethnic differences in beliefs and attitudes about lung cancer treatment, fatalistic and spiritual beliefs, communication about prognosis and palliative care among among minority and nonminority patients with recently diagnosed lung cancer.	Patients (N=355)- of 18y. or older with a new diagnosis of lung cancer; from four medical centers in New York City	Quantitative: questionnaire (cross-sectional).	Self-Regulation Model of Leventhal	Representation of danger (5 domains of illness representations: identity, timeline, cause, consequences and control) ADDITIONAL: Attitude & spirituality	Situational stimuli (inner and outer); coping procedures - action plans, appraisal; representation of fear, coping procedures, appraisal.	To communicate about lung cancer care To decide receiving lung cancer care	Minority patients hold more fatalistic views about the disease and misperceptions about ACP and hospice care .

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**	**Behavior**	**Most important results**	**Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)**
						Explored/measured	Not explored/measured		
28	Rand et al.[58] Life and treatment goals of patients with advanced, incurable cancer (2016) QualSyst score: 0.65.	To elicit and describe the life and treatment goals of patients with advanced cancer who would soon be facing the end of life 2. To describe the values and expectancies associated with these goals guided by Self-Regulation Theory.	Patients (N=60)-with an anticipated progression free or overall survival of less than 1 year (advanced lung cancer, gastrointestinal cancer, or melanoma) identified from clinic schedules at the Indiana University Simon Cancer Center (USA).	Quantitative: questionnaire (cross-sectional)	Self-Regulation Theory[e]	Goals, value and expectancy (perceived likelihood)	Not clear[e].	To manage the uncertainty and distress associated with end-of-life care	Patients do not perceive a connection between their cancer treatment goals and their broader life goals. Patients hold optimistic expectancies for achieving their goals and for survival.
29	Allen et al.[29] Living well with living wills: application of protection motivation theory to living wills among older Caucasian and African American adults. (2009) QualSyst score: 0.85	To investigate racial differences in intent to complete a living will, rational problem solving and maladaptive coping responses to a health crisis.	General public (N=60): 29 Caucasian & 31 African American) of 55y. or older from the community, not currently possessing a living will	Quantitative: questionnaire + vignette (cross-sectional)	Protection Motivation Theory	Adaptive response ->Threat appraisal (severity, vulnerability, rewards); maladaptive response -> coping appraisal (response efficacy, self-efficacy)	Fear arousal	The use of adaptive responses predicted intent to execute a LW.	The use of adaptive responses predicted intent to execute a LW.

	Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)	**Aims**	**Participants**	**Methods**	**Behavioral theory**	**Constructs**	**Behavior**	**Most important results**	**Author Title (Year) Quality (QualSyst Tool score range 0.00-1.00)**
						Explored/measured	Not explored/measured		
30	Nolan et al.[59] Development and validation of the family decision-making self-efficacy scale. (2009) QualSyst score: 0.80	To develop and validate a scale to measure family member confidence in making decisions with (conscious patient scenario) and for (unconscious patient scenario) a terminally ill loved one.	Family carers (N=30) – Family members of patients with pancreatic cancer or amyotrophic lateral sclerosis (ALS) in the ALS Comprehensive Care Clinic in USA.	Quantitative: questionnaire – pilot study (cross-sectional)	Self-efficacy Theory	Previous performance of the desired behavior, vicarious experience of observing others perform the behavior, positive feedback that one can successfully perform the behavior		To participate in decision-making in end-of-life care of terminally ill family members (family decision making)	The Family Decision-Making Self-Efficacy Scale is valid, reliable, and easily completed in the clinic setting.
31	McAfee et al.[55] Predicting Racial and Ethnic Disparities in Advance Care Planning Using the Integrated Behavioral Model. (2017) QualSyst score: 0.90	To explain and predict racial or ethnic disparities in (ACP) behaviors among American by using the Integrated Behavioral Model and the Precaution Adoption Process Model.	General public N=386: non-institutionalized American adults of all races aged 40 to 80.	Quantitative: questionnaire (cross-sectional)	Integrated Behavioral Model (IBM-+ the Precaution Adoption Process Model (PAPM).	IBM: behavioral intention, attitudes (direct & indirect attitude), perceived norms (direct & indirect perceived norm), personal agency (self-efficacy); PAPM: stage of readiness - motivation to comply (unaware, unengaged, undecided, dediced not to act, decided to act, process of acting, maintenance)	IBM: personal agency: (perceived control)	To complete ACP (three subbehaviors: 1. To complete a living will 2. To complete a durable power of attorney for health care document 3. To discuss end-of-life medical treatment preferences with a least one family member or loved one.	Significant differences were found by race or ethnicity: 33% of Whites had completed ACP versus Hispanics (18%) and Blacks (8%). Whites had statistically significantly higher levels of most IBM constructs compared with Blacks and Hispanics.

ACP: Advance Care Planning; LW: Living Will; AD: Advance Directives

a Constructs are not measured, but are not relevant for the research question

b Consructs are mentioned, but it is not fully clear if they are also measured

c Two different theories are combined

d Which processes exactly is not known

e It is not clear on what self-regulation theory this study is based on. It seems to be a combination of the self-regulation theory, the expectation-value theory and the goal-setting theory.

4 Discussion

To our knowledge, this is the first systematic review mapping the use of individual behavioral theories in end-of-life care research. We found 31 studies that met our inclusion criteria, indicating that the use of these theories in the research on end-of-life care is rather limited. Of these, only four were intervention studies (three quasi-RCTs without random assignment and one RCT). The Theory of Planned Behavior and the Transtheoretical Model were the most commonly used theories. Only nine studies explored or measured all the main theoretical constructs of the theory used. Furthermore, in more than half of the included studies the behavior under study was related to advance care planning.

4.1 Behavioral theories

This review resulted in a small number of studies using behavioral theories in research on end-of-life care, although these theories are commonly used in successful studies within other health domains such as prevention of substance use, promotion of physical activity, medication adherence etc.[5,15,60]. The small number of studies, almost all published in the last 10 years, is in contrast with the relatively recent growth of end-of-life care research[61]. A possible explanation for the limited use of behavioral theories in this area might be the practice-driven approach in end-of-life care[62]. Furthermore, health promotion researchers rarely seem to have an interest in end-of-life care research.

The low number of intervention studies found in this review suggests that a limited number of intervention studies in end-of-life care are developed based on the principles of behavioral theories. Only three quasi-RCTs and one RCT were identified and this is in contrast to the growing number of available behavioral intervention studies in end-of-life care research[63]. The development of interventions aimed at improvement of quality end-of-life care usually starts from the practical problems related to identified needs and less often from mechanistic models for a behavior[64]. Based on this finding we could argue that behavioral interventions in end-of-life care may be insufficiently supported by theory.

One notable finding was the frequent use of the Theory of Planned Behavior and the Transtheoretical Model. More than half of the studies chosen used one or the other(N=17); this is not surprising since these are two of the most commonly used theories in the research field of health promotion[12,15]. Like all theories, they have advantages and disadvantages. A meta-analysis of research using the Theory of Planned Behavior shows that this model explains on average between 40% and 50% of the variance in intention, and between 19% and 38% of the variance in behavior[20]. According to the designers of the theory, it is a weakness that it must often be supplemented by additional theoretical constructs (e.g. awareness, moral norm) to understand a targeted behavior[19]. Another major weakness is that it is highly cognitive and does not take into account unconscious or automatic processes[19]. The Transtheoretical Model is a more complex theory whose main construct 'stages of change', translating the degree of readiness to perform a targeted behavior, is not easy to measure in end-of-life care behaviors. Despite these weaknesses, the Transtheoretical Model has the strength to provide strategies that can be incorporated into a targeted intervention[26,65]. Because of the limitations of each single theory, (intervention) studies in health promotion research should combine the constructs of two or more theories[66]. However, this review identified only four out of the 31 studies that combined two theories to describe an end-of-life care behavior.

Three of the 12 full-text articles that were excluded referred to a behavioral theory in the abstract, but when the full text was looked at it was clear that they did not use the theory as a theoretical framework or did not explore or measure any constructs at all. This is in line with the findings of a review of behavioral theory use in studies on health behavior[12] which found that two-thirds of the behavioral studies included claimed to use a behavioral theory although none of the theoretical constructs were effectively explored/measured[12]. One possible explanation for studies referring to a theory without using it effectively could be publication bias i.e. reference to a theory may improve the chances of publication as some journals and referees demand a theoretical framework for a study.

4.2 Constructs

In this review only nine of the 31 studies identified fully used an individual behavioral theory i.e. by exploring, operationalising and/or measuring all theoretical constructs. This could be due partly to a lack of detailed description of the exploration or measurement of the constructs of the theories by the authors[12]. However, incomplete use is not automatically insufficient; the exploration or measurement strongly depends on the research question. Some studies only want to assess a person's degree of readiness for participation in advance care planning. In this case the use of the main construct 'stages of change' of the Transtheoretical Model is sufficient to achieve the research aim[1,5]. Future studies should adequately describe the use of any behavioral theory. The more constructs are explored or measured, the better a behavior can be described and/or predicted and the more effectively further interventions can be developed.

4.3 Health behaviors

The review resulted in sixteen of the 31 studies using a behavioral theory focusing on behaviors within advance care planning such as ‘to complete an advance directive’ and ‘to complete a living will’. In current research, a lot of attention is paid to advance care planning (specifically regarding the completion of advance directives and the discussion about advance care planning). A review of Houben et al. from 2014 analysed the efficacy of advance care planning interventions in different adult patient populations and resulted in 55 interventional studies being published between 1966 and 2013[63] which goes some way towards accounting for the high number of such studies. Another possible reason could be that it is easier to define a specific behavior within advance care planning than in other areas of end-of-life care such as the early initiation of palliative care. There is evidence that focusing on specific behaviors in studies concerning end-of-life care results in more positive outcomes in the studies[67]. Defining relevant and specific behaviors makes theories more useful, because they will be better able to predict the behavior and lead to more effective interventions. Despite half of the behaviors within this review being related to advance care planning, findings demonstrate that behavioral theories can also be used for a wide range of end-of-life care behaviors. However, there is limited empirical knowledge about what key end-of-life care behaviors and factors relating to them are relevant in the context of end-of-life care [7,68]. Analysis of targeted behaviors is a scientific field that deserves further in-depth exploration within the context of end-of-life care[2,26,69] and careful consideration of which behaviors and associated determinants lead to the best health gains in end-of-life care is needed.

4.4 Strengths and weaknesses

To our knowledge this is the first study to conduct a thorough systematic search of the available literature concerning the use of individual behavioral theories in end-of-life care research. Since we wanted to make an overview of the use of behavioral theories in end-of-life care research and we wanted to get insight in all behaviors that were considered for this kind of research, we have consciously opted for a broad approach by including all end-of-life care research that may have used a behavioral theory, despite of the differences between the behaviors and determinants. We believe it represents a well-rounded picture of new thinking for the use of behavioral theory for improving end-of-life care research. We used a strong methodology based on the PRISMA and COREQ guidelines for the study design and the reporting of the results, and the search strategy was applied to five different databases. Nevertheless, there are also some limitations. It is possible, for instance, that we missed studies that used behavioral theories without explicitly mentioning them, though in these cases the fact that they were not mentioned suggests that they were not really central or important to the study. It is also possible that we missed studies using theories that are little known and/or rarely used and that the search strategy did not find them. We tried to minimize the risk of missing such studies by developing and applying an all-encompassing search strategy. Another noteworthy limitation is that this review did not look at whether the theories were used correctly; constructs may be misinterpreted or poorly explored or measured. However, this has no significant impact on the results of our review as the research questions only concerned which of the main theoretical constructs of a theory were explored or measured and to what extent.

4.5 Implications for clinical practice and future research

It is recommended for researchers to make more use of behavioral theories. We only found few end-of-life care studies that used a behavioral theory, while there is evidence that the use of behavioral theories in end-of-life care research can help to understand end-of-life care behaviors and to develop more effective behavioral interventions (see included studies e.g. [1,4,5,38,43,45]), potentially contributing to quality of (end of) life. On the basis of strong indications from other scientific fields about the relevance of behavioral theories we can hypothesise that they do form a suitable theoretical framework for improving the quality of end-of-life care. From the included studies investigating the applicability of a behavioral theory aimed at an end-of-life care behavior, we can conclude that there was some support for their use (eg [43]). From the studies aimed at understanding end-of-life care behavior we can conclude that the use of behavioral theories can be useful to identify determinants related to end-of-life care behaviors (eg [14]) while the intervention studies indicate that interventions based on principles of a behavioral theory are effective in changing certain determinants and, consequently, changing behaviors (eg [45]). However, in order to be able to conclude that the use of behavioral theories in end-of-life care research is really effective, more intervention studies are needed. Further research is needed to determine which theories are most useful or suitable and to determine how they are best used. There is also need for additional research aimed at the identification of the most relevant behaviors and which ones may be open to change.

5 Conclusion

This systematic review of the use of behavioral theories in end-of-life care research showed that their use is limited. There were few studies that explored or measured all the main constructs of the theory used and only four intervention studies were included. Regarding the health behaviors themselves, more than half of the studies focussed on behaviors relating to advance care planning. Behavioral theories have been shown to be successful in understanding other health and health care behaviors and could be useful in better understanding and, eventually, in influencing targeted end-of-life care behaviors. Increasing the use of behavioral change theories may improve the development of future interventions and ultimately the quality of end-of-life care.

Funding

The analyses and preparation of the manuscript were supported by a grant of the Vrije Universiteit Brussel (VUB) (HOA24). Lenzo Robijn is a predoctoral Fellow of the Research Foundation Flanders (FWO). None of these funders played any role in the study design, collection, analysis or interpretation of data, or in the drafting of this paper.

Conflicts of interest

The authors have no conflict of interest in the authoring of this manuscript.

Authorship

The search string was developed by ALS and NSP. ALS and LR performed the screening. ALS, LR and KB performed the data-extraction. ALS and KB wrote the first draft of the manuscript and revised the manuscript after receiving comments from all co-authors. JC, BD and LD supervised the study. All authors contributed to the interpretation of the data and critically reviewed and approved the final manuscript.

Research ethics

Ethical approval was not required because of the type of review (narrative review of the literature).

Data management and sharing

All relevant data is available. The method of data collection is described in detail in the paper. The search strategy within each data base can be found in additional file 1. The whole screening process is demonstrated in the flow chart in the manuscript (Figure 1). The data used of each included study is clearly described in the manuscript and in Table 3.

Acknowledgements

The authors would like to thank Jane Ruthven for help with editing the text.

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CHAPTER 3

USING BEHAVIORAL THEORIES TO STUDY HEALTH-PROMOTING BEHAVIORS IN PALLIATIVE CARE RESEARCH

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[Submitted]

Abstract

Background - Behavioral theories are often used to better understand and change health-promoting behaviors and develop evidence-based interventions. They can also be used in palliative care and in people confronted with serious illness. However, little is known about how to do this.

Aim - To describe how behavioral theories can be used to gain insight into critical factors of health-promoting behavior in seriously ill people, using a case example of 'starting a conversation about palliative care with the physician' for people with incurable cancer.

Methods - Step 1: We chose a theory. Step 2: We applied and adapted the selected theory by performing 25 interviews with the target population which resulted in a new behavioral model. Step 3: We operationalized the factors of this model. An expert group (n= 14) checked content validity. We tested the questionnaire cognitively (n=8). Step 4: We conducted a survey study (n=80) and performed logistic regression analyses to identify the most important factors.

Results - Step 1: We selected the Theory of Planned Behavior. Step 2: This theory was applicable to the target behavior, but needed extending. Step 3: The final survey included 131 items. Step 4: Attitudinal factors were the most important factors associated with the target behavior of starting a conversation about palliative care with the physician.

Conclusions - This paper describes a method applied to a specific example, offering guidance for researchers and practitioners interested in understanding and changing a target behavior and its factors in seriously ill people.

Key words

Health promotion; behavior; behavioral theory; critical illness; palliative care; health communication

Key statements

What is already known about the topic?

- A health promotion approach and focusing on promoting health behaviors in people confronted with serious illness can potentially improve their quality of life
- Behavioral theories are useful to better understand and change behaviors of people
- Behavioral theories are scarcely applied to behaviors in those confronted with serious illness, for example palliative care behaviors, and their use is often not precisely described

What this paper adds

- This paper describes how a behavioral theory can be used to better understand a specific behavior in seriously ill people
- This paper demonstrates how the theory of planned behavior was used to better understand the factors related to starting a conversation about palliative care with the physician in people with incurable cancer

Implications for practice, theory or policy

- Researchers in the field of palliative care might want to use behavioral theories more often and apply them more adequately in order to develop effective interventions to change behavior
- This paper provides guidance for researchers and practitioners interested in understanding and changing a target (palliative care) behavior and its behavioral factors in seriously ill people.

3.1 Introduction

Worldwide, palliative care is frequently started late or not at all[1], which can lead to suboptimal care in the final months of life[2]. Palliative care research is mainly dominated by the paradigm of pathogenesis, i.e. focusing on assessing and improving the biopsychosocial factors causing problems and suffering[3]. Additionally, the focus is usually on the role of health services or professional carers in achieving this[4]. Only some of the empirical literature uses a health promotion or salutogenic approach that focuses on factors (e.g. empowerment) that stimulate health and on enabling people confronted with serious illness (e.g. patients, family carers) to have control of these factors and to make healthy choices[3]. Nevertheless, there is growing evidence showing that using a health promotion approach and focusing on promoting health behaviors in those confronted with serious illness can potentially improve their quality of life in their final days[5]. However, this approach is scarcely applied to behaviors in those confronted with serious illness, because of researchers' lack of knowledge about how to apply it and a lack of tools available to support them in such a relatively new domain in health promotion research.

A variety of behaviors is related to timely initiation of palliative care. One important behavior (among others) is communication about palliative care. Although well-timed communication is important for timely initiation of palliative care, it is often postponed or avoided[6]. It is clear from previous literature that significant barriers, and hence opportunities for initiating palliative care, also exist among patients[7,8]. More patient empowerment can help people with cancer in starting a conversation about palliative care[9,10]. An important prerequisite for developing effective interventions to support people with serious illness in starting that conversation is to understand why they do or do not and to identify factors that facilitate or hinder them[4,11–15].

Behavioral theories can help researchers to better understand behaviors. In general, little is known about how behavioral theories can be used, i.e. selected, applied, adapted, operationalized and evaluated, in order to gain insight into factors related to palliative care behaviors in people who are seriously ill[11,16]. This paper describes in detail the process – in four different steps- of how a health promotion approach can be applied to behaviors in seriously ill people (methods section). Next, this paper demonstrates how a behavioral theory was used to better understand the factors related to starting a conversation about palliative care in people with incurable cancer. Although this paper focuses on one specific behavior, the methodology described could also be used for other (palliative care) behaviors in seriously ill people (e.g. to make a living will).

3.2 Methods

The four steps described below are not prescriptive, but are based on evidence-based protocols[12] and experiences from previous studies by a multidisciplinary expert group. This expert group consists of the (co-)authors, who are experts in either health promotion (n=2) or end-of-life care research (n=3).

3.2.1 Step 1) Describing the health problem, identifying the most important risk behavior and choosing a theoretical framework

Describing the health problem and identifying and defining the most important risk behavior

First, the health problem of interest was clearly described[12]. Next, possible causes of the health problem were identified based on literature and experiences of the multidisciplinary expert group. As a variety of risk behaviors were related to the health problem, the multidisciplinary expert group selected one important behavior to target[12,17]. In a next step, the risk behavior was translated into a health-promoting behavior that contributes to improvement of quality of life in the target population[12,18].

Choosing an appropriate theoretical framework

There is a wide range of behavioral theories, which made it challenging to choose an appropriate one. Behavioral theories are by nature abstract and not content- or topic-specific[13]. They can be generalized over behaviors and populations, but the weight of each behavioral factor can vary[12]. Our choice was not based on familiarity with a theory[13], but depended on the study purpose and population. We studied a comprehensive overview of existing behavioral theories[12]. Furthermore, we searched for evidence of which behavioral theories were already used in studying palliative care behaviors and which theories or behavioral factors were proven to be relevant[17]. Our systematic review[11] also showed which theories were mostly used in palliative care research. Based on this information, our multidisciplinary expert group selected a theory that was expected to be relevant for the selected target behavior and target group[17].

3.2.2 Step 2) Applying and adapting the selected theory

A deductive and inductive method were used[19] respectively to apply and adapt the selected theory and (the relevance of) its factors. Qualitative, individual face-to-face interviews with the target group, i.e. people with incurable cancer (n=25), were performed. The deductive approach was used to apply the factors from the theory selected in step 1 to the specific target behavior of starting a conversation about palliative care with the physician. This theory formed the basis for the development of the semi-structured interview guide[12,19]. Questions covered 1) the perception of the behavior, 2) facilitating and hindering factors derived from the selected theory and 3) other facilitating and hindering factors not part of the selected theory (see **Appendix A**)[9]. The latter questions created the opportunity to adapt and extend the selected theory. We then used an inductive approach to analyse the collected data and modify the theoretical model accordingly. This made the newly developed behavioral model more complete and applicable to our target behavior[19]. Details about the methodology of this qualitative interview study are published elsewhere[9].

3.2.3 Step 3) Operationalizing the factors of the newly developed behavioral model

For the development and validation of the survey, no standard approach was used. We conducted a literature search searching for studies focusing on behavioral factors, to decide on measurement and operationalization of the factors of the newly developed model. Our systematic review[11] showed that few surveys assessing factors related to specific behaviors in end-of-life and palliative care were available (e.g. practice of euthanasia, advance care planning[11,20,21]). So besides these survey studies, we searched for practical guidance[22–24] and survey studies assessing the specific behavioral factors related to more conventional health behaviors (e.g. physical activity[21]). The relevant information retrieved from existing survey instruments was then integrated into our survey and adapted where necessary. We translated it into Dutch, and adapted it according to the specific target behavior. We added more content to the behavioral factors based on the qualitative findings from step 2 and input from the multidisciplinary expert group. To avoid abstractness, special attention was paid to the wording of the items and the type of responses[19]. The multidisciplinary expert group reviewed all survey items one by one with constructive face-to-face meetings by evaluating their relevance, language and structure. Face and content validity were also checked by asking the opinion of other experts in end-of-life care (n=4) and health promotion research (n=10) through one-time feedback on each survey item. As some questions might be perceived as complex and/or confrontational in seriously ill people, we checked the appropriateness of the various items by cognitively testing a preliminary survey during face-to-face interviews with eight people with incurable cancer[27]. During these cognitive interviews, a standardized template for the evaluation of the items (clear/unclear or confusing/difficult/confronting) was completed. At the end of this operationalization process, the expert group checked again whether the operationalized items matched the meaning of each determinant.

3.2.4 Step 4) Empirically examining the factors of the newly developed behavioral model

We performed a cross-sectional survey with computer-assisted, answer-based personal interviews using a structured questionnaire among the target population, i.e. people with incurable cancer (n=80), to quantitatively test and evaluate the strength of the association of each factor in our adapted theoretical model with our target behavior. The target population was recruited through selected oncologists and nurses. Purposive sampling of the target population, taking into account the theoretically important heterogeneity, was used with the aim of theoretical or scientific generalization about associated factors rather than statistical generalization[28]. We needed a sufficient number of people who had already started the conversation about palliative care with their physician or had the intention to do so. We used descriptive statistics to describe participants' characteristics and conducted logistic regression analyses to find out which factors were associated with the behavior.

In total, steps one to four took about two years and four months (see **Figure 1**).

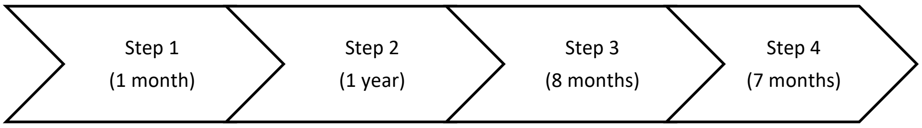

Figure 1. Overview of the time process needed to complete the four steps

3.3 Results

3.3.1 Step 1) Describing the health problem, identifying the most important relating risk behavior and choosing a theoretical framework

Health problem and behavior

The health problem was that palliative care for people with incurable cancer is frequently started late or not at all. Avoidance of a conversation about palliative care with the physician by people with incurable cancer was found to be one of the most important risk behaviors for not (timely) starting palliative care. Starting a conversation about palliative care with the physician by people with cancer was found to be the matching health-promoting behavior[13].

Theory of planned behavior (TPB) as theoretical framework

After performing a systematic literature review, we concluded that the available evidence of useful theories to better understand health behaviors in people with incurable cancer was limited[11]. We found that the TPB is most frequently used and that its factors are relevant to understand palliative care behaviors[11]. The TPB incorporates three factors (‘attitude’, ‘subjective norms’ and ‘perceived behavioral control’) that influence a behavioral ‘intention’, which in turn is the most important determinant for actual behavior[29,30] (see **Figure 2**[29]). Literature showed that this theory is widely used in multiple health domains, populations and settings[31]. Findings show that important shortcomings of the TPB are that it is highly cognitive and does not take into account unconscious or automatic processes or environmental factors[29]. However, as it would be difficult to operationalize and measure these unconscious processes related to communication about palliative care, this was not considered a reason not to use this theory as a framework for our project. In addition, step 2 creates the opportunity to add perceived environmental factors to the model if these appear important and relevant. Based on this analysis, our multidisciplinary expert group selected the TPB as a relevant theoretical framework.

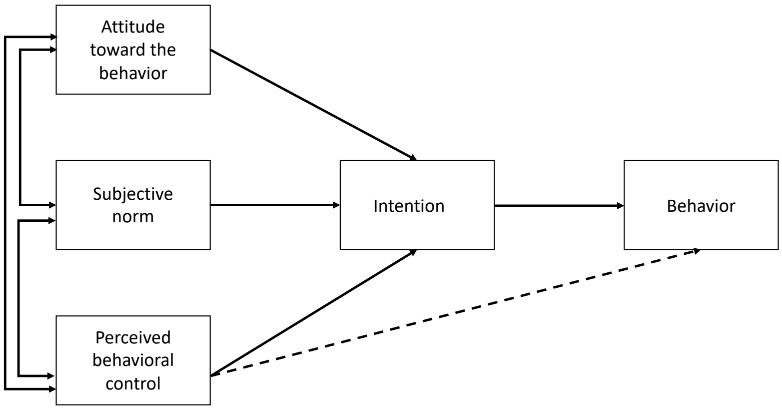

Figure 2. The Theory of Planned Behavior, redrawn from Ajzen (1991)[29]

3.3.2 Step 2) Applying and adapting the selected theory

The face-to-face interviews with people with incurable cancer confirmed that the TPB is applicable to the target behavior. The inductive analysis of the data led to extension of the model. Relevant factors from other behavioral theories were identified: awareness, knowledge and perceived social influence. The detailed findings of the qualitative interviews are published elsewhere[9]. Step 2 resulted in a newly developed palliative care behavioral model for starting a conversation about palliative care with the physician by people with incurable cancer (see **Figure 3**).

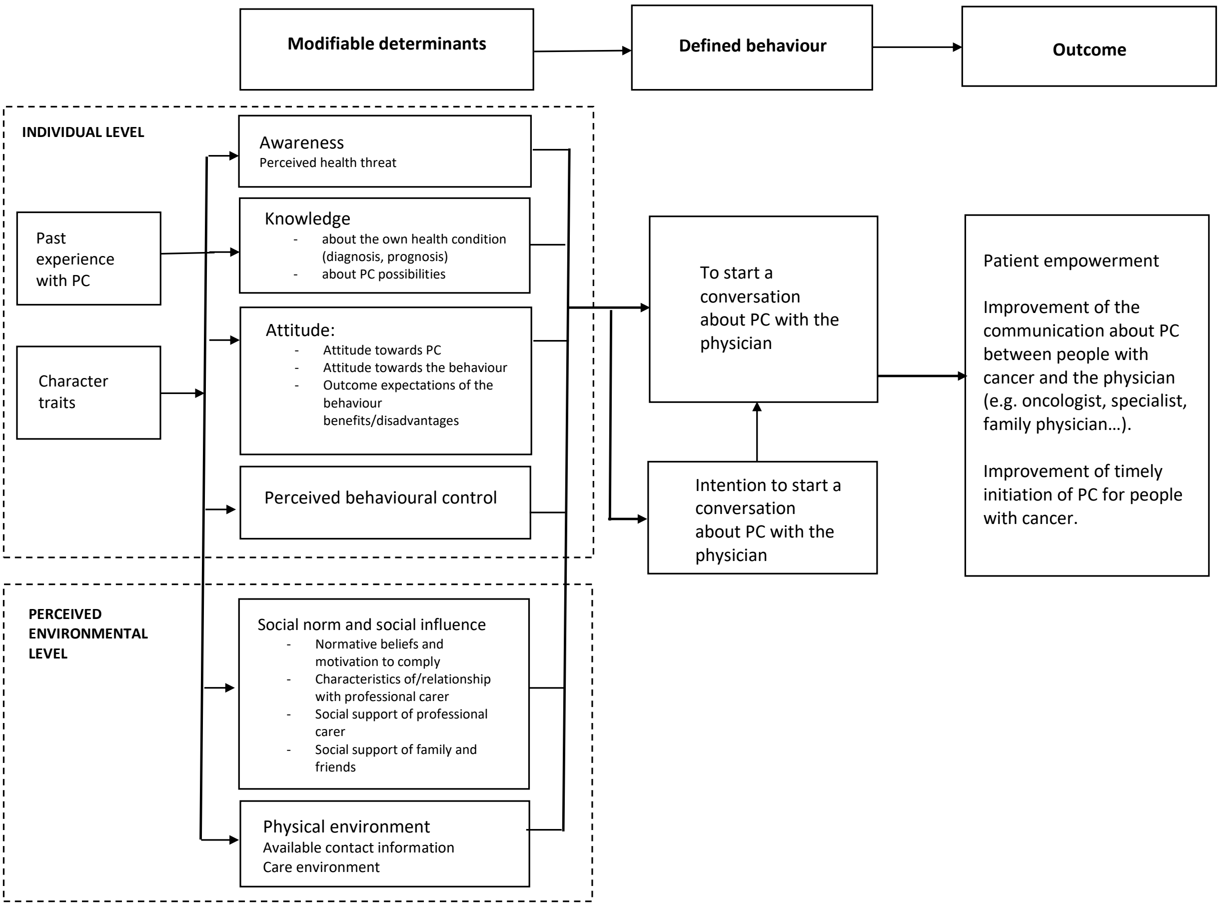

Figure 3. The palliative care (PC) behavioral model developed

3.3.3 Step 3) Operationalization of the factors of the newly developed behavioral model

Operationalization of the factors

The literature search identified few guidelines on how to operationalize the TPB, but it offered many survey instruments assessing factors of more conventional health-promoting behaviors. Our systematic review also showed that most of the existing studies focusing on palliative care behaviors failed to precisely describe the behavioral theory used or how the factors were operationalized[18].

The number of items for the survey and their content are based on the results from the previous qualitative interviews and the model. The operalization and formulation of the survey item were based on existing surveys, of which most were based on behavioral theories (step 2). To illustrate this, the operationalization of the factor “affective beliefs towards palliative care” is described below. Studies in cancer and end-of-life care research measured affective beliefs towards palliative care as ‘how good/bad do you feel about palliative care?’ (five-point Likert scale ranging from strongly positive to strongly negative)[12, 15]. Our previous qualitative findings revealed that people with incurable cancer associate the term palliative care with feelings such as stress, anxiety and depression. We operationalized affective attitude towards palliative care with the following two items: At this moment… '…the words palliative care give me stress or anxiety' and '…thinking about palliative care makes me feel depressed' (five-point Likert scale ranging from strongly disagree to strongly agree). All results of the literature study and how we operationalized the relevant factors (and specific behavioral beliefs) related to the specific target behavior into a questionnaire is described in **Table 1**.

Validity checking

Testing the preliminary survey by cognitively interviewing eight people with incurable cancer (5 men, mean age 65 years) revealed that the questionnaire was acceptable and suitable, only needing minor adjustments to the order of the items and word choice. The final survey includes 131 items [see **Appendix B & C**].

3.3.4 Step 4) Empirically examining the factors of the newly developed behavioral model

A total of 135 people with incurable cancer were contacted and invited to participate. Of these, 88 people effectively participated (response rate = 65.2%) with 80 surveys fully completed; ten had already started a conversation about palliative care themselves and 18 had the intention to do so. People holding a positive attitude towards this behavior (OR 4.74; 95%CI 2.35-9.54), perceiving more benefits of it (OR 2.60; 95%CI 1.37-4.96) and perceiving a positive attitude towards the behavior in family/friends (OR 2.07; 95%CI 1.26-3.41) and the physician (OR 2.19; 95%CI 1.39-3.45) were more likely; people perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI 0.15-0.63) were less likely to perform the behavior or have the intention to do so. These factors explained 64% of the variance.

Table 1. Operationalization of the behavioral factors related to starting a conversation about palliative care with the physician

Behavioral factor	**Description**	**Main constructs (underlying beliefs)**	**Operationalization**
Awareness	Need recognition or problem appraisal: the extent to which a person perceives his/her own behavior as unhealthy (e.g. health condition, care needs etc.).	/	Awareness about palliative care (n=3 items) In literature, awareness of palliative care was operationalized as ‘Have you ever heard of palliative care? Do you know what palliative care is? Do you know when palliative care can be used? (yes/no)[32]. These items (n=3) were integrated and translated into the survey. Because of known misconceptions about palliative care, the response categories were adapted from yes/no to no, I don’t know/I think so/yes, I know for sure.
Knowledge	The individual’s knowledge about health and disease; specific information about health risks of unhealthy behaviors; information about how to change. This knowledge is needed to obtain behavioral change[23].	/	Knowledge about palliative care (n=12 items) In health promotion research, knowledge about a concept was operationalized by ‘I know that…’ and ‘I know how to…’[23]. In the study by Eguidanos et al., knowledge about palliative care was operationalized by asking if palliative care statements based on the WHO definition, eg ‘palliative can alleviate the pain’, were false or true[33]. In the current survey, knowledge about palliative care was also operationalized based on eight statements in the WHO Definition, for example: ‘palliative care also addresses possible psychological problems’ (definitely false, probably false, probably true, definitely true). Four extra items were added based on incorrect knowledge or negative connotations found in the previous qualitative study such as ‘palliative care equals the end, death’. Knowledge about starting a conversation about palliative care with the physician (n=1 item) To operationalize knowledge about our specific target behavior, the following item was designed ‘Do you know you can start a conversation about palliative care with the physician yourselves?’(yes/no).

Behavioral factor	**Description**	**Main constructs (underlying beliefs)**	**Operationalization**
Attitude	The individual’s positive or negative evaluation of an object/a concept/ performing the particular behavior of interest. Behavioral outcome expectations (advantages/ disadvantages).[12, 29]	Attitude is composed of three components: affective beliefs, cognitive beliefs and outcome beliefs[12]. 1) Affective beliefs: related to feelings (pleasant or unpleasant) 2) Cognitive beliefs: related to knowledge (important or not important; relevant or irrelevant)	Attitude towards palliative care (n=6 items) General attitude towards starting a conversation about palliative care with the physician (n=5 items) Perceived reasons to start a conversation about palliative care with the physician myself (n=7 items) Perceived reasons not to start a conversation about palliative care with the physician myself (n=6 items) Perceived benefits to starting a conversation about palliative care with the physician myself (n=12 items) Perceived disadvantages to starting a conversation about palliative care with the physician myself (n=5 items) Guidelines for how to measure theory of planned behavior constructs as well as studies related to physical activity show that affective beliefs can be operationalized as ‘displaying the behavior is e.g. good/bad, irrelevant/relevant, satisfying/dissatisfying’ (seven-point semantic differential scale)[24,26]. Studies in cancer and end-of-life care research measured affective attitude as ‘How do you feel about palliative care? (Five-point Likert scale ranging from strongly positive to strongly negative)[12, 15]’. The previous qualitative interviews showed that stress, anxiety and depression were related to the term palliative care. In the current survey, affective attitude towards palliative care was operationalized by the following two items ‘At this moment … the words palliative care give me stress or anxiety’ and ‘…thinking about palliative care makes me feel depressed’. Cognitive beliefs were measured in existing health behavior studies as ‘I think it is important/relevant/necessary that…’ (Five-point Likert scale ranging from strongly disagree to strongly agree)[29]. Studies focusing on attitude towards advance care planning measured the cognitive beliefs as ‘ACP is important’, ‘ACP can improve satisfaction with care…’ (Five-point Likert scale ranging from strongly disagree to strongly agree)[30]. In the current study, cognitive beliefs about palliative care (4 items) were operationalized as e.g. ‘I am interested in palliative care’, ‘I think palliative care is necessary for me’ (4 items). Cognitive beliefs about the specific target behavior (4 items) were operationalized as e.g. ‘I think starting a conversation about palliative care with the physician myself is important‘. Some studies also captured reasons to perform the behavior and reasons to not perform the behavior. For example, an end-of-life care survey measured ‘I am/I am not interested in displaying the behavior, because … ‘(Four-point Likert scale ranging from fully disagree to fully agree)[34]. In the current study, reasons to perform (6 items) and not to perform the behavior (7 items) were based on reasons identified in the previous qualitative study. For example: ‘A reason why I should start or started a conversation about palliative care with the physician myself is or was that my quality of life decreases’, ‘a reason for me to not start a conversation about palliative care with the physician myself is or was that I am feeling good’.

Behavioral factor	**Description**	**Main constructs (underlying beliefs)**	**Operationalization**
		3) Outcome beliefs: expected outcomes of the behavior (advantages/ disadvantages) and evaluation beliefs: how important these outcomes are [12,29].	In existing literature outcome beliefs (benefits/disadvantages) were measured with 'perceived benefits/disadvantages of the behavior for me are that…'[24,26,34–36]. The previous qualitative interviews identified benefits such as receiving information about palliative care. This led to the following items (11 items) in the survey, e.g. 'A perceived benefit of starting a conversation about palliative care with a treating physician myself was/would be that… I received information about palliative care', '…that I could express my care wishes'. The previous qualitative interviews also identified disadvantages such as feeling stress and anxiety afterwards. This led to the following statements (5 items) e.g. 'A perceived disadvantage of starting a conversation about palliative care with a treating physician myself was/would be that… I would feel/felt stress and anxious afterwards'. All attitude-items were scaled on a five-point Likert ranging from totally disagree to totally agree.
Perceived social norm	The perceived social expectations[37].		Perceived social norm in attitude towards palliative care – family/friends (n=4 items) Perceived social norm in attitude towards palliative care – physician (n=4 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – family/friends (n=5 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – physician (n=4 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – fellow sufferers (n=1 item)
		1) Normative beliefs (the estimated important others' opinion)	In existing surveys normative beliefs were measured as follows: Important others think that…[29], important others approve/disapprove…[24], Important others expect of me that I…. [23], Do you think that other people around you (e.g. other patients) perform the behavior?[38]. According to guidelines describing how to measure this determinant of the theory of planned behavior, it can be measured as 'Important others think I (should not -3 to +3 should or disapprove -3 to +3 approve) perform the behavior'[24]. Qualitative interviews showed that the perceived opinion of important others such as the partner/family/friends/the physician about palliative care and the behavior were influential.

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
			Operationalization of the social norm towards palliative care resulted in 'My partner/family/friend think(s) that palliative care is important (Five-point or four-point Likert scale ranging from nobody to everybody)' and the social norm in attitude towards the specific target behavior was operationalized as 'My partner/family/friend think(s) that starting a conversation about palliative care with the physician myself is important (Five-point Likert scale ranging from nobody to everybody).
		2) The motivation to comply with this opinion (how important is it to comply with the social expectations)	In literature, the motivation to comply was measured as 'I am willing to do what people around me expect of me' (Five-point Likert scale ranging from strongly disagree to strongly agree)[23]. Guidelines suggest measuring it as 'I think doing what my environment expects of me is…'(important/not important)[24]. Operationalization of the motivation to comply resulted in 'the motivation to comply with the opinion of family/friends is important to me' (Five-point Likert scale ranging from strongly disagree to strongly agree).
Perceived behavioral control	The subjective probability that a person is capable of executing a certain course of action[37].	Control beliefs[29].	Perceived behavioral control (n=1 item) Guidelines describing how to measure this determinant of the theory of planned behavior, describe measuring it with the following statement 'I am confident that I can display the behavior' (Seven-point semantic differential scale ranging from fully disagree to fully agree)[24]. In the current survey, we specified it for the defined behavior. This resulted in the statement 'I would be / was confident that I can / could start a conversation about palliative care with the physician myself '(Five-point Likert scale ranging from strongly disagree to strongly agree).
Perceived social influence	Interpersonal processes that can change someone's thoughts, feelings and/or behavior.[38]		Social influence – partner/family/friends (n=4 items) Social influence – physician (n=10 items) Social influence – fellow sufferers (n=3 items)

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
	The social support or pressure to perform or not to perform a given behavior[39].	Social support (emotional support, informative support) versus social pressure	Practical guidelines to operationalize the theory of planned behavior describe to measure social influence as follows: My partner/friends/family… support(s) me in…, … encourage(s) me to…, … stop(s) me from…[23]. Previous qualitative interviews showed that positive social support was related to family (e.g. attending the conversation), the physician (good relationship, being empathetic…) and fellow sufferers (supporting). The interviews showed that negative social support was mainly related to the physician (e.g. weak connection, perceived time constraints, perceived negative attitude towards palliative care…). Again a distinction was made between family/friends (n=4), the physician (n=10) and fellow sufferers (n=3). For example, my partner/friends/family… would encourage or encouraged me to start a conversation about palliative care with the physican myself. A social factor that would help me or helped me to start a conversation about palliative care with the physician myself is or was that I have a good relationship with my physician (Five-point Likert scale ranging from strongly disagree to strongly agree).
Behavioral intention	The extent to which someone intends to display a certain behavior, ie to start a conversation about palliative care with the treating physician themselves.		Behavioral intention (n=4 items) Behavior (n=2 items) The main outcome (i.e. the intention to start a conversation about palliative care with the treating physician as well as the behavior itself) was operationalized on a dichotomous scale (yes/no). Participants could indicate whether they had already started a conversation about palliative care themselves. If the participants responded no, they were asked if they had the intention to do so in the next (six) month(s) in case of not (yet) receiving specialist palliative care (yes/no), or if they were receiving specialist palliative care, they were asked if they would do it with hindsight (yes/no).

4 Discussion

This paper uniquely describes the four steps that can be taken to use a behavioral theory to gain deeper insight into factors related to a health-promoting behavior in people confronted with serious illness: 1) choose a theory, 2) apply and adapt the selected theory, 3) operationalize the factors of the newly developed behavioral model, 4) empirically examine the factors of the newly developed behavioral model. Our case illustrates how the TPB is used to identify factors related to the specific target behavior of starting a conversation about palliative care with the physician in people with incurable cancer. This allowed us to identify the most important factors for impacting this specific patient behavior regarding palliative care.

One of the challenges we faced during the process was choosing a suitable behavioral theory as the starting point in step one. Literature revealed a wide range of different theories[40]. It was not clear which theories would be most relevant to better understand the factors of our specific target behavior. As environment-oriented theories seem to be rarely applied to palliative care behaviors[11], we opted for an individual behavioral theory[40] rather than a model taking into account environmental factors such as meta-models[40]. However, individual behavioral theories can also be used to better understand the behaviors of environmental agents who are responsible for environmental factors influencing people with serious illnesses (e.g. family carers, professional carers, etc.)[12]. There may be no literature available showing which theories could be relevant to better understanding the factors of a certain target behavior. If so, researchers could start atheoretically and perform inductive qualitative research to build a theory.

Steps one to four, combining qualitative and quantitative approaches, resulted in a behavioral model that explained 63.8% of the variance in starting a conversation about palliative care with the physician (or the intention to do so). The explained variance of most behavioral models ranges from 20 to 30%[40]. By carefully selecting, applying and adapting the theory, we seem to have included important and domain-specific[41] factors. This might have contributed to a higher predictive value of our model. However, researchers using behavioral theories should bear in mind that a behavioral model will only ever explain a proportion of variance in (the intention to perform) a behavior, as other unmeasured and unknown factors may also play a role[40]. To be able to develop highly effective behavioral interventions in palliative care, future research should focus more empirically on operationalization and evaluation of behavioral theories.

The entire process showed that it might be more complex to use behavioral theories to gain insight into critical factors related to palliative care behaviors than more conventional health behaviors such as physical activity or stopping smoking. There might be a difference in qualitatively and quantitatively testing the factors related to more complex and less familiar behaviors compared to those related to well-known health behaviors. People can easily imagine being physically active, smoking, eating fruit, etc. [5] but it is more difficult to imagine talking about palliative care. It is not easy to say if one would do so or not, or why. The participants might need cognitive skills to answer questions related to (future or past) palliative care behaviors. Therefore, it might be important to use face-to-face interviews and to provide clear interviewer instructions to enable interviewers to help the participants imagine themselves displaying the behavior. The current study made use of ‘if…then’ questions to stimulate this thinking process. For example, if the participant indicated that palliative care might be discussed after hearing that the cancer had metastasized, the interviewer asked “if you heard that the cancer had metastasized, would a benefit of starting a conversation about palliative care be that you received more information about palliative care?”

The challenges of using behavioral theories to gain better understanding of factors related to health-promoting behavior in seriously ill people do not outweigh the added value. The adequate use of behavioral theories will lead to more in-depth insight into factors influencing health behaviors. This information is crucial to be able to develop health promotion interventions in palliative care [12]. These theory-based behavioral interventions can help to empower people confronted with serious illness to take the initiative in communication about palliative care[12], for example, and to improve their health and quality of life[5].

5 Conclusion

This paper describes a method of using behavioral theories in detail applied to the specific target behavior of starting a conversation about palliative care with the physician. It provides guidance for researchers and practitioners interested in understanding and changing a target behavior and its behavioral factors in seriously ill people.

Declarations

Authorship

All authors substantially contributed to the outline of this methodological paper. A-LS and KB wrote the first draft of the manuscript and critically revised the manuscript after receiving comments from all authors. B.D., L.D, J.C & K.B. supervised the study. All authors approved the final manuscript to be published. All authors have participated sufficiently in the work to take public responsibility for appropriate portions of the content. A-LS was responsible for final submission and as guarantor of content.

Funding

This work was supported by the Research Foundation Flanders.

Conflicts of interest

The authors declare that there is no conflict of interest.

Ethics and consent

For the studies (step 2-4) that involved human subjects (i.e. people with incurable cancer), ethical approval was obtained from the Ethical Committee of Ghent university and AZ Sint-Lucas Ghent.

Data sharing

The data that support the findings of this study are available from the corresponding author, AS, upon reasonable request.

Acknowledgements

The authors wish to thank the expert group of both the health promotion and end-of-life care research groups for their contributions. The authors are very grateful to the physicians, nurses and patients for participating in the qualitative interviews, the cognitive testing of the survey and the quantitative interviews. We further thank Helen White for help with linguistic editing of the text.

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PART III

USING HEALTH BEHAVIOR THEORIES TO UNDERSTAND AND DECLARE THE BEHAVIOR OF STARTING A CONVERSATION ABOUT PALLIATIVE CARE IN PEOPLE WITH INCURABLE CANCER

CHAPTER 4

THE PERCEPTION OF PEOPLE WITH CANCER OF STARTING A CONVERSATION ABOUT PALLIATIVE CARE: A QUALITATIVE INTERVIEW STUDY

Scherrens A, Cohen J, Mahieu A, Deliens L, Deforche B* & K Beernaert*. The perception of people with cancer of starting a conversation about palliative care: a qualitative interview study. (2020). *European Journal of Cancer care;* 29(5):e13282.

[Published]

Abstract

Objective - Communication and patient-centred care are important determinants for timely initiation of palliative care. Therefore, we aimed to understand and explain the behavior 'starting a conversation about palliative care with a professional carer' from the perspective of people with incurable cancer.

Methods - A qualitative study using semi-structured face-to-face interviews with 25 people with incurable cancer: 13 not (yet) receiving palliative care and 12 receiving palliative care; 4 started the conversation themselves. Determinants related to the defined behavior were matched with concepts in existing behavioral theories.

Results - Both positive and negative stances towards starting a conversation about palliative care with a professional carer were found. Influencing behavioral factors were identified, such as knowledge (e.g. about palliative care), attitude (e.g. association of palliative care with quality of life) and social influence (e.g. relationship with the professional carer). We modelled the determinants into a behavioral model.

Conclusion - The behavioral model developed helps to explain why people with incurable cancer do or do not start a conversation about palliative care with their professional carer. By targeting the modifiable determinants of the model, promising interventions can be developed to help patients taken the initiative in communication about palliative care with a professional carer.

Key words

Qualitative research; palliative care; terminal care; neoplasms; health communication; health promotion; behavior; behavioral theory

4.1 Introduction

People with cancer may need palliative care early in the disease trajectory[1,2]. It can improve their quality of life[3,4], but it is often initiated late or not at all[3,5]. No palliative care or late initiation can lead to suboptimal care in the final months of life[6]. Studies focusing on palliative care initiation frequently do so from a health service or professional carer perspective. Late recognition of palliative care needs[7] or late referral[3] by the professional carer[4,8] are examples of factors hindering timely initiation of palliative care. These studies also showed that adequate and timely communication about palliative care is important for initiation[9], but there is room for improvement[10]. Initial palliative care discussions often seem to be postponed or avoided by the professional carer[2]. Physicians wait until the person with cancer brings palliative care up because they fear that doing so themselves would be intrusive or discomforting[2,11]. Inadequate communication about palliative care leads to unmet information needs in people with cancer[11], whose perspective seems to be entirely absent in the study approaches mentioned above.

Besides barriers among health services or professional carers, it is clear from previous literature that significant barriers, and hence opportunities for initiating palliative care, also exist among patients[11,12]. Patients' communicative behaviors greatly influence the quality of palliative care[2,6]. Qualitative research has indicated that patients often do not start a conversation about palliative care because they associate it with death and because they do not want to burden the professional carer with their psychosocial or existential needs but turn to them purely for physical and disease-related (as opposed to illness-related) problems[6]. Nevertheless, patients prefer an active role in decision-making at the end of life[13]. Many want to be informed about palliative care before the terminal phase of their illness[2,11] and attach value to their treating physician knowing their palliative care wishes [14].

Higher quality of palliative care can be achieved through greater patient-centred care and patient empowerment in communication[15] about palliative care[16]. Therefore, insight into the determinants of patients' communicative behaviors related to palliative care initiation is important. This study focuses on the behavior 'starting a conversation about palliative care with a professional carer', implying the patient starts a conversation by using the words palliative care himself. Using the term palliative care enabled to identify hindering factors (including misconceptions) as well as certain facilitating factors. Evidence from research domains other than palliative care research[17,18] shows that the identification of behavioral determinants can be best supported by the use of behavioral theories such as the Theory of Planned Behavior[19]. Using a behavioral theory helps to explain why people with cancer do or do not display certain communicative behaviors[20]. This knowledge is needed to develop promising theory-based interventions[21]. Achieving change in the behavior ‘starting a conversation about palliative care with a professional carer’ among people with cancer could improve communication with the professional carer and increase timely initiation of palliative care.

The aims are 1) to better understand the communicative behavior ‘starting a conversation about palliative care with a professional carer (e.g. (family) physician)’ from the perspective of people with incurable cancer by identifying related determinants with the help of behavioral theories (e.g. the Theory of Planned Behavior) and 2) to develop a theoretical behavioral model for the defined behavior.

4.2 Methods

4.2.1 Study design

We conducted a qualitative study, using semi-structured, face-to-face interviews with people with incurable cancer. This study design was deemed most suitable for this explorative study aimed at developing a palliative care behavioral model. In choosing this design, we also considered the vulnerability of these people and the sensitivity of the subject. We used the criteria for reporting qualitative research from the SRQR guidelines (see **Appendix 1**)[22].

4.2.2 Participants

We took the following inclusion criteria into account: 18 years or older; any type of incurable cancer; aware of the diagnosis; decision-making capacity; ability to participate in a Dutch interview; incurable cancer was diagnosed at least one month ago. We assumed that perceptions of starting a conversation about palliative care with a professional carer him or herself and related determinants might differ depending on whether or not people have had the experience of palliative care. We included people with incurable cancer who were receiving specialised palliative care and people who were not (yet). The physician or nurse, specialised in oncology or palliative nursing, was asked whether the participant already had contact with a specialized palliative care team member (palliative home care, support team or day care centre). We opted for specialised palliative care for pragmatic reasons. Generalist palliative care -at least in Belgium- is not always defined well and not easy to measure. Focusing on specialised palliative care made it possible to identify the people who have had experience with palliative care easily. We formulated the following exclusion criteria: cognitively incapable of participating in an interview or too tired to do so; estimated life expectancy of more than five years; in follow-up or remission.

4.2.3 Recruitment

Physicians or specialist nurses were the intermediaries for reaching people with incurable cancer. The intermediaries were selected by purposeful sampling through hospitals, a regional Palliative Care Network and the Flemish Palliative Day Care Centres. The physicians/nurses informed eligible people about the study and asked them to participate. If the person with cancer was willing, the physician/nurse gave the contact details of the participant to researcher AS. AS contacted the participant by phone and provided additional information about the study objectives, interview themes and some ethical considerations. Upon oral confirmation of participation, AS made an appointment for an interview.

4.2.4 Data collection

Two female researchers (AS, a nurse, and AM; both have an MSc in Health Education and Health Promotion) conducted individual interviews at the participants’ home, hospital unit or palliative day centre between February and June 2018. A topic guide (**Appendix 2**) was developed by a multi-disciplinary team including experienced researchers in the fields of end-of-life care and health promotion. We paid special attention to the structure of the topic guide to prevent palliative care from being perceived as threatening. Before the questions related to palliative care, we gave a definition of palliative care (see Table Appendix 2, based on the World Health Organization’s definition of palliative care[23]. Both the definition and the questions focused on communication about generalist and specialised palliative care. The questions covered three major themes: 1) perception of starting a conversation about palliative care with a professional carer, 2) facilitating factors and 3) hindering factors. For identifying behavioral factors, we based some prompts on determinants of the Theory of Planned Behavior (‘attitude’, ‘social norm and influence’ and ‘behavioral control’) with an opportunity to identify other determinants not included in this theory (multi-theory approach). The Theory of Planned Behavior includes the behavioral intention, which was relevant to the group who had not yet started a conversation about palliative care and had to answer hypothetical questions. We used ‘if…then’ questions to stimulate hypothetical thinking. For example: the participant indicated that palliative care might be discussed after hearing that the cancer had metastasised; the interviewer asked ‘if you heard that the cancer had metastasised, would you start a conversation about palliative care?’ All interviews were audio-recorded and lasted approximately one hour.

At the end of each interview, a brief questionnaire was administered to collect some socio-demographic data. We collected medical/clinical data (estimated life expectancy, specialized palliative care etc.) from the treating physician.

4.2.5 Data analysis

We transcribed the interview recordings verbatim, using Nvivo 11 for data structuring and thematic content analysis for data analysis[24]. AS and AM independently and openly coded the transcripts. The data analysis was both inductive and deductive. Firstly, we searched for influencing factors in the answers to the questions 'what helped or would help you/what made or would make it difficult for you to start a conversation about palliative care?'. Secondly, these factors were deductively matched with concepts in behavioral theories (e.g. 'attitude' defined by the Theory of Planned Behavior; 'perceived health threat' defined by the Health Belief Model). The coders compared and debated their code nodes and trees. Where coding discrepancies occurred, consensus was sought. During data collection we filled in a preliminary model for the identified factors related to the defined behavior. We collected data until no new factors emerged from the interviews and data saturation was achieved. This resulted in a final behavioral model, which all authors agreed upon.

4.3 Results

Twenty-five interviews with people with 11 different types of cancer were conducted. Thirteen participants were not yet receiving specialised palliative care; twelve were. Their ages ranged from 39 to 77 years (see **Table 1)**.

Table 1. Characteristics of the participants

Characteristics of participants with incurable cancer	Total (N =)
Number of people with incurable cancer interviewed	25
Sex	
Male	11
Female	14
Age	
<30	0
30-39	1
40-49	1
50-59	6
60-69	11
70-79	6
>= 80	0

Characteristics of participants with incurable cancer	Total (N =)
Mean age (SD)	63 (9)
Date of cancer diagnosis	
≤1 year ago	11
>1 year - ≤5 years ago	11
>5 years ago - <10 years ago	2
≥10 years ago	1
Cancer type	
Respiratory	7
Gastrointestinal	4
Soft tissue sarcoma	3
Breast	2
Urological	2
Gynaecological	1
Bone	1
Head and neck	1
Other[a]	4
Estimated life expectancy	
Few weeks	2
<6 months	2
<1y.	4
<2y.	5
<3y.	3
<4y.	0
<5y.	2
Unknown	3
Contact with specialized palliative care member (yes or no)	
Yes	12
No	13

[a] Other: this group contains all other cancer types that were identified as adenocarcinoma (n=2), non-Hodgkin's lymphoma (n=1) and malignant peripheral nerve sheath tumour (n=1)

4.3.1 Perception of the defined behavior

Both positive and negative stances towards 'starting a conversation about palliative care with a professional carer' were found. Nine of the twelve participants who were receiving specialised palliative care had a positive stance towards the defined behavior, as did eleven of the thirteen participants who were not. These twenty participants had already started a conversation about palliative care (N=4; three receiving specialised palliative care and one not) or could imagine doing so (N=16). The four participants who started a conversation did so with a family physician, oncologist, another specialist and an acquaintance specialized in palliative care. The others would choose to start a conversation with a family physician, oncologist, nurse or psychologist. Half the respondents were initially negative towards the defined behavior, but the majority reported that their perception might change with time and depending on their health. For example, they would not start the conversation when feeling good, but they would if they felt worse.

> I do not know how I am going to react (...). When you approach death, you see life differently.
> (Woman, 65 y., not yet receiving specialised palliative care)

Five participants (three receiving specialised palliative care and two not) held an absolutely negative stance towards the defined behavior.

4.3.2 Determinants related to the defined behavior

The interviews revealed various factors both facilitating and hindering the behavior. The following individual and perceived environmental determinants can be related to the behavior: awareness (and perceived health threat); knowledge (and past experience); attitude; perceived behavioral control; character traits; social norm and social influence; physical environment. These determinants interact with each other and most are easy to change in behavioral interventions. **Table 2** shows all identified determinants.

Awareness (individual level)

The participants mentioned *awareness* of palliative care needs and *perceived health threat* as a facilitating factor. The participants mentioned that if they became aware of the incurability of their cancer (e.g. if the tumour marker rose spectacularly or if metastases occurred), if they felt physically unwell, felt that life was no longer worth living or that the end was near, they might start a conversation about palliative care.

> I think if I felt really physically bad, then +++ the threshold would be overcome to start talking about it [refers to palliative care]
> (Woman, 39 y., already receiving specialised palliative care)

Lack of awareness and perceived health threat were identified as hindering factors. The respondents indicated it was too early to start palliative care conversations and they were not necessary yet (e.g. treatment options left, convinced that they would 'beat' the cancer); they felt too good and believed the end was not near.

> For the moment I do not feel ready at all to start a conversation about palliative care with anyone. Because I do not feel threatened by death at all. Maybe it is near, but I do not feel it. I do not know. I am more concerned with life than with death.
> (Woman, 65 y., not yet receiving specialised palliative care)

Knowledge (individual level)

Participants mentioned that knowledge of palliative care and its possibilities was a facilitating factor. *Past experiences* such as experience with family/friends who received palliative care led to increased knowledge of palliative care.

> I think that having a little bit more information about palliative care would be facilitating for starting a conversation about palliative care, because you know what you are talking about.
> (Man, 66 y., not yet receiving specialised palliative care)

Participants identified lack of knowledge about palliative care timing, providers and possibilities as hindering factors. Few participants indicated that the high costs of palliative care were hindering. Some respondents indicated that they did not want to ask about palliative care, because if they did not know more about it they could stay in the dark. They also reported a lack of knowledge of their own health condition, care needs and treatment as hindering, which may be related to the aforementioned *limited perceived health threat*.

> I would not have started a conversation myself because I did not know anything about palliative care. I could hardly pronounce 'palliative’. I had not heard that word before.
> (Woman, 72y., already receiving specialised palliative care)

> Palliative care costs a lot of money. I would not like to lie somewhere and pay a lot of money to the government.
> (Woman, 51 y., not yet receiving specialised palliative care)

Attitude (individual level)

Participants reported that they were generally not afraid of starting a conversation about palliative care with a professional carer. They indicated *positive outcome expectations* (advantages) as facilitating. The following outcome expectations of starting a conversation about palliative care were cited: a comfortable end of life; emotional support; information about their health condition, their care and palliative care (possibilities); and preventing the care burden on family carers from becoming too high.

> I have asked the physicians about palliative care, because I do not want to waste away.
> (Woman, 65 y., not yet receiving specialised palliative care)

> I want to start a conversation about palliative care as soon as possible. I think it is important to know what my health condition is so I can make decisions.
> (Man, 65 y., not yet receiving specialised palliative care)

The respondents, especially the group who were not receiving specialised palliative care yet, identified a negative attitude towards palliative care and the defined behavior as hindering factors. These participants had not yet accepted the diagnosis and were not yet interested in palliative care. They associated palliative care with terminal care and death. They were afraid of the words ‘palliative care’ and avoided them during the interview by using reference words such as ‘that’ and ‘there’. The participants also indicated some *negative outcome expectations*. They did not know what to expect from such a conversation. They wondered why they would start a discussion about palliative care now, why anticipate. They were afraid of being confronted with information they would rather not know. They expected to experience the feeling of giving up afterwards.

> Palliative care is something I do not think about or think about as little as possible. It makes me feel depressed.
> (Man, 77 y., not yet receiving specialised palliative care)

> Palliative care means the end for me.
> (Woman, 66 y., not yet receiving specialised palliative care)

Some expected professional carers to take initiative in starting a conversation about palliative care.

> I think that the physician plays the most important role in discussions about palliative care. I can say that I have a lot of pain, but it is the physician’s job to start the conversation and ask if it is time to consider palliative care. It is difficult for me to determine whether discussions about palliative care are necessary.
> (Woman, 39 y., already receiving specialised palliative care)

Perceived behavioral control (individual level)

The participants who were positive towards the defined behavior mentioned that they would feel confident about starting the conversation. They reported their confidence would increase in specific situations. For example, if they felt their health was threatened or if their professional carers already used the term ‘palliative care’.

> If I no longer feel good I might be ready to ask if it would be better to start palliative care. Unless my children were faster, because they have been thinking about palliative care for a long time.
> (Woman, 71 y., not yet receiving specialised palliative care)

Some respondents reported that starting a conversation about palliative care was difficult and emotional. They found it difficult to assess their perceived threat and to determine whether palliative care was needed. They felt that physicians knew better what was medically feasible.

> Even though I would consider it, I would never dare to start the conversation myself. I would try to postpone it.
> (Woman, 46 y., not yet receiving specialised palliative care)

Character traits (individual level)

The participants reported character traits both facilitating and hindering. Participants reported the following traits as facilitating: extroversion; arranging everything in advance; quickly trusting someone; and knowing themselves best. They often repeated that it was their choice ('my life, my choice').

> I know myself better than the physician knows me. I know better how I feel.
> (Man, 58y., not yet receiving specialised palliative care)

Others were reluctant to start a conversation about palliative care due to optimism or wanting to retain their independence.

> I am a very independent person. I will try to do everything myself.
> (Woman, 62y., not yet receiving specialised palliative care)

Social norm and influence (perceived environmental level)

Participants reported that their family and professional carers' opinions about palliative care and the defined behavior were influencing factors. Family wishes in favour of the defined behavior (e.g. the family really wants the conversation to happen) and positive social support (e.g. the family has a positive attitude towards palliative care, the family attends the conversation) were considered as facilitating. The participants stated that suddenly being alone and losing family care was facilitating (e.g. death of their partner). Social capital (e.g. knowing a palliative nurse) was also considered a facilitator. Moreover, the participants reported professional carers' characteristics (e.g. reliability, openness to communication about palliative) and the relationship with the professional carer (e.g. strong and trustful) as facilitating factors.

> I think I would start a conversation with a physician first. My physician is my confidant.
> (Woman, 66 y., not yet receiving specialised palliative care)

The respondents also considered social influence as a hindering factor. Family reluctance to consider palliative care or participants experiencing sufficient family care were hindering factors. The respondents indicated that negative characteristics of professional carers (e.g. perceived time constraints, limited knowledge about palliative care, negative attitude towards palliative care etc.) and a weak connection with the professional carers (e.g. limited contact) were hindering.

> I can do everything. I know I have a very aggressive and difficult cancer to treat. The only thing they [professional carers] can do is to control the cancer. (…) I can take care of myself with the support of my family and friends. I have enough with that support for the time being.
> (Man, 54 y., not yet receiving specialised palliative care)

Physical environment (perceived environmental level)

A physical environment that easily enables the participant to make an appointment (e.g. available contact information or regular consultation during a long-term hospital stay) was reported as facilitating. A lack of privacy (e.g. shared hospital room) was perceived as hindering.

Table 2. Overview of the determinants related to 'starting a conversation about palliative care with a professional carer' by people with incurable cancer

DETERMINANT	Facilitating factors	Hindering factors
INDIVIDUAL level		
Awareness Perceived health threat	Awareness of the poor health condition (e.g. sudden paralysis, incurable cancer, spectacular rise in tumour marker; feeling physically unwell, believing the end is near) Awareness that that curative treatments no longer make sense or/and that additional care support (e.g. pain relief, palliative care) is needed	Feeling too good - To feel too good (e.g. to think about palliative care yet, to be eligible for palliative care) - To feel the end is not near (e.g. to be convinced one will live 10 more years, to feel no death threat yet) Palliative care is too early and is not necessary yet - There are still treatment options, the treatment is still effective - To be convinced one will beat the cancer - To not need palliative care yet; to not need physical or psychological help
Past experience with palliative care	Having experience with palliative care among family, friends, acquaintances etc. Having experience with palliative care through work activities (e.g. voluntary work in a nursing home)	Having no experience with palliative care among family, friends, acquaintances etc.
Knowledge	Knowledge about palliative care (possibilities) Knowledge about the option of talking or starting a conversation about palliative care Knowledge about one's own health condition (e.g. a known prognosis of maximum 1 year) Basic medical knowledge	Enough knowledge about palliative care (possibilities) - To know enough about palliative care to make a conversation no longer relevant Lack of knowledge about palliative care (possibilities) - Palliative care and palliative care services are something unknown - Not knowing when one can receive palliative care - Not knowing who is qualified to have a conversation about palliative care Inaccurate knowledge about palliative care (possibilities) - To believe that palliative care is only for bedridden patients - Associating palliative care with financial costs

DETERMINANT	Facilitating factors	Hindering factors
INDIVIDUAL level		
		Limited knowledge about one's own health condition (e.g. disease, prognosis) and care situation (e.g. the need of palliative care, the possible treatment options)
Attitude	Attitude towards palliative care - Being convinced palliative care is important (e.g. for a comfortable life, to improve the quality of life, to prevent deterioration or asphyxiation) Attitude towards starting a conversation about palliative care with a professional carer (e.g. not being afraid) Other facilitators (e.g. fearing physical complaints may cause shame to the patient's family, if it all gets too much, if the words 'palliative care' have already been used by another professional carer)	Attitude towards palliative care - Connotation of palliative care: association of palliative care with terminal care, with the last step, with death; with deterioration - To prefer other options than palliative care (e.g. euthanasia) - To be afraid (e.g. of the words 'palliative care', of the palliative care phase) - To not want to think about palliative care yet (too early, too soon after diagnosis), not to be interested in palliative care yet - To be convinced that palliative care is not relevant at the moment - To be convinced that palliative care takes away all hope of getting better Attitude towards starting a conversation about palliative care with a professional carer (negative attitude) - To be convinced that palliative care conversations are not necessary or relevant yet - To expect the professional carer to take the initiative in starting a conversation about palliative care o To accept that the professional carer starts a conversation about palliative care o To be convinced the professional carers know better what is medically feasible o To be convinced that the professional carer will start a conversation about palliative care sooner o To be convinced that starting a conversation about palliative care is part of the job of professional carers, that they will help if necessary Other barriers (e.g. cannot yet accept the disease/diagnosis)

DETERMINANT	Facilitating factors	Hindering factors
INDIVIDUAL level		
Outcome expectations	Advantages related to the defined behavior - Getting information e.g. about diagnosis, palliative care possibilities… - Getting the chance to arrange things (e.g. activities that one would like to do while one’s health permits) and to make decisions - Experiencing reassurance and/or relief - Relieving family carers from burden becoming too great - Informing the professional carer about how one feels and about one’s wishes - Expecting the professional carer to take over the conversation, to elaborate on palliative care - The professional carer immediately follows up the conversation (e.g. by referring to palliative care services) - The professional carer cannot start the conversation about palliative care unexpectedly (e.g. if palliative care is not perceived as relevant yet)	Disadvantages related to the defined behavior - Not knowing what to expect of such conversation - Being convinced that such conversations are difficult and emotionally charged - Getting depressed when thinking about palliative care
Perceived behavioral control	To feel able/to be confident about a conversation about palliative care (e.g. tomorrow, if one perceives health threat, if the words ‘palliative care’ have already been used by another professional carer etc.)	Not being able to start a conversation about palliative care (difficult and emotionally charged, lacking the courage) Not being able to assess the perceived threat Not being able to determine whether palliative care is needed
Character traits	Conviction that they know themselves best - E.g. nobody knows me better than I do, I know myself better than my professional carers do, I know better how I feel than my professional carers do Conviction that they have to make their own choices in life - E.g. I have to choose to talk about palliative care, because it is my life; I have to be able to decide for myself what I want and do not want	Character traits - E.g. someone who manages on their own, optimistic, hopeful etc.

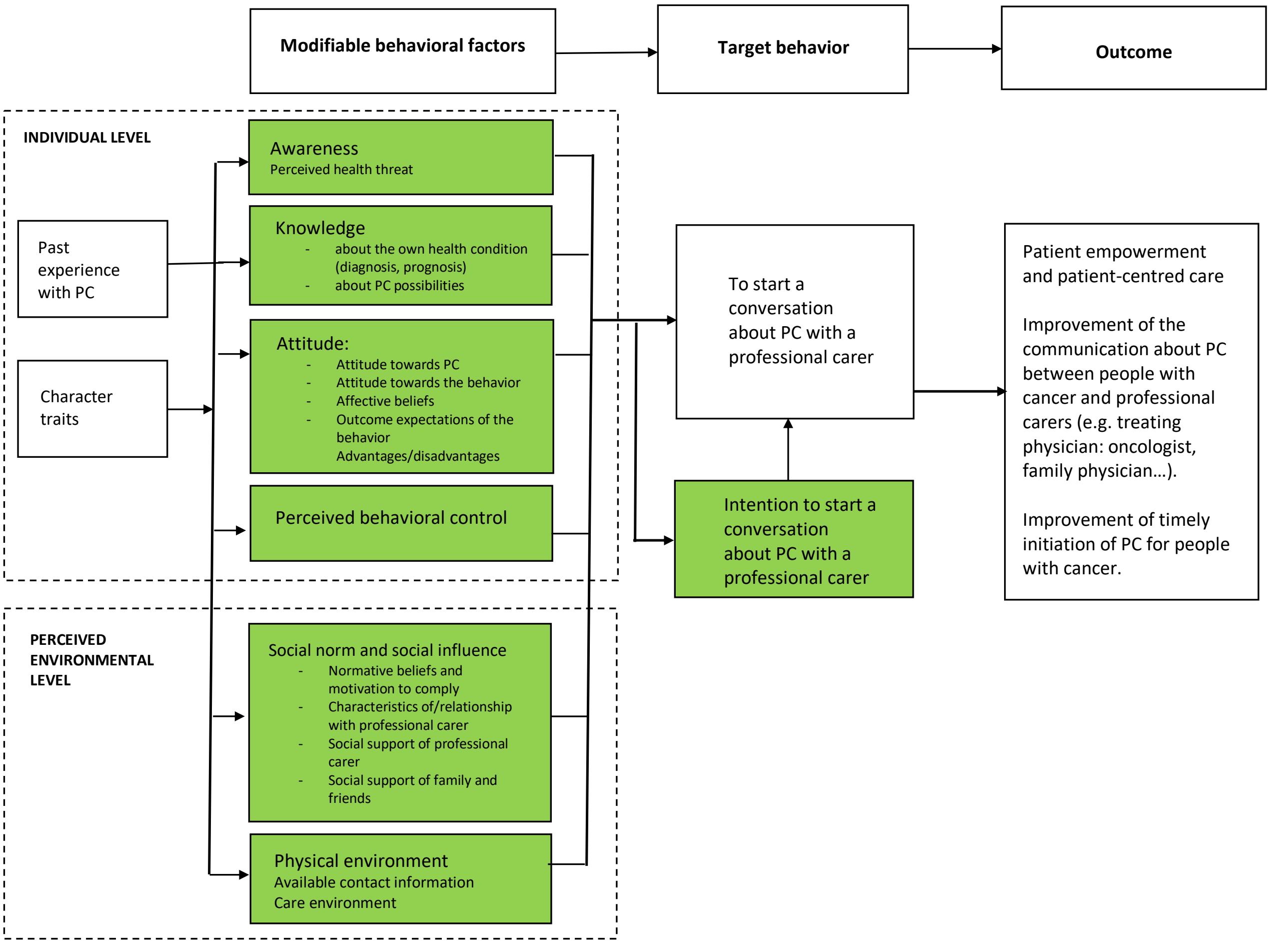
DETERMINANT	Facilitating factors	Hindering factors
INDIVIDUAL level		
	Other character traits - E.g. being a down-to-earth person, someone who arranges everything in advance, someone who is quick to turn to someone else, an extravert (who finds it easy to talk)	
PERCEIVED ENVIRONMENTAL level		
Social norm and social influence		
Related to professional carers (E.g. oncologist, family physician, nurse etc.)	Perceived professional carers' positive attitude towards palliative care (conversations) (<social norm) Wanting to know the professional carers' opinion (< social norm) Perceived professional carers' characteristics - Someone who is reliable, empathetic, straightforward, neutral (e.g. less emotionally involved), correct, fantastic, honest, competent, does not place themself above the patient (e.g. no macho behavior) - Someone who makes time, who will clearly explain - Someone who knows about one's background, about one's health condition and treatment, about one's attitude and how one deals with health problems - Someone who works in the medical sector - Someone who has experience with palliative care Connection with professional carers - Good, strong, trustful, long-term connection	Perceived professional carers' negative attitude towards palliative care (conversations) (<social norm) Perceived professional carers' factors - Limited competence (e.g. the perception that family physicians only prescribe drugs addressing acute needs, do not offer added value to the care, always have to check with another physician etc.) - Limited time (e.g. the perception that professional carers have a lot of work to do and have limited time, which one does not want to waste) - Someone in whom one has no trust No connection with professional carers - The professional carer is a stranger, not knowing the professional carer well enough (e.g. because they have not been acquainted for long) - Limited contact with the professional carer (e.g. limited contact with the family physician due to a long hospital stay)

DETERMINANT	Facilitating factors	Hindering factors
PERCEIVED ENVIRONMENTAL level		
	Social support from the professional carers - If professional carers take initiative to come by (e.g. shortly after diagnosis) If professional carers offer sufficient guidance	
Related to family and friends	Perceived attitude of family and friends towards palliative care (conversations) (<social norm) - E.g. holding a positive attitude towards palliative care, believing it is important to start the conversation about palliative care with a professional carer	Perceived attitude of family and friends towards palliative care (conversations) (<social norm) - E.g. holding a negative attitude towards palliative care, not knowing how to react to the words ‘palliative’ and ‘incurable’, avoiding such conversations
	Social support from family and friends - E.g. they easily accept the disease and the treatment options, having had a conversation about palliative care with family and friends first, they accompany the patient to the conversation, they understand that the patient wants to start a conversation about palliative care, they stimulate the patient to start the conversation about palliative care	No social support from family and friends - Family is no support because they are upset - To have enough care support from family or friends
	Suddenly being alone and losing family care (e.g. death of the partner)	
Physical environment	Availability of contact details to know who one can contact	No private room (e.g. a shared hospital room)
	Long-term hospital stay	

4.3.3 Determinants reported by specific groups of participants

Whether particular determinants were reported depended on (intentional) behavior performance and whether or not palliative care was received. Respondents who had started conversations about palliative care in the past (N=4) had experience with palliative care in their social network and claimed this was facilitating (*past experience*). They also said they were afraid of the term palliative care and associated it with death (*attitude*) prior to the conversation, but did not experience these factors as hindering. They did not identify any *awareness* and *perceived behavioral control* factors as hindering either. The group who had a convincingly negative stance towards the behavior (in any health situation and with any professional carer) and who were receiving specialised palliative care (N=3) reported that they expected professional carers to take the initiative for palliative care conversations (*attitude*). They also reported experiencing a *lack of knowledge* about palliative care. The group with a convincingly negative stance towards the behavior who were not receiving specialised palliative care yet (N=2) mentioned the determinants *lack of knowledge* about diagnosis and palliative care possibilities, *negative attitude* towards palliative care, *limited perceived health threat* and *lack of social support* as hindering. They were not interested in palliative care and did not want to communicate about it at all. These last two groups did not identify any facilitating factor. Factors within *perceived health threat* mainly came up in the group who were not yet receiving specialised palliative care.

The identified determinants were combined in one behavioral model (see **Figure 1**).



PC=Palliative Care
Green boxes = modifiable determinants

Figure 1. Illustration of the identified determinants related to the defined behavior.

4.5 Discussion

4.5.1 Summary of main results

This qualitative study contributed to understanding and explaining why people with incurable cancer do or do not start a conversation about palliative care with a professional carer. A behavioral model was developed consisting of individual (*awareness, knowledge, attitude, perceived behavioral control*) and environmental determinants (*social norm and social influence, physical environment*).

4.5.2 Discussion of main findings

Despite palliative care conversations with regular professional carers being difficult and emotional, the stance towards them was predominantly positive, irrespective of whether study participants already received palliative care. Many participants indicated that they could imagine starting a conversation about palliative care with a professional carer. This finding somewhat contradicts a systematic review of patient-physician discussions in palliative care suggesting that professional carers usually guide such conversations[25]. During our interviews, participants were challenged to think about starting such conversations themselves, whereas participants in other interview studies might not consider it an option. However, we have to take the possible gap between imagined and effective behavior into account[21].

Factors positively and negatively determining the behavior 'starting a conversation about palliative care with a professional carer' were identified, resulting in a theoretical behavioral model that may help to improve communication about palliative care between people with cancer and professional carers.

Awareness of the need for palliative care and poor health are important determinants for initiating these conversations. As was found in a review study[26] and clinical trial[27] in cancer research, most participants overestimated their prognosis or minimized their disease. Participants stated that a perceived change in disease status (e.g. cancer metastases) would be facilitating. Literature from both the perspective of people with cancer and professional carers shows that understanding the poor prognosis is an important factor influencing initiation of palliative care conversations[28,29]. Low prognostic awareness might be related to participants' lack of knowledge about their disease and prognosis. However, it is better to initiate palliative care conversations early in the disease trajectory[9], independent of the prognosis, to prevent people with cancer from being unable to make care decisions due to cognitive delay or too severe weakness[30].

Participants' knowledge of palliative care possibilities is another important determinant. A previous review study on unmet supportive care needs showed that 39% of the people with advanced cancer lacked information about treatment etc.[31]. Another study showed that only 7% of people with cancer with a life expectancy of >1y and 33% with a life expectancy of <6m received palliative care information. Up to 27% of these people wanted more information[11]. The participants with a convincingly negative attitude towards starting a conversation about palliative care found it difficult to imagine themselves doing so. Possibly they first need to know more about their health situation, what palliative care is and how it can be relevant to their situation[32]. It remains a challenge for the health care system and for professional carers to provide timely palliative care information.

Participants' attitude towards palliative care (conversations) is an important determinant too. Some participants associated palliative care with terminal care and/or death and believed that starting a conversation about palliative was not necessary yet, even though research shows the benefits of timely palliative care conversations[3,4]. This belief that palliative care is only for people dying within a few days or weeks corresponds to the attitude towards palliative care among the general public[3,6,27]. These restricted connotations may be explained by the current practice of late initiation of palliative care[3,5]. In the present study, some participants were afraid to use the term palliative care and avoided it during the interview. This demonstrates that a strong stigma is still attached to the term, which confirms previous findings[33]. Behavioral interventions that inform and educate people about palliative care -including patient-centred care and a planned approach- might change preconceptions and might result in destigmatization of the term palliative care in both patients and professional carers. However, it is an ongoing discussion whether to use the term palliative care or to use other terms such as supportive and anticipatory care to avoid the stigma attached to palliative care and to refer to total care with attention to physical, psychological and social care needs[34–37]. Future research should examine to what extent patients receive the care they need and wished for when using the term palliative care compared to an alternative term. Furthermore, advance care planning (i.e. reflecting on goals and preferences for future medical treatment and care) may enable patients to start a conversation about palliative care with the physician[38]. A small group was convinced that the physician would initiate the conversation, which was also found in people with advanced cancer participating in another qualitative study about advance care planning discussions[39]. These participants believed that physicians usually know better what is medically feasible and what care is needed (perceived behavioral control). These results illustrate that patient empowerment is not yet established and that the currently existing culture of physicians having higher medical authority in clinical decision-making needs to be changed[40]. Previous research showed that professional carers wait until the patient brings palliative care up, because they fear that bringing it up themselves would be discomforting[2,11]. The combination of patients waiting for physicians and physicians for patients might result in patients not receiving timely palliative care. These findings emphasize the importance of stimulating people with cancer to start a conversation about palliative care with a professional carer[2].

We also found that social influence (e.g. professional carers' factors) was an important environmental determinant. The participants frequently emphasized the importance of the relationship with the professional carer and professional carers' characteristics such as reliability and empathy. This contrasts with findings from a recent study where professional carers perceived their own characteristics as less important in care discussions than patients' and family members' factors[41]. It seems that a combination of professional carers', family carers' and patients' factors and the relationships are important for people with cancer to start a conversation about palliative care.

The physical environment was mentioned as an influencing determinant as well. A shared hospital room was perceived as hindering; it was in a previous qualitative study also identified by professional carers as a barrier to end-of-life care conversations [42]. Professional carers should always be aware of privacy and creating a patient-friendly environment to stimulate patients to start such conversations.

The intention to start a conversation about palliative care with a professional carer and the other determinants identified are not stable over time. The perception of the participants of the behavior was partly determined by feelings and thoughts at the time of the interview and differed depending on their health status. However, we were able to cover all the influencing factors by interviewing a wide variety of patients with different characteristics and health conditions as well as posing hypothetical questions and asking participants to think about 'what-if' situations. The modifiability of these factors shows that it is easy to change them with the help of an intervention.

4.5.3 Strengths and weaknesses

This study is innovative because it uses behavioral theories to identify and model determinants related to the behavior 'starting a conversation about palliative care with a professional carer'. The model developed can serve as basis for developing effective and successful interventions[43]. Another strength compared to previous studies is the focus on patients' perspectives rather than only those of professional carers. A detailed exploration of how people with cancer perceive starting a conversation about palliative care themselves does not exist so far. Certain limitations need to be acknowledged. Selection bias may result from the deliberate selection of people with cancer by the professional carers[44]. We asked the professional carers to select both participants interested and not interested in palliative care and to inform the participants that the study is about communication in care. We deliberately only started talking about palliative care in the interviews. Some professional carers may have presented the study to their own selection of patients (e.g. articulate patients) and informed them that the study was about palliative care. Few people dropped out when they heard it was about palliative care. The participants interviewed were possibly more willing to consider the subject. People with cancer without any interest in participating in palliative care studies could possibly have identified other determinants. However, the interviewed group was sufficiently varied and included five people who had a convincingly negative stance towards the behavior. We found comparable determinants in different types of participants.

4.6 Conclusion & practical implications

This study identified determinants related to the behavior ‘starting a conversation about palliative care with a professional carer’ from patients’ perspective through behavioral theories. The developed model contributes to understanding why people with cancer would or would not start such conversations. Based on our findings, we argue that interventions should focus on providing positive and correct information about palliative care to close the awareness and knowledge gap (*awareness, knowledge)* and on educating people with cancer about the relevance and benefits of palliative care conversations early in the disease trajectory (*attitude*). It helps them to be prepared. The findings suggest involving family members and professional carers. For example, professional carers should know how to communicate early in the disease trajectory that they are open to palliative care discussions. The model needs confirmation in a quantitative study evaluating which determinants are strongly, moderately or weakly related to the behavior. The importance of the different determinants might inform behavioral interventions, suggesting the most important factors to focus on to stimulate people with cancer to start a conversation about palliative care. The more related factors are considered, the greater the chance of behavioral change. These interventions can improve patient empowerment in communication about palliative care and the communication between patients and professional carers. This may lead to more patient-centred care, more timely initiation of palliative care and improvement of quality of life in people with cancer.

Ethics

The study was approved by the ethics committee of Ghent University Hospital (registration number B670201734263) and AZ Sint-Lucas Ghent (2017/1465). Participants gave signed informed consent.

Acknowledgments

The authors wish to thank all the physicians and palliative care nurses for their contributions in recruiting patients. We are very grateful to the patients who participated in an interview. We further thank Helen White for help with linguistic editing of the text.

Conflicts of Interest Statement

The authors have no conflict of interest in the authoring of this manuscript.

Funding

The analyses and preparation of the manuscript were supported by grants from the Research Foundation Flanders (FWO) and Special Research Fund Ghent University (BOF). AS is a Predoctoral Fellow at the Research Foundation Flanders. None of these funders played any role in the study design, collection, analysis or interpretation of data, or in the drafting of this paper.

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CHAPTER 5

THE INITIATION BY PEOPLE WITH CANCER OF A CONVERSATION ABOUT PALLIATIVE CARE WITH THE PHYSICIAN: A SURVEY STUDY IDENTIFYING THE MOST IMPORTANT FACTORS RELATED TO STARTING THIS CONVERSATION

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[Submitted]

Abstract

Objective - A late conversation about palliative care needs can lead to suboptimal care in the final months/weeks of life. Insight into factors related to patients' communication about palliative care is needed. This paper aims to identify the factors associated with starting or intending to start a conversation about palliative care with the physician.

Methods - We performed a cross-sectional survey by personally interviewing 80 people with incurable cancer. Purposive sampling was used, taking into account theoretically relevant heterogeneity. The questionnaire was developed based on the theory of planned behavior. Uni- and multivariable logistic regression analyses were performed.

Results - Ten participants (13%) started the palliative care conversation and 18 (23%) intended to do so. People holding a positive attitude towards this behavior (OR 4.74; 95%CI 2.35-9.54), perceiving more benefits of it (OR 2.60; 95%CI 1.37-4.96) and perceiving a positive attitude towards the behavior in family/friends (OR 2.07; 95%CI 1.26-3.41) and the physician (OR 2.19; 95%CI 1.39-3.45) were more likely to start/intend to start a palliative care conversation; people perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI 0.15-0.63) were less likely to do so. These factors explained 64% of the variance.

Conclusions - Our findings show that several psychological and perceived socio-environmental factors, particularly patients' attitudes, are associated with starting a conversation about palliative care with their physician. Interventions targeting these strong associations can empower people with cancer to take the initiative in communication about palliative care and might improve timely initiation of palliative care.

Keywords

Behavior; behavioral theory; health communication; health promotion; neoplasms; palliative care; quantitative research.

5.1 Background

Although people with cancer experience palliative care needs before the terminal phase of the disease[1], palliative care is often initiated too late or not at all[2–4]. As a result, care for people with cancer is often suboptimal in the final months or weeks of life[5]. A variety of behaviors can play a role in timely initiation of palliative care. One of these is communication about palliative care[6], which seems to be frequently avoided or postponed[7,8]. However, when asked about preferences and information needs, a majority wants to be informed about palliative care earlier, wants their physician to know their palliative care wishes[7,9] and prefers an active role in decision-making at the end of life[10].

Surprisingly, most studies of communication about palliative needs focus on the role of professional carers in starting it[11–13]. Despite opportunities[10,14], few studies focus on the role and perspective of people with cancer themselves[7,10,15]. In a previous interview study in people with incurable cancer we aimed to understand better how palliative care conversations with the physician started (target behavior) by identifying the reasons why some people do and others do not[16]. This study suggested a palliative care behavioral model inspired by the Theory of Planned Behavior (TPB) in which starting such conversation is influenced by psychological and perceived socio-environmental factors (**Figure 1**). There is no evidence so far about the relative importance of the different factors in this palliative care behavioral model in determining the target behavior. This model needs to be quantitatively tested by studying the strength of the associations between the factors and the target behavior among a larger sample of people with cancer[17]. Such quantitative information is essential if we want to use this model as a theoretical framework to develop an effective intervention to help people with cancer start conversations about palliative care with their physician themselves[17–20]. Interventions targeting the most important behavioral factors could improve patient empowerment in communication about palliative care[17,21,22], the timely initiation of palliative care (according to patients' needs and wishes) and quality of life[2,23].

The aim of this study is to assess factors that are associated with having started a conversation about palliative care with the physician or intending to do so in people with incurable cancer. The study focused on modifiable factors determined in our behavioral model[16]:

- psychological factors (e.g. illness perception, knowledge of palliative care, awareness, attitude towards palliative care and the target behavior)
- perceived socio-environmental factors (e.g. subjective norm regarding palliative care and the target behavior, social influence).

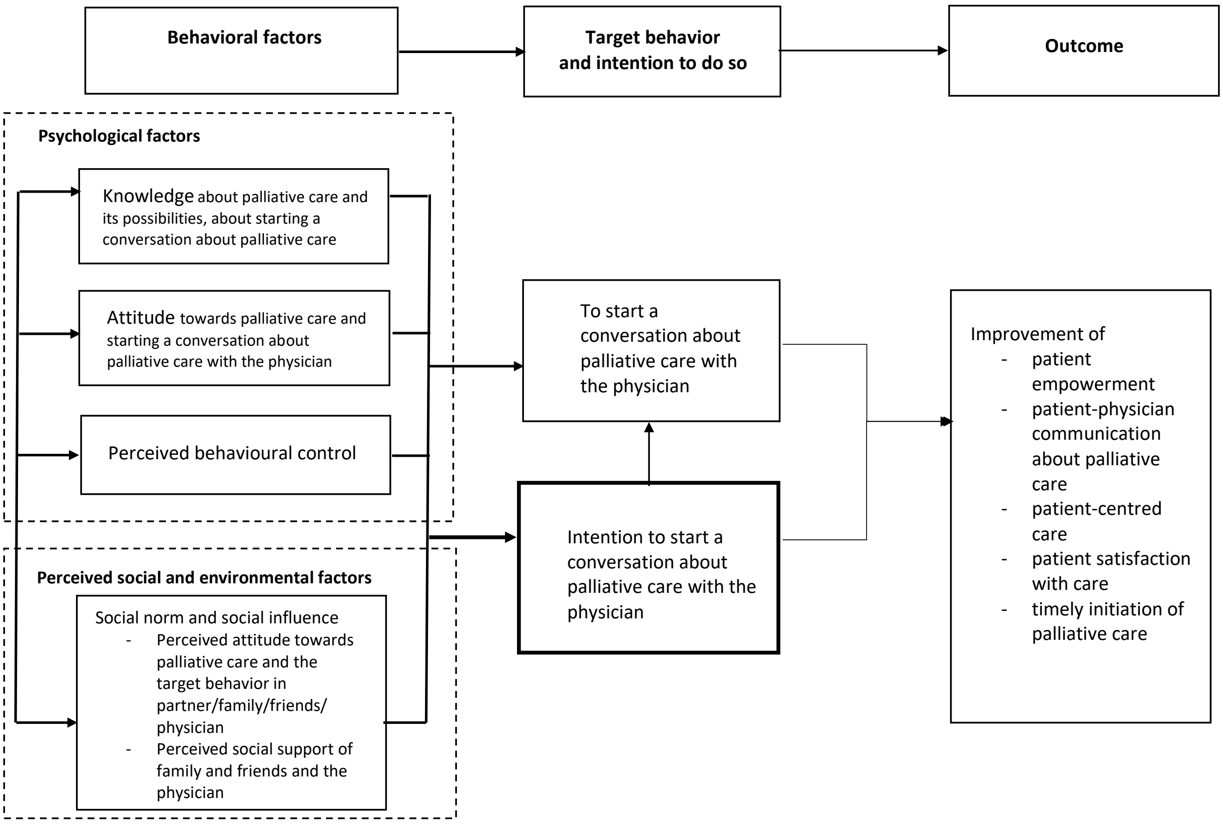

Figure 1. Palliative care behavioral model by Scherrens et al.[16]

5.2 Methods

This study is reported in line with the STROBE statement[24].

5.2.1 Study design and setting

We performed a quantitative cross-sectional survey with computer-assisted personal interviews (CAPI). Face-to-face structured interviews were held with people with incurable cancer about starting a conversation about palliative care with their physician. The choice of face-to-face interviews was due to better control of the correct interpretation of the rather complex and abstract questions and the answers than in self-administered questionnaires. The specific target behavior implies that people with cancer start to use the words palliative care (either verbally or by showing palliative care documentation) or alternative words that cannot be interpreted very differently (e.g. comfort care) in a conversation with the treating physician. Palliative care refers to both generalist and specialist palliative care. The study was conducted in Flanders (Belgium). All data were collected at the hospital or the participants' home, between August 2019 and March 2020.

5.2.2 Participants

We took the following inclusion criteria into account: adults with any type of incurable, awareness of the diagnosis, decision-making capacity, and ability to participate in a Dutch interview. We excluded people with incurable cancer if they were cognitively incapable of participating in an interview or too tired to do so, had an estimated life expectancy of more than five years, or were in follow-up or remission.

Sources and methods of selection of participants

We used purposeful sampling to select oncologists and oncology nurses from Ghent University Hospital. They identified potential participants and helped us as researchers to contact them. We needed a sufficient number of people who already started the conversation about palliative care with their physician or intended to do so. As the chance of recruiting people who had started the conversation previously was higher among people already receiving palliative care, we also involved the Palliative Care Network and the hospital palliative care unit. Purposive sampling of the target population, taking into account the theoretically important heterogeneity, was used with the aim of theoretical generalization about associated factors rather than statistical generalization towards populations. An overview of the recruitment process is demonstrated in a flow chart (**Figure 2**).

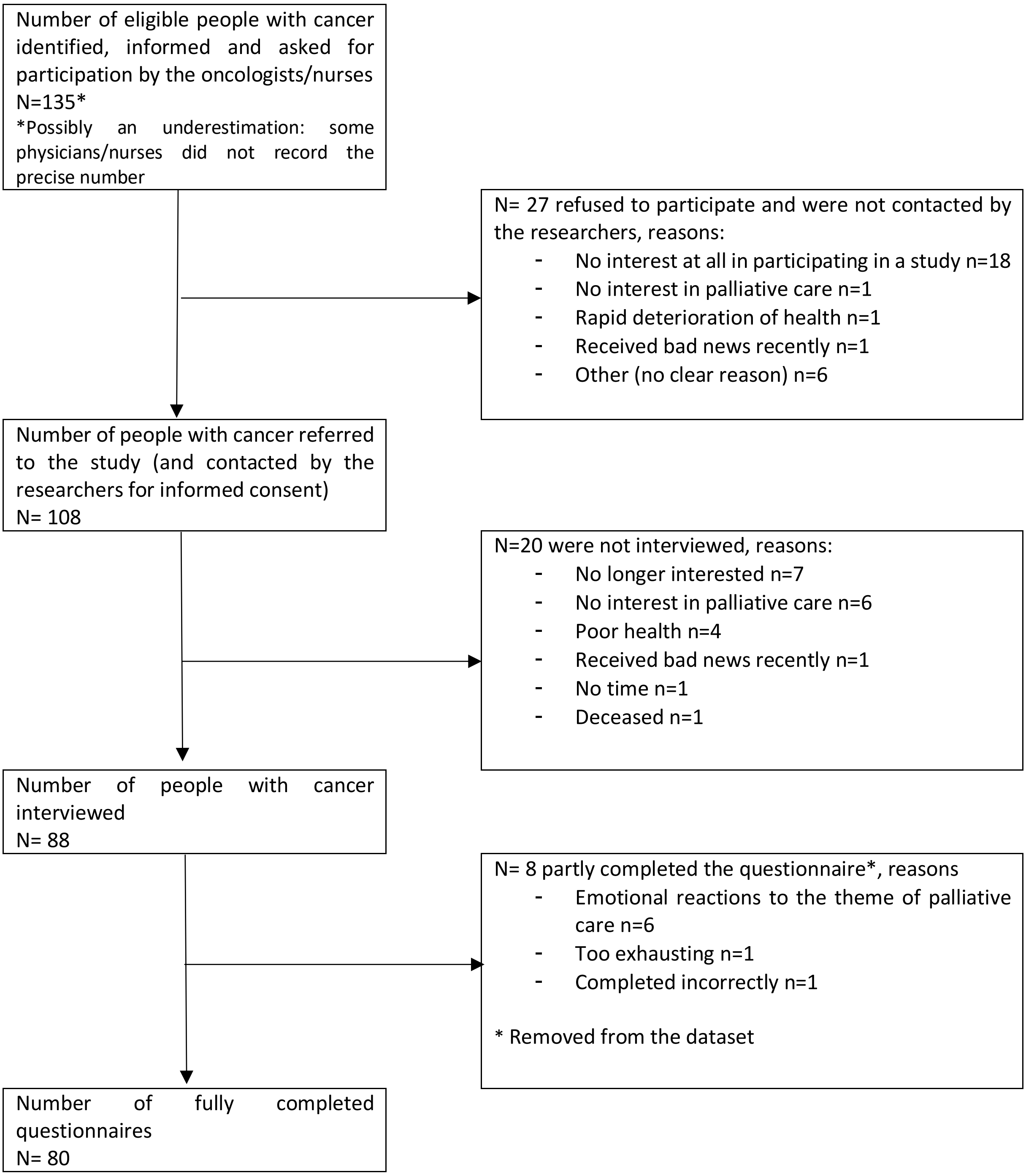

Figure 2. Flow chart of people with cancer recruited, enrolled and retained in the study

Ethics

The study protocol was approved by the Ethical Review Board of Ghent University Hospital (Belgian registration number: B670201940338) and we obtained written informed consent from all study participants.

5.2.3 Measures and data collection

Patient questionnaire

A specific patient questionnaire was used. The items were mainly based on our previously described palliative care behavioral model[16], but illness perception was added.

The questionnaire started with the health status and cancer diagnosis. The total questionnaire contained 131 items, of which 5 were related to behavior or intention and 98 to behavioral factors: firstly psychosocial and perceived socio-environmental factors related to palliative care, and secondly psychosocial and perceived socio-environmental factors related to starting a conversation about palliative care with the physician or intending to do so (see **Supplementary file 1** for a detailed description of how these items were assessed). After the participants answered the questions related to the awareness, knowledge and attitude towards palliative care, they received a clear definition of palliative care. At the end, a number of sociodemographic questions (see **Table 1**) were added.

Computer-assisted personal interviewing

Computer-assisted personal interviewing was used for data collection on a portable device, via a web-based survey server (Survey Monkey). This technique was easy to use, resulting in fewer missing data and immediate availability of data. The researchers read the questions aloud and participants were asked to answer the questions orally. The researchers filled out the questionnaire. For the questions that had to be answered on a scale, answer cards presenting the answer options were provided.

5.2.4 Sample size

A priori power analyses (power=0.80, alpha=0.05) for calculating sample size showed that at least 79 participants were needed to detect an odds ratio of 1.2 (alternative hypothesis) using logistic regression with a continuous predictor (e.g. attitude score), assuming a percentage of positive outcomes of 16% in the total group. This percentage was based on the number of participants in the previous qualitative study[16] who had started a palliative care conversation with the physician or intended to do so, as no similar studies focusing on this outcome were available. The patients interviewed had a wide variety of characteristics and health conditions.

5.2.5 Statistical methods

Data processing

We coded the outcome as binary: having started the conversation about palliative care with the physician + not having started the conversation about palliative care with the physician yet, but intending to do so (1) versus not having started the conversation about palliative care with the physician themselves and receiving specialist palliative care + not having started the conversation about palliative care with the physician and not intending to do so (0). In addition to the theoretical assumptions concerning how several items formed a construct, Cronbach's Alpha (cut-off of 0.60) was used to check internal consistency of the constructs. To increase internal consistency of the scales, a few items were removed or kept as a single item (**Supplementary file 1**).

Data analyses

All analyses were conducted using IBM SPSS Statistics 26. We conducted univariable logistic regression analyses to find out which factors were associated with starting a conversation about palliative care with the physician or intending to do so. Univariable models were used because of the small number of events in the positive group. R square (Nagelkerke) values were used to find out which factors were most strongly associated with the outcome. Additionally, multivariable logistic regression analyses were performed to calculate the explained variance (**Supplementary file 2**). Beforehand, we tested for multicollinearity with Pearson correlation tests ($r > 0.60$). To test the mutual relations between the (border-)significant factors, we performed Independent T-Tests with Levene's Test <0.05 and Pearson Correlation Tests. These results were put into a quantified palliative care behavioral model (see **Figure 3**).

5.3 Results

Physicians/nurses contacted 135 people with incurable cancer and invited them to participate. Eighty-eight patients participated (response rate=65.2%), with 80 questionnaires fully completed. **Table 1** provides a summary of the participants' characteristics.

Table 1. Characteristics of the participants with incurable cancer.

	Total (N=80)	
Socio-demographic characteristics	*n=*	*(%)*
Sex		
Male	42	52.5%
Female	38	47.5%
Age (years)		
Min.	29	
Max.	88	
Average ± SD	66.41	± 12.31
Native language		
Dutch	79	98.75%
Other	1	1.25%
Country of birth		
Belgium	74	92.5%
Other[a]	6	7.5%
Importance of faith/beliefs in care choices		
Min. (not important)	1	
Max. (very important)	5	
Average ± SD	2.33	± 1.32
Education		
Primary to postsecondary education	48	60%
Higher to university education	32	40%
Living situation		
Living alone	19	24.1%
Living with parents, partner, children etc.	58	73.4%
Living in a care institution	2	2.5%
Work experience in healthcare		
No	73	91.3%
Yes	7	8.7%
Having children		
No	6	7.5%
Yes	74	92.5%
Illness and care characteristics	*n=*	*%*
Cancer type		
Respiratory	18	22.5%
Gastrointestinal	15	18.8%
Urological	15	18.8%
Blood	11	13.8%
Breast	8	10%
Head and neck	4	3.8%
Gynecological	3	5%
Thyroid	2	2.5%
Bone	1	1.3%
Other[b]	3	3.8%
Time since diagnosis		
< 1 year	18	22.5%
>= 1 years – ≤ 5 years	36	45%
> 5 years	26	32.5%
Received care from specialist palliative care service		
Yes	18	22.5%
No	62	77.5%
Metastasis		
Yes	58	72.5%
No	22	27.5%
Time since metastasis		
< 1 year	26	44.8%
>= 1 years – < 5 years	24	41.4%
>= 5 years	18	13.8%

Missing values –living situation (n=1)

[a] This group includes the Netherlands (n=5) and Denmark (n=1)

[b] This group includes all other cancer types: sarcoma (n=2) and melanoma (n=1)

Out of 80 participants, 29 had already had a palliative care conversation. Of those 29, 10 had started it themselves. Seven did so with the family physician, two with the oncologist and one with another specialist. Participants who had not started a conversation and were not receiving specialized palliative care (n=56) were asked about their intention to do so in the near future. Eighteen had a positive intention and 38 did not. Twenty-eight would start the conversation with the family physician, 26 with the oncologist and 16 with another specialist. None of the socio-demographic, illness or care characteristics were significantly associated with our outcome.

Table 2 shows the results from the univariable logistic regression. Participants were more likely to have started the conversation or to have intended to do so when they held a more positive attitude towards starting a conversation about palliative care with the physician (OR 4.74; 95% CI 2.35-9.54); perceived more behavioral benefits (OR 2.61; 95% CI 1.37-4.96); perceived a more positive attitude in family/friends (OR 2.07; 95% CI1.26-3.41) and in their physician (OR 2.19; 95% CI 1.39-3.45) towards starting a conversation about palliative care themselves. Starting a conversation about palliative care with the physician or intending to do so was less likely in participants who perceived more behavioral disadvantages (OR 0.53; 95% CI 0.32-0.87), and more barriers (OR 0.33; 95% CI 0.16-0.68). The attitude towards the target behavior had the highest explained variance (R^2=0.406).

Table 2. Associations between factors and having started a conversation about palliative care with the physician or intending to do so

	n= ; mean (± SD)	OR	95% CI for OR	p-value	Nagelkerke R Square
Psychological factors					
Illness perception: care to cure					
No (ref.)	n=45				
Yes	n=35	0.85	0.34-2.13	0.723	0.002
Illness perception: care to live longer					
No (ref.)	n=12				
Yes	n=68	0.92	0.25-3.36	0.896	0.000
Illness perception: care to feel better					
No (ref.)	n=38				
Yes	n=41	0.72	0.29-1.83	0.490	0.008
Illness perception: impact on daily activities	3.05 (0.87)	1.35	0.78-2.32	0.282	0.020
Awareness of palliative care	2.22 (0.74)	0.63	0.34-1.17	0.145	0.037
Knowledge about palliative care	5.50 (2.53)	0.91	0.76-1.10	0.330	0.017
Behavioral awareness					
No (ref.)	n=31	Ref			
Yes	n=49	0.39	0.14-1.07	**0.068****	0.060
Attitude towards palliative care	3.14 (1.01)	1.44	0.92-2.29	0.123	0.041
Attitude towards the behavior	2.88 (1.01)	4.74	2.35-9.54	**<0.001***	0.434
Perceived benefits	3.50 (0.98)	2.61	1.37-4.96	**0.004***	0.180
Perceived disadvantages	2.43 (1.07)	0.53	0.32-0.87	**0.012***	0.118
Perceived facilitators	3.36 (0.95)	1.32	0.79-2.22	0.287	0.020
Perceived barriers	2.54 (0.79)	0.33	0.16-0.68	**0.002***	0.177
Perceived behavioral control	4.40 (0.99)	1.97	1.00-3.89	**0.050****	0.087
Perceived socio-environmental factors					
Subjective norm palliative care (family/friend): perceived attitude	2.57 (0.90)	1.23	0.75-2.04	0.416	0.011
Subjective norm palliative care (physician): perceived attitude	2.97 (1.18)	1.30	0.87-1.94	0.209	0.029
Subjective norm behavior (family/friend): perceived attitude	2.76 (1.02)	2.07	1.26-3.41	**0.004***	0.151
Subjective norm behavior (family/friend): motivation to comply	2.79 (1.65)	1.04	0.79-1.38	0.781	0.001
Social influence, social support (family/friend)	3.01 (1.63)	0.91	0.68-1.22	0.525	0.007
Subjective norm behavior (physician): perceived attitude	2.90 (1.24)	2.19	1.39-3.45	**0.001***	0.221
Subjective norm behavior (physician): motivation to comply	3.93 (1.44)	0.98	0.71-1.34	0.883	0.000
Social influence: social support (physician)	3.38 (1.41)	0.88	0.56-1.22	0.437	0.010
Subjective norm behavior (fellow sufferers)	3.00 (0.90)	1.42	0.84-2.43	0.194	0.030
Social influence, facilitator (family/friend)	3.97 (1.32)	1.00	0.70-1.41	0.982	0.000
Social influence, facilitator (physician)	4.49 (0.80)	1.56	0.74-3.29	0.242	0.029
Social influence, facilitator (fellow sufferer)	3.53 (1.65)	0.95	0.71-1.28	0.742	0.002

OR = odds ratio

CI = confidence interval

Bold text* indicates P-value <0.05

Bold text** indicates P-value >= 0.05-<0.10

Missing values: knowledge about palliative care(n=1), illness perception: care to feel better(n=1), subjective norm palliative care (physician): perceived opinion(n=4), subjective norm behavior (family/friend): perceived attitude(n=1), subjective norm behavior (physician): perceived attitude(n=1), social influence support (family/friend)(n=1), subjective norm behavior (physician): perceived attitude(n=1), social influence support (physician)(n=1), social influence, facilitator (fellow sufferer)(n=8)

No multicollinearity was detected. The final multivariable analysis (**Supplementary file 2**) showed attitude towards the behavior (OR 3.29;95% CI 1.38-7.84), perceived benefits of it (OR 5.48;95% CI 1.78-16.87), and perceived barriers (OR 0.18;95% CI 0.05-0.60) as significant factors related to starting a conversation about palliative care or intending to do so. The perceived attitude towards the behavior in the physician (OR 1.89;95% CI 0.10-3.57) turned border-significant. This model, retaining only these four factors, resulted in a Nagelkerke R square of 63.8%.

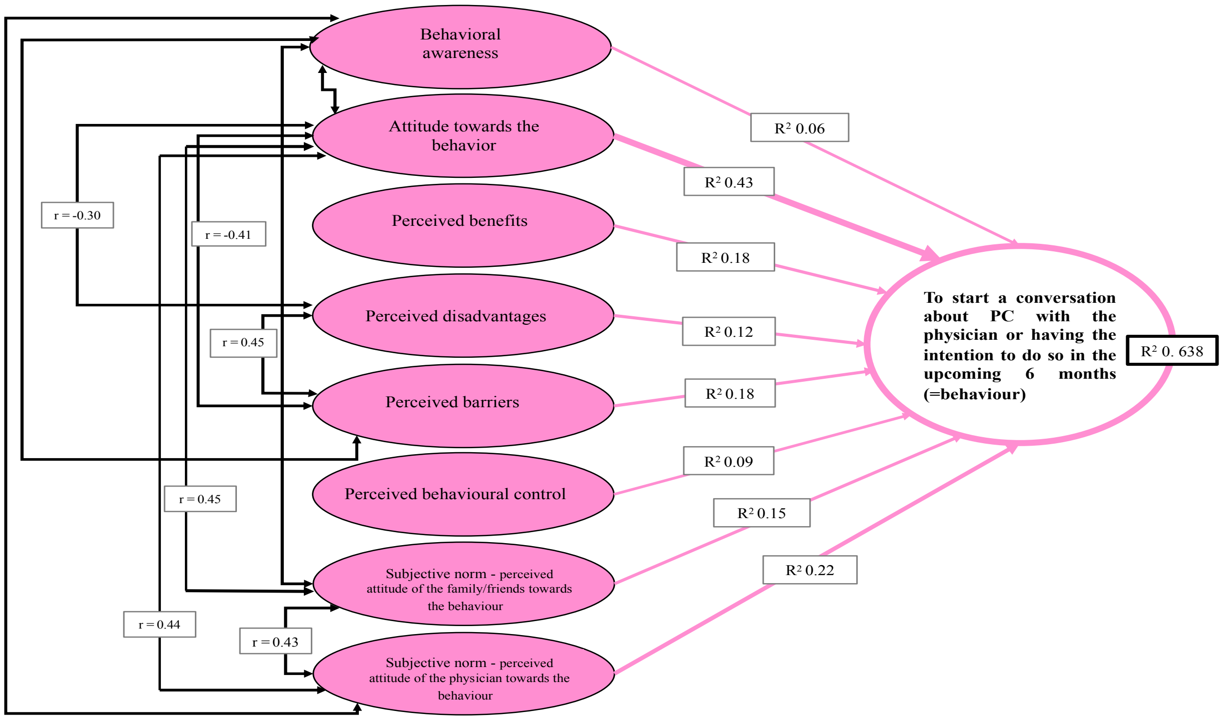

Figure 3. Quantified palliative care behavioral model illustrating on the left side the mutual relations (r ≥(-)0.30) among the (border-) significant (p<0.10) factors associated with the target behavior; and on the right side the Nagelkerke R square values of the (border-) significant (p<0.10) factors associated with the target behavior.

5.4 Discussion

This quantitative study in people with incurable cancer shows significant associations between psychological and perceived socio-environmental factors and intending to start or starting a conversation about palliative care with the physician. Attitudes towards the target behavior, i.e. general attitude, perceived benefits, perceived disadvantages and perceived barriers, and the subjective norm towards the target behavior were found to be the most important factors related to this target behavior and should therefore be the focus of future interventions to change patients' behavior[17].

5.4.1 Study strengths and limitations

Using a palliative care behavioral model, inspired by the theory of planned behavior[25] that was applied and adapted by performing interviews around the topic[16], is quite unique and promising in palliative care research. By doing so, we ensured that the most important and relevant factors related to intending to start or starting a conversation about palliative care with the physician were assessed[17]. The personal interview method for the survey was more time-consuming than sending postal surveys, for example, but it ensured the quality of the data collected. A first limitation is that although the participants varied in terms of other socio-demographic, illness and care characteristics, only one non-native Dutch speaker participated and only six were not born in Belgium. Another limitation is that the cross-sectional design limits the possibility to make causal claims about what influences the behavior due to a large potential residual confounding. Additionally, it does not allow the study of temporality, such as whether a pre-existing attitude influenced intended behavior at a later time point (rather than attitudes being the result of post-hoc rationalization of an intention). Longitudinal studies might be needed to provide better evidence. Nevertheless, participants in different phases of their illness were included in this study and "illness characteristics" were not associated with intending to start or starting a conversation about palliative care.

5.4.2 Interpretation of the most important findings

Our multivariable model showed an explained variance of 64%, which is quite high compared to other research using the TPB to explain health behavior, which showed an average explained variance of 41%[25,26]. This high explained variance shows that our palliative care behavioral model[16] is useful to better understand why people with incurable cancer start a conversation about palliative care with the physician (or not). This is in accordance with a systematic review showing that behavioral theories (especially the TPB) are useful in better understanding palliative care behaviors[27]. Our results also suggest that interventions based on our model have a high potential to achieve preferred behavioral change and to improve patient empowerment, patient-physician communication about palliative care, patient-centered care and the quality of life of both people with cancer and their families. However, a higher percentage may be slightly affected by the methodological choice to include the intention in the behavioral outcome. Other behavioral factors, i.e. independent variables, are often better predictors of intention than behavior[25]. We should bear in mind the possible gap between intention and behavior[17].

We found that people with cancer who held a “more positive attitude towards the behavior” and “perceived more benefits of it” were more likely to perform the target behavior or intend do so. These participants believed that starting a conversation about palliative care with the physician was important, relevant and, for example, an opportunity to gain more control over their care. Previous advance care planning (ACP) studies also show that patients with a positive attitude are more likely to engage in ACP[28]. Bravo et al. identified a positive relation between attitude and patient empowerment[29]. In the present study participants’ mean scores on the attitudinal factors (Table 2) are rather moderate. Our study results also show that a minority of participants started the conversation about palliative care themselves or had the intention to do so. In practice, physicians usually start the conversation about palliative care rather than the patient[30]. People with cancer might expect their physician to take the initiative at the appropriate time[31]. These findings illustrate that patients’ positive attitudes towards starting a conversation about palliative care are not yet standard attitudes and that patient empowerment is not yet well established and embedded in palliative care research and policies. This contrasts with the increasing interest in patient empowerment in high-quality care[32,33]. This emphasizes the need for the application and implementation of adequate theoretical strategies such as arguments and persuasive communication[17] to change patients’ attitudes towards palliative care and increase patient empowerment.

We also found that people with cancer who “perceived more disadvantages and barriers” towards starting a conversation about palliative care were less likely to do so or intend to do so. These participants believed, for example, that starting a conversation about palliative care with the physician would cause stress and anxiety and would feel like getting ahead of themselves. They reported barriers such as feeling too good, associating palliative care with terminal care and not being interested in palliative care. Based on other study results, barriers such as the association of palliative care with terminal care might also be related to lack of understanding of the behavioral benefits[14]. As described above, attitudinal factors are the most important factors related to starting a conversation about palliative care. Therefore, we suggest that it would be interesting to invest in changing patients' attitudes rather than focusing on knowledge and prognosis[34], which seems to be the current prevailing research and practice focus. There is a need to inform patients about what timely communication about palliative care can offer them by highlighting its benefits and discussing the disadvantages and finding solutions for barriers[35].

The perception about the social environment also plays an important role in whether or not patients will start a conversation about palliative care. "The subjective norm towards the behavior" was significantly associated with the target behavior. Participants who perceived that their partner, family, friends and physician found it important, relevant or not too early to start the conversation were more likely to do so or intend to do so. The importance of the subjective norm corroborates previous studies of various health behaviors[36]. Previous studies also show that physicians recognize the importance of their own attitude towards palliative care in the communication with patients[12]. These physicians' attitudes might possibly determine whether they show patients that they are open to talk about palliative care or not, which in its turn affects the patients' perceptions of the physician's attitudes.

5.4.3 Clinical implications

This study looks for a way to empower the patient to take the initiative in conversations about palliative care. As the study results show, more attention should be paid to their role. Clinicians can encourage people with cancer to start the conversation about palliative care by highlighting its importance, relevance and benefits. They can inform patients that timely communication about palliative care can enhance patient-centered care and active involvement in decision making and inform them about the disadvantages of waiting until it is urgent[37]. Clinicians can also help people with cancer to identify their barriers and how to overcome them, for example, by providing prepared lists of simple questions such as how are you now or what do you want to do in the coming weeks/months?[38]. It can be facilitating if clinicians show their positive attitude towards palliative care and openness to talking about it. Furthermore, our findings emphasize the need for involvement of patients' family carers in encouraging people with cancer to start a palliative care conversation. Clinicians need to inform family carers better about palliative care and the benefits for themselves of timely communication as well (e.g. less care burden)[39]. More training aimed at improving clinicians' communication skills is suggested[40].

5.5 Conclusion

Our findings suggest that several psychological and perceived socio-environmental factors – particularly patients' attitudes – are important determinants of starting a conversation about palliative care with the physician in people with incurable cancer. This is important information for developing a targeted behavioral intervention aimed at helping to empower people with cancer to take the initiative in starting the conversation about palliative care with the physician.

Authorship

A-L.S., K.B., L.D., BD, JC, were responsible for the literature search, planning and design of the study. A-LS was responsible for data collection and data analysis. All authors contributed to the interpretation of the data. A-LS and KB wrote the first draft of the manuscript and critically revised the manuscript after receiving comments from all authors. K.B., L.D., BD, JC supervised the study All authors approved the final manuscript. A-LS was responsible for final submission and as guarantor of content.

Acknowledgments

The authors are very grateful to the physicians, nurses and patients for participating in the quantitative interviews. We further thank Helen White for help with linguistic editing of the text. This work was supported by the Research Foundation Flanders.

Conflict of interest statement

The authors declare that there is no conflict of interest.

Data availability statement

The data that support the findings of this study are available from the corresponding author, AS, upon reasonable request.

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Chapter 5 Supplementary file 1: Overview of the behavior, intention, factors and the Cronbach's alpha scores

Behavioral factor	**Items**	**Scale**	**Cronbach's alpha**	**Cronbach's alpha if (cut-off of 0.60 – or theory-based)**
Behavior and intention				
1. Behavior	1. If you had a conversation with a physician (family doctor, oncologist, another specialist), did you start this conversation yourself?	Dichotomous scale (yes/no)	/	
2. Intention	*Participants who don't receive any specialist palliative care yet* 2.1 I'm planning to start a conversation about palliative care with my physician soon (within the month) 2.2 I'm planning to start a conversation about palliative care with my physician in the longer run (within half a year) 2.3 I'm not planning to start a conversation about palliative care with my physician within half a year Participant who already receive specialist palliative care 2.4 Looking back to before I received palliative care, I would have started a conversation myself about it with my physician	Dichotomous scale (yes/no)	/	
*Psychological factors**				
1.Illness perception: care to cure	1.1Are you currently receiving therapies/treatments to help you recover?	Dichotomous scale (yes/no)	/ *(single item)*	
2.llness perception: care to live longer	2.1 Are you currently receiving therapies/treatments to help you live longer?	Dichotomous scale (yes/no)	/ *(single item)*	
3.Illness perception: care to feel better	3.1 Are you currently receiving therapies/treatments to make you feel better?	Dichotomous scale (yes/no)	/ *(single item)*	
4. Illness perception: impact on daily activities	4.1 How strongly do you experience complaints/discomforts/problems because of your illness? 4.2 How much do you worry about your illness? 4.3 How much does your illness influence your daily life? 4.4 How much does your illness influence your mood/state of mind?	5 point Likert scale ranging from none at all to a lot	0.743	

Behavioral factor	Items	Scale	Cronbach's alpha	Cronbach's alpha if (cut-off of 0.60 – or theory-based)
5. Awareness of palliative care	5.1 Are you aware of the existence of palliative care? 5.2 Do you know what palliative care is? 5.3 Do you know when you can get palliative care?	No, I don't know/ I think I know/ Yes, I know for sure	0.598	0.724 if item 5.1 was deleted *Item 3.1 was deleted*
6. Knowledge about palliative care	6.1 Palliative care can provide relief from pain 6.2 Palliative care intends to hasten death 6.3 Palliative care also addresses possible psychological problems 6.4 Palliative care intends to postpone death 6.5 Palliative care also addresses possible spiritual or existential problems 6.6 Palliative care offers support to the patient 6.7 Palliative care offers support to the patient's family/carer 6.8 Palliative care equals end-of-life care 6.9 Palliative care equals the end, death 6.10 Palliative care aims to enhance the quality of life 6.11 Palliative care is only for the bedridden 6.12 Palliative care costs the patient a lot of money	Four-point rating scale ranging from 1 certainly incorrect to 4 certainly correct	/ *(knowledge test)*	
7. Behavioral awareness	7.1 Prior to this interview, were you aware that you could start a conversation about palliative care with your physician yourself, as a patient?	Dichotomous scale (yes/no)	/ *(single item)*	
8. Attitude towards palliative care	8.1…I am interested in palliative care 8.2…I feel palliative care is important to enhance my quality of life 8.3…I think palliative care is necessary for me 8.4…the words 'palliative care' give me stress or anxiety 8.5…It is too early to think about palliative care 8.6…thinking about palliative care makes me feel low or depressed	5 point Likert scale ranging from strongly disagree to strongly agree	0.721	

Behavioral factor	**Items**	**Scale**	**Cronbach's alpha**	**Cronbach's alpha if (cut-off of 0.60 – or theory-based)**
9. Attitude towards the behavior	9. 1…is important 9.2…is relevant to me 9.3…is too soon for me 9.4…is my own choice 9.5…is the responsibility of my physician	5 point Likert scale ranging from strongly disagree to strongly agree	0.713	
10. Perceived benefits	10.1…that I can express my care wishes 10.2… that I could get information about e.g. my illness, possible treatment etc. 10.3…that I could get information about palliative care 10.4…that I could get emotional/psychological support 10.5…that I would feel relieved 10.6…that I would feel reassured 10.7…that palliative care would be initiated 10.8…that I could lead a more comfortable life with palliative care 10.9…that I would feel like I had more control over my care 10.10…that it would relieve the burden on the people around me (e.g. partner, children) 10.11…that my physician wouldn't bring it up unexpectedly 10.12…that I would find out my physician's opinion about palliative care	5 point Likert scale ranging from strongly disagree to strongly agree	0.866	
11. Perceived disadvantages	11.1…that I would feel stressed and anxious because of the conversation 11.2…that I would feel sad because of the conversation 11.3…that I would give up 11.4…that I would burden my physician when it's not necessary yet 11.5…that I would get ahead of myself	5 point Likert scale ranging from strongly disagree to strongly agree	0.765	
12. Perceived facilitators	12.1…that I have accepted my diagnosis 12.2…if I felt worse than I do now 12.3…if my quality of life decreased 12.4…if no treatment was effective for me any longer 12.5…if someone around me had already received/was receiving palliative care 12.6…if the words 'palliative care' had been mentioned before, e.g. by one of the professional carers 12.7…if I had already started a conversation about palliative care with a partner, nurse, etc.	5 point Likert scale ranging from strongly disagree to strongly agree	0.692	

Behavioral factor	**Items**	**Scale**	**Cronbach’s alpha**	**Cronbach’s alpha if (cut-off of 0.60 – or theory-based)**
13. Perceived barriers	13.1…that I feel good 13.2…that I’m afraid to do so 13.3…that I’d rather start a conversation about palliative care with someone other than my physician 13.4…that I associate palliative care with end of life care 13.5…that I’m not interested in palliative care 13.6…that I can’t assess my medical health status	5 point Likert scale ranging from strongly disagree to strongly agree	0.464	No increase if items were deleted *All items were kept*
14. Perceived behavioral control	14.1 I am confident that I would be able to start a conversation about palliative care with my physician myself	5 point Likert scale ranging from strongly disagree to strongly agree	*/ (single item)*	
Perceived socio-environmental factors				
15. Subjective norm towards palliative care (family/friend): perceived attitude of the people around the patient towards palliative care	15.1…that it is too soon for you to have palliative care 15.2…that palliative care is necessary for you 15.3…that palliative care in general is important 15.4…that palliative care is your own choice	5 point Likert scale ranging from none of them to all of them	0.531	0.535 If item 15.4 was deleted *Item 15.4 was deleted*

Behavioral factor	**Items**	**Scale**	**Cronbach’s alpha**	**Cronbach’s alpha if (cut-off of 0.60 – or theory-based)**
16. Subjective norm towards palliative care (physician): perceived attitude of the physician of the patient towards palliative care	16.1…that palliative care in general is important 16.2…that palliative care is necessary for you 16.3…that it is too soon for me to have palliative care 16.4…that palliative care is my own choice	5 point Likert scale ranging from strongly disagree to strongly agree	0.613	0.724 If item 16.4 was deleted *Item 16.4 was deleted*
17. Subjective norm behavior (family/friend): perceived attitude of the people around the patient towards the behavior	17.1…find it important for you to start a conversation about palliative care with your physician yourself? 17.2…find it relevant for you to start a conversation about palliative care with your physician yourself? 17.3…find it too soon for you to start a conversation about palliative care with your physician yourself? 17.4…think that it’s your own choice whether or not you start a conversation about palliative care with your physician yourself? 17.5…I find it important to do what my partner/family/friends expect of me concerning starting a conversation about palliative care with my physician myself	5 point Likert scale ranging from none of them to all of them	0.579	0.693 If item 17.5 was deleted *Item 17.5 was kept as single item*
18. Social influence, social support (partner/family/friend)	18.2…My partner/family/friends would encourage me to start a conversation about palliative care with my physician myself 18.3…My partner/family/friends would stop me from starting a conversation about palliative care with my physician myself	5 point Likert scale ranging from strongly disagree to strongly agree	*0.232*	*Item 18.3 was deleted, item 18.2 was kept as single item*

Behavioral factor	**Items**	**Scale**	**Cronbach's alpha**	**Cronbach's alpha if (cut-off of 0.60 – or theory-based)**
19. Subjective norm behavior (physician): perceived attitude of physician of the patient towards the behavior	19.1… it is important for me to start a conversation about palliative care with him/her myself 19.2… would find it relevant for me to start a conversation about palliative care with him/her myself 19.3…would find it too soon for me to start a conversation about palliative care with him/her myself 19.4…I find it important to do what my physician expects of me	5 point Likert scale ranging from strongly disagree to strongly agree	0.495	0.649 if item 19.4 was deleted *Item 19.4 was kept as single item*
20. Social influence: social support (physician)	20.1…My physician would encourage me to start a conversation about palliative care with them myself 20.2…My physician would stop me from starting a conversation about palliative care with them myself	5 point Likert scale ranging from strongly disagree to strongly agree	*0.199*	*Item 20.2 was deleted, item 20.1 was kept as single item*
21. Social influence, facilitator (partner/family/ friend)	21.1…support from my family 21.2…that my family would come with me during this conversation	5 point Likert scale ranging from strongly disagree to strongly agree	0.622	
22. Social influence, facilitator (physician)	22.1…that I trust my physician 22.2…that I have a strong connection with my physician 22.3…that my physician knows me (my attitudes, how I cope with problems, my background etc.) 22.4…that my physician is empathetic 22.5…that my physician is appropriate and honest 22.6…that my physician makes or has time for me 22.7…that my physician is open to the concept of palliative care 22.8…that my physician has experience with palliative care	5 point Likert scale ranging from strongly disagree to strongly agree	0.867	

Behavioral factor	**Items**	**Scale**	**Cronbach’s alpha**	**Cronbach’s alpha if (cut-off of 0.60 – or theory-based)**
23. Subjective norm behavior (fellow sufferers)	23.1…Do you think that, in general, other people with cancer or fellow sufferers start a conversation about palliative care with their physician themselves?	5 point Likert scale ranging from I am sure they don’t to I am sure they do	/ *(single item)*	
24. Social influence, facilitator (fellow sufferer)	24.1…that my fellow sufferer(s) would support me	5 point Likert scale ranging from strongly disagree to strongly agree	/ *(single item)*	

* The items assessing the psychological and perceived socio-environmental factors related to starting a conversation about palliative care with the physician or intending to do so were slightly different in verb tenses depending on two previous answers (whether the participant was receiving specialist palliative care yet and the reported behavior or intention). The described questions in the table above were asked to people who were not receiving specialist palliative care yet and had no intention to start the conversation about palliative care with the physician.

Chapter 5 Supplementary file 2: Multivariable analysis

Table S1A Associations between psychological factors [continuous, except of one dichotomous] and started a conversation about palliative care with the treating physician and intending to do so [dichotomous] using multivariable logistic regression analysis

Psychological factors	OR	95% CI	p-value	Nagelkerke R Square
				0.653
Knowledge of the behavior				
No (ref.)	0.571	0.126 ; 2.582	0.467	
Yes				
Attitude towards the behavior	**2.885**	1.193 ; 9.756	**0.019**	
Perceived benefits	**7.640**	2.321 ; 27.160	**0.001**	
Perceived disadvantages	0.515	0.231 ; 1.151	0.106	
Perceived barriers	0.240	0.071; 0.810	**0.021**	
Perceived behavioral control	1.320	0.781 ; 2.231	0.299	

OR = odds ratio
CI = confidence interval
Bold text indicates **P-value <0.10**
Missing cases n=3

Table S1B Associations between perceived socio-environmental factors [continuous] and starting a conversation about palliative care with the treating physician or intending to do so [dichotomous] using multivariable logistic regression analysis

Perceived socio-environmental factors	OR	95% CI	p-value	Nagelkerke R Square
				0.250
Subjective norm behavior (family/friend): perceived attitude	1.555	0.901 ; 2.683	**0.113**	
Subjective norm behavior (physician): perceived attitude	**1.849**	1.140 ; 2.999	**0.013**	

OR = odds ratio
CI = confidence interval
Bold text indicates **P-value <0.10**
Missing cases n=2

Table S1C Final model: associations between significant factors [continuous] from tables 1 and 2 and starting a conversation about palliative care with the treating physician or intending to do so [dichotomous] using multivariable logistic regression analysis

	OR	95% CI	p-value	Nagelkerke R Square	ROC curve: Area Under Curve
				0.638	
Attitude towards the behavior	**3.288**	1.379 ; 7.841	**0.007**		0.810
Perceived benefits	**5.477**	1.778 ; 16.868	**0.003**		0.720
Perceived barriers	0.180	0.054 ; 0.604	**0.006**		0.265
Subjective norm behavior (physician): perceived attitude	1.888	0.998 ; 3.570	**0.051**		0.749

OR = odds ratio
CI = confidence interval
Bold text indicates **P-value <0.10**
Missing cases n=1

CHAPTER 6

DEVELOPMENT OF A THEORY-BASED BEHAVIORAL INTERVENTION TO HELP PEOPLE WITH CANCER WITH STARTING A CONVERSATION ABOUT PALLIATIVE CARE: COMBINING INTERVENTION MAPPING WITH A PARTICIPATORY APPROACH

METHODS AND RESULTS

Scherrens A, Cohen J, Deliens L, Beernaert K* & B Deforche*.

[Ongoing]

6.1 Introduction

Part III of this dissertation focuses on the specific target behavior of starting a conversation about palliative care with the physician and its factors (barriers, facilitators) in people with incurable cancer, as evidence shows that this target behavior could contribute to more timely communication about palliative care and more timely initiation of palliative care[1,2]. In Chapter 4, we used qualitative interviews with people with incurable cancer to identify the factors related to starting a conversation about palliative care with the physician or having the intention to do so. In Chapter 5, the quantitative importance of the different factors identified in the qualitative study was examined through surveys among people with incurable cancer. The findings of this qualitative and quantitative study were used as basis to develop a health promotion intervention at improving the patient-physician communication about palliative care. Below we describe how we developed an intervention to stimulate people with cancer in starting a conversation about palliative care with their physician themselves and to support physicians in reacting appropriately by combining Intervention Mapping and a participatory approach and the outcomes of this process.

6.2 Methods

The behavioral intervention was developed systematically following the Intervention Mapping Protocol (IMP)[3], i.e. an iterative stepwise approach for developing theory-based and evidence-based health promotion interventions and by using a participatory approach for creation and design of the intervention. A schematic representation can be found in **Figure 1**.

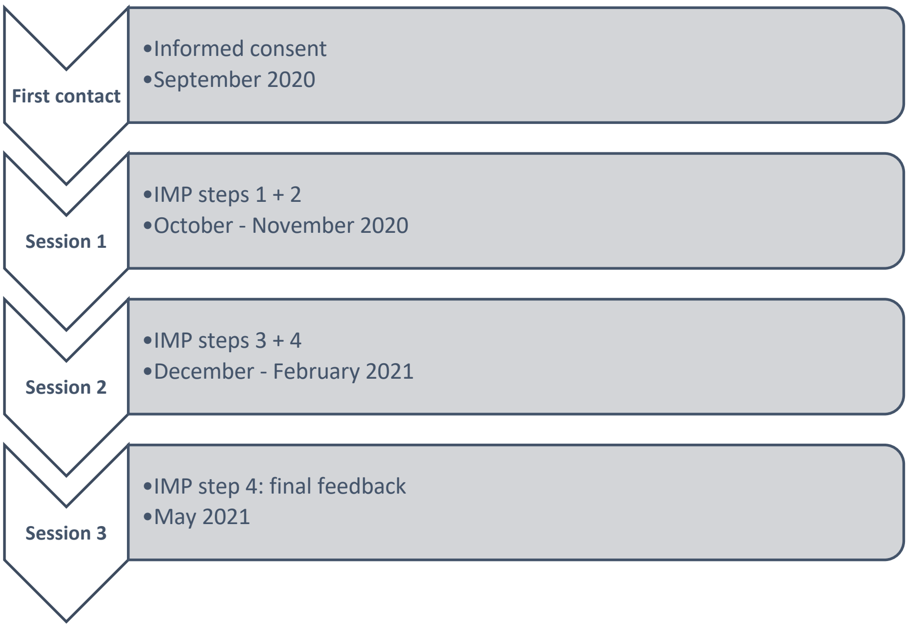


Figure 1. Schematic representation of the contact moments and elaboration of the IMP steps

This study was approved by the Committee for Medical Ethics of Ghent University (B6702021000308).

6.2.1 Procedure and recruitment of planning group members

A planning group was composed based on the various perspectives needed: people being the end-users, i.e. people with cancer, physicians, family carers of people with cancer, other potential stakeholders and (inter)national researchers. The recruitment strategy used were convenience and snowball sampling strategies. People with cancer were recruited through patient committees of Kom Op Tegen Kanker, patient organizations such as vzw Hersentumoren and researchers' personal networks. Physicians were recruited through Ghent University Hospital and regional general practitioner practices. Family carers were recruited via informal care associations such as Samana and Steunpunt Mantelzorger vzw, home care services such as Wit-Gele Kruis and personal networks. Palliative care nurses were recruited via the regional palliative care network Gent-Eeklo. Potential stakeholders were recruited via institutions having expertise in the fields of oncology care and palliative care such as Kom Op Tegen Kanker, Federatie Palliatieve Zorg Vlaanderen and Domus Medica. A multidisciplinary team of researchers, i.e. experts in either health promotion or end-of-life care research, supervised the previous qualitative and quantitative studies as well as the development of this theory-based intervention. Additionally, national and international researchers with relevant expertise in patient empowerment and patient-physician communication were invited via Ghent University, Vrije Universiteit Brussel and Nivel (The Netherlands). Most people were invited through e-mail or phone. To invite people from the personal networks, an invitation call was launched via a flyer on social media (Facebook and Twitter). During a first contact, either physically or online, with potential participants interested in joining the planning group, a researcher elaborated on the intervention goal, the planned participatory development process and expected input from participants. Considering the participatory degree, the goal was to co-create the intervention (materials) with the planning group. By co-creating this intervention, we ensured that the preliminary intervention (materials) were more tailored to the needs of people with cancer. If people were willing to join the planning group, they gave written informed consent and a follow-up meeting was planned.

During three semi-structured sessions the planning group went through the first four steps of the IMP. All sessions were prepared and led by the executive researcher of this study, in collaboration with master thesis students in Health Promotion at Ghent University. The first two sessions were individually, because we assumed that participants would be more stimulated to share their expertise and opinion and would not be hindered by presence of others (e.g. patients vs physicians). The third and final session, consisted of one group session and a few individual sessions with people who were not able or willing to participate to the group session. However, we ensured that at least one person with cancer, physician, family carer, researcher and other potential stakeholder were represented in the group session. Our multidisciplinary research team met six-weekly to discuss the intervention procedure and progress. Due to the governmental corona measures, most of the individual sessions and the group session were held online. An advantage was that this was accompanied with lower participation costs (e.g. time), but a disadvantage was that it was more difficult to write down and structure the brainstorm ideas. Few individual sessions were held face to face if this was preferred by the participant (e.g. patients and family carers). For all sessions we used a PowerPoint presentation, which mainly consisted of images, figures and keywords. During the online sessions we shared our screen where the participants could see a page with notations to structure the brainstorm ideas. During the face to face sessions, we used big white pages and colored post-its to do so. All sessions were audio-recorded. Each session started with explaining the goal of the session. After the first and the second session, the executive researcher analyzed the written notes and the audio-recorded data. Next, a summary was drawn up. The following session started with the summary of the previous session and highlighted biggest discrepancies found in results. These discrepancies were discussed again to reach consensus. The sessions took place between October 2020 and May 2021.

6.2.2 Combining a Participatory Approach with Intervention Mapping

Session 1: step 1 needs assessment + step 2: performance and change objectives

During this first session, the researcher and the planning group member got to know each other in order to have a trustful connection. The researcher explained in detail the background, previous study results, the intervention aims and its potential impact. Next, information about the planning group was given such as its composition and importance, about the participants' role and expectations, and about the sessions. Participants were asked to fill out a short questionnaire to collect the following data: age, sex, expertise (e.g. being a patient, physician, family carer etc.), whether they already have knowledge about palliative care and have experience with participating in scientific studies.

The first step of the IMP includes carrying out a needs assessment and defining the main aim of the intervention. The purpose of this needs assessment is to assess the risk behavior, its relation with health and quality of life, environmental conditions and the associated determinants for both the risk behavior and environmental conditions[3]. This needs assessment was already largely conducted by our multidisciplinary research team through previous literature search and a qualitative[4] and quantitative study (Chapters 4 & 5). The health problem was described by the researchers as palliative care being frequently initiated too late[5] or not at all[6] in people with incurable cancer, resulting in suboptimal care during their last weeks/days of life[7]. People with incurable cancer avoiding or postponing a conversation about palliative care with the physician was the risk behavior for not (timely) initiating palliative care chosen by the researchers[1,8]. People with incurable cancer were defined by the researchers as people diagnosed with any type of incurable cancer who were not receiving either generalist nor specialised palliative care and for whom palliative care could possibly address their palliative care needs. Based on the previous qualitative and quantitative study we have chosen to involve physicians as environmental agents[3]. Their perceived attitudes towards the patient in starting the conversation about palliative care to them were found to be important factors related to the patient behavior[4] and they currently avoid palliative care conversations as well[8]. Physicians were defined by the researchers as oncologists, specialists or family physicians who provide care to people with incurable cancer. Therefore, the aim of the intervention was twofold: 1) to help people with incurable cancer *(= target population 1)* in starting the conversation about palliative care with their physician *(= target health-promoting behavior 1)* and 2) to support physicians *(= target population 2)* in reacting appropriately when the patient is starting a conversation about palliative care with him/her *(= target health-promoting behavior 2).* Thus, the target population included patients and physicians from both the hospital setting and the home care setting. The above -evidence-based- decisions were made by the researchers prior the intervention development. These decisions were only presented to the planning group, but were no longer subject to change unless it would provoke objection. Together with the planning group, the strengths and weaknesses of both target groups were discussed. Behavioral factors related to the patient risk behavior were assessed through the previous qualitative and quantitative study and checked with the planning group. The behavioral factors related to the physicians' risk behavior were partially identified by the researcher through a literature study, but factors were added with the help of the planning group. To explain the members of the planning group what behavioral factors are and how they can be identified, we started with an exercise, in which they were asked to think aloud about which factors facilitated or hindered (= behavioral factors in this exercise) their participation in this intervention development (= target behavior in this exercise).

The second step of IMP focuses on what should change to induce behavioral change and improve health. Performance objectives (i.e. specific sub behaviors), behavioral factors and change objectives (i.e. what needs to change about a behavioral factor to reach a performance objective) related to the target behavior have to be formulated. First, the target behaviors were further concretized with the help of the planning group. For example, following questions were asked: how do you interpret the behavior in which people with cancer start a conversation about palliative care with their physician? Do you think they explicitly have to mention the words 'palliative care'? How do you interpret the behavior in which physicians react appropriately? Second, performance objectives were formulated for the target behavior of people with cancer and of the target behavior of physicians. An example of physical activity (running) was used to facilitate this process: what intermediate steps (e.g. to buy good running shoes, to provide an alternative in case of rain etc.) should someone take to effectively go running outside twice a week? Behavioral factors related to the patient target behavior were also already assessed through the previous qualitative and quantitative study. The behavioral factors related to the physician target behavior were partially identified through a literature study, but factors were added with the help of the planning group. The importance and modifiability of these factors were discussed with the planning group members. As formulating change objectives is theoretical and complex, this task was done by our multidisciplinary research team.

Session 2: step 3 methods and practical applications + step 4 intervention development

The third step of IMP is about targeting the most important and modifiable factors for change by choosing theory- and evidence-based change methods[3] and translating these methods into practical applications relevant for the target population and setting. At the start of session two, examples of methods and practical applications were showed to the planning group. All change objectives were clustered per factor. As methods are difficult and abstract for non-researchers, we started with a presentation of cards with possible methods. We asked the participants what methods they believed are important and relevant to achieve the change objectives. Following this exercise, a brainstorm about relevant applications linked to the selected methods by the participants and taking into account the strengths and weaknesses of the target population, was performed. For example, this intervention aims to increase knowledge in people with cancer about their own wishes and needs. Therefore, we asked the planning group: ‘What material(s) could help people with cancer to think about their own wishes and needs?’ Another example, this intervention aims to improve physicians’ skills to provide minimal time to react appropriately to patients starting a conversation about palliative care to him/her. We asked the planning group: ‘How could we help physicians to learn more skills to take minimal time to react appropriately, taking into account the workload and time constraints?’ Our multidisciplinary research team checked whether the selected methods were correctly translated into practical applications afterwards. A logo (colors, images) and slogan (keywords) were also discussed within the planning group.

Session 3: step 4 final feedback and agreement on preliminary intervention materials

The fourth step of the IMP focusses on the production of program components, design and production. First, our multidisciplinary research team designed drafts of the intervention materials based on the practical applications chosen in session 2, which were combined into a coherent intervention including two components. The first component was aimed at patient behavioral change and the second on physician behavioral change. Second, the planning group members provided feedback on ideas for the slogan and logo and on drafts of the intervention materials for both people with cancer and the physicians. We asked them about their first thoughts by seeing the slogan/logo/materials. Then we asked them more specifically about their perceptions of the attractiveness and clarity (e.g. colors, letter type, language, structure) as well as of the importance and relevance. We asked them what elements they would definitely keep or change. In the group session, consensus was sought as much as possible.

After this session, our multidisciplinary research team performed a thorough theoretical check of the intervention developed and adapted the draft materials accordingly. Next, these drafts were refined with the help of a professional graphical designer and small numbers were produced. These materials are currently being tested on acceptability and feasibility.

Steps 5 (designing the implementation) and 6 (effect and process evaluation) of the IMP still need to be developed.

6.3 Results

Planning group composition

The planning group consisted of 22 people being the end-users, other potential stakeholders and researchers with relevant expertise:

- People with cancer (n=4*)
- Physicians: oncologist (n=1), family physician (n=1)
- Family carers (n=4)
- Palliative care nurse (n=2)
- Member of Palliatieve Zorg Vlaanderen (n=1)
- Member of Kom Op Tegen Kanker (n=1)
- Member of Domus Medica (n=1**)
- Researchers with relevant expertise in oncology care and palliative care (n=3), health promotion (n=1), patient empowerment (n=1), patient-physician communication (n=1) and the use of IMP in patient-physician communication studies (n=1)

*One participant with cancer also cared for her partner who died from cancer.

** A family physician being member of Domus Medica participated

Of these 22 participants, only one person with cancer and one family carer reported to have no knowledge about palliative care.

Step 1 Needs Assessment

The planning group members agreed with the researchers' choices regarding the health problem, the risk behavior and the target populations.

Following strengths and weaknesses of targeting people with incurable cancer were identified by the planning group to be taken into account in the development of the intervention:

People with incurable cancer	
Strengths	Weaknesses
Being diagnosed with cancer is (unconsciously) linked to 'what if…' thinking e.g. what if the cancer can no longer be treated… Talking about these 'what if…' scenarios can bring relief.	The taboo surrounding the loaded term 'palliative care'. People with cancer are rather afraid of the term palliative care. Hearing or reading about palliative care evokes resistance.
Being diagnosed with incurable cancer (unconsciously) arouses interest in palliative care	The psychological impact of the disease. Many people with cancer keep on hoping that the cancer can still be cured. They do not wat to think about their (unfavorable) situation all the time.
Willing to take actions that improve their care and health outcomes	Often dealing with information overload
Often having to deal with waiting time e.g. before a consultation, during a hospital stay, which creates time to be exposed to intervention materials	Often having limited illness perception. It hinders their long-term thinking. They do not feel that conversations about palliative care are important and necessary for them.
Frequently having a good connection with a professional carer e.g. nurse	Feeling rather stressed when visiting the physician.
Frequently receiving positive support from their partner, family (carer) or friends	Often suffering from fatigue, concentration problems, cognitive problems, visual problems etc.
There is usually a warm group feeling between the fellow sufferers	A large age range (18-90+ years old)
	An average age of 66 years: - they might experience problems with processing and remembering new information - using digital materials and internet might be more difficult
	A various group: some might have lower health and communication skills (cf. health literacy)
	They could be accompanied by a family carer who is very negative towards palliative care and who avoids palliative care communication

Following strengths and weaknesses of targeting physicians were identified by the planning group and should be taking into account in the development of the intervention:

Physicians (oncologists, specialists, family physicians)	
Strengths	Weaknesses
Highly educated	High work load and little time for both participating to training courses as communicating about palliative care with patients and their families
Growing awareness about the importance of communication (skills)	Some physicians resist change
Having interest for training courses that are beneficial and accredited	Therapeutic persistence. Some physicians have more attention for curative care and less for palliative or comfort care.
Easy to reach via hospitals, general practitioner practices or other organizations such as Domus Medica	Inconsistent collaboration and communication between the various professional carers involved
Surrounded by a broad multidisciplinary team	Restrictions at organizational level such as remuneration

The previous qualitative interview study (Chapter 4) showed that following factors were perceived as facilitating or hindering to start a conversation about palliative care with the physician or having the intention to do so: awareness e.g. of their illness, knowledge about palliative care (possibilities), attitude towards palliative care and the target behavior, perceived behavioral control (e.g. self-confidence), perceived social norm (e.g. perceived attitude towards palliative care and the target behavior in their partner/family/friends/physician) and social influence (approval of disapproval from others). Based on these qualitative findings, a palliative care behavioral model was developed[4]. Through quantitative surveys among people with incurable cancer, the quantitative importance of the different factors identified in the qualitative study was examined (Chapter 5). These quantitative results showed the most important factors being associated with starting a conversation about palliative care with the physician or having the intention to do so. This survey study identified that attitude towards the behavior (general attitude, perceived benefits, disadvantages and barriers), perceived behavioral control and the social norm towards the behavior in the partner/family/friends/the physician were the most important factors associated with starting a conversation about palliative care with the physician or having the intention to do so. People holding a positive attitude towards the behavior, perceiving more benefits of it and perceiving a positive attitude towards the behavior in family/friends and the physician were more likely to perform the behavior or to have the intention to do so. People perceiving more disadvantages and barriers were less likely to perform the behavior or to have the intention to do so. These factors explained 64% of the total variance in the target behavior (paper submitted). The planning group had nothing to add.

Literature search showed that following behavioral factors were related to physicians not reacting appropriately in palliative care communication: lack of knowledge about palliative care[9,10]; negative attitudes towards palliative care and the important role they can play in communication about palliative care[11–14]; low perceived behavioral control[15,16]; and the perceived social norm[11,14]. The planning group also identified lack of knowledge about the personal situation of the patient; lack of knowledge about palliative care possibilities (palliative care services, contact details, etc.); lack of communication skills; and lack of consistent communication between the various physicians involved in the care for the patient as factors causing inappropriate response to patient's concerns and questions about palliative care.

Step 2 Performance objectives, behavioral factors and change objectives

While defining the patient target behavior, there was a heavy discussion about whether the patient starting the conversation about palliative care with their physician should explicitly mention the words palliative care or not. People with cancer starting a conversation about palliative care with their physician was defined as 1) starting to use the words palliative care either verbally or by showing palliative care documentation in a conversation with the treating physician or 2) starting to use alternative words that cannot be interpreted very differently (e.g. comfort care) in a conversation with the treating physician. Palliative care refers to both generalist and specialist palliative care. The patient target behavior definition assumes that physicians are able to recognize these cues and link them to palliative care, which emphasized the importance of targeting the physicians as well. For starting a conversation about palliative care with the physician following performance objectives were formulated by the planning group:

- PO1: The person with cancer thinks actively about what he/she finds important, what his/her wishes and needs are and what this could mean for his/her care (current vs future situations)
- PO2: The person with cancer informs him-/herself about what palliative care means
- PO3: The person with cancer signals that he/she could benefit from palliative care or identifies (future) circumstances in which he/she could possibly benefit from palliative care OR the person with cancer determines that he/she is currently not wanting/never wants to receive palliative care
- PO4: The person with cancer considers whether he/she wants to discuss palliative care and/or his/her palliative care wishes with a confidant (e.g. partner, family, friend, fellow sufferer, nurse, social worker, onco-coach…)
- PO5: The person with cancer is thinking about starting a conversation about palliative care with his/her physician him-/herself
- PO6: The person with cancer prepares him-/herself to start a conversation about palliative care with his/her physician and makes an appointment if necessary (e.g. goes through general instructions, thinks about how to start the conversation, about what they want to discuss, if

he/she wants to bring someone along, how to react if physician does not understand him/her very well…)
- PO7: The person with cancer starts a conversation about palliative care with his/her physician.

Based on the previous qualitative[4] and quantitative study by the researchers and after checking with the planning group, following behavioral factors were selected: knowledge about palliative care, knowledge about the target behavior, attitude towards palliative care, general attitude towards the behavior (e.g. important, relevant, timely), perceived benefits, perceived disadvantages, perceived barriers, perceived behavioral control and perceived social norm in their partner/family/friends and physician. Despite of knowledge about palliative care and the behavior and attitude towards palliative care not being significantly related to the target behavior (Chapter 5) and thus not being the most important factors, it was decided with the planning group to add them to the targeting factors as well. The planning group confirmed that people with incurable cancer lacked knowledge about palliative care and the behavior. They also confirmed that that most of people with incurable cancer held a negative attitude towards palliative care because of the association with terminal care. The planning group was convinced that these factors had to be changed first, before other factors can be changed. The planning group emphasized the importance of targeting these factors with the behavioral intervention.

Physicians reacting appropriately to people with cancer starting a conversation about palliative care was defined as taking minimal time to at least find out how the question or concern of the patient raised and how the patient feels about it. For reacting appropriately following performance objectives were formulated by the planning group:

- PO1: The physician informs him-/herself about all palliative care possibilities, more specifically in the care for people suffering from cancer
- PO2: The physician further develops his/her communication skills with regard to a conversation about palliative care started by the patient
- PO3: The physician shows non-verbally to the patient and other important people around them that difficult topics such as palliative care can and may be discussed (e.g. by showing a positive attitude towards palliative care)
- PO4: The physician acknowledges that the person with cancer wants to start a conversation about palliative care
- PO5: The physician frees up minimal time and helps the patient e.g. the physician adopts an empathetic attitude, listens actively and explores what the patient means

- PO6: The physician examines the individual expectations, wishes and needs with regard to palliative care, on a physical, psychological, social and spiritual level
- PO7: If necessary, the physician provides clear and honest information about the health situation and possibilities of care support, including palliative care, for both patient and family
- PO8: The physician asks if the patient would like the conversation to be recorded, if things should be written on paper or if something needs to be printed out
- PO9: The physician ensures that this conversation is followed up (he/she schedules a follow-up conversation or provides correct referral).

Literature search showed that following behavioral factors were related to physicians reacting appropriately in palliative care communication (mainly the same as those related to the risk behavior in physicians): knowledge about palliative care and the patients' palliative care needs[11], positive attitude towards palliative care[12,13,17] and the target behavior[18,19], perceived social norm in patients, their families and colleagues[15,16] and perceived behavioral control (+ barriers and skills)[11,14,20]. Most were confirmed by the planning group, with exception of the perceived social norm. There was disagreement about the importance of the perceived social norm in colleagues. After some discussion, the planning group agreed that although the role of the perceived social norm in colleagues was rather limited, it was important to target it during the intervention (e.g. by involving a role model with whom physicians can identify themselves). Time constraints, lack of knowledge about palliative care information and possibilities, and lack of skills were stressed by the professional carers within the planning group.

In a next step, our multidisciplinary research team formulated change objectives (see Supplementary files 1 and 2, in Dutch).

Step 3 Methods and Practical Applications

To help people with cancer in starting a conversation about palliative care with their physician, the planning group selected five applications: a short introduction movie, poster, flyer, theme pen and website. To support physicians in reacting appropriately, the planning group selected three applications: a poster, online training and conversation card. An overview of these practical applications, behavioral factors targeted and the theoretical methods covered can be found in **Table 1**.

Table 1. Overview of the practical applications selected and the theoretical methods covered

Practical application	**Content**	**Behavioral factor targeted**	**Theoretical methods covered**[3]
Component (1) for people with cancer			
Short introduction movie	Introduces the intervention (materials), the importance of communication about palliative care; and includes illustrations	Knowledge, attitude, perceived behavioral control, perceived and social norm	Advance organizers; using imagery; information about others' approval; information (processing); arguments; persuasive communication; elaboration; scenario-based risk information; elaboration; belief selection; modeling; mobilizing social support; conscious regulation of impulsive stereotyping and prejudice; planning coping responses
Poster	Gives an overview of the intervention (materials), the importance; includes positive statements about palliative care		
Flyer with question and conversation cards	Description of palliative care; highlights importance of patient empowerment and target behavior; demonstrates how to perform the behavior; illustrates important others' opinions; and lists information sites. The flyer contains three cards: 1) the question card to identify one's needs and wishes, 2) the quiz card to test one's knowledge, and 3) the conversation card to prepare one to start a conversation about palliative care (what, when, who, how…).		
Theme pen with rolling paper	Contains an image of the intervention logo as well as of a QR-code and link to the website		
Website	Gives a digital overview of all the materials: https://mijnzorgmijnstem.wixsite.com/testproject.		
Component (2) for physicians			
Poster	Highlights intervention and practical information	Knowledge, attitude, perceived behavioral control, perceived social norm	Information (processing); elaboration; belief selection; shifting perspective; verbal persuasion; tailoring information; arguments; advance organizers; consciousness raising; providing opportunities for social comparison; environmental reevaluation; information about other's approval; modeling; active learning; goal setting; coping responses; implementation intentions; modeling
Online training	Three modules: 1) general information, 2) communication about sensitive topics such as palliative care and 3) how to respond appropriately to patients starting a conversation about palliative care. Theory is alternated with exercises		
Conversation card	Step-by-step plan to respond appropriately and information for contacting palliative care experts		

Step 4 Preliminary intervention materials

The first and second session resulted in the slogan ‘My care my voice’ (‘Mijn zorg mijn stem’ in Dutch) (see **Figure 2**).

Figure 2. My care my voice logo

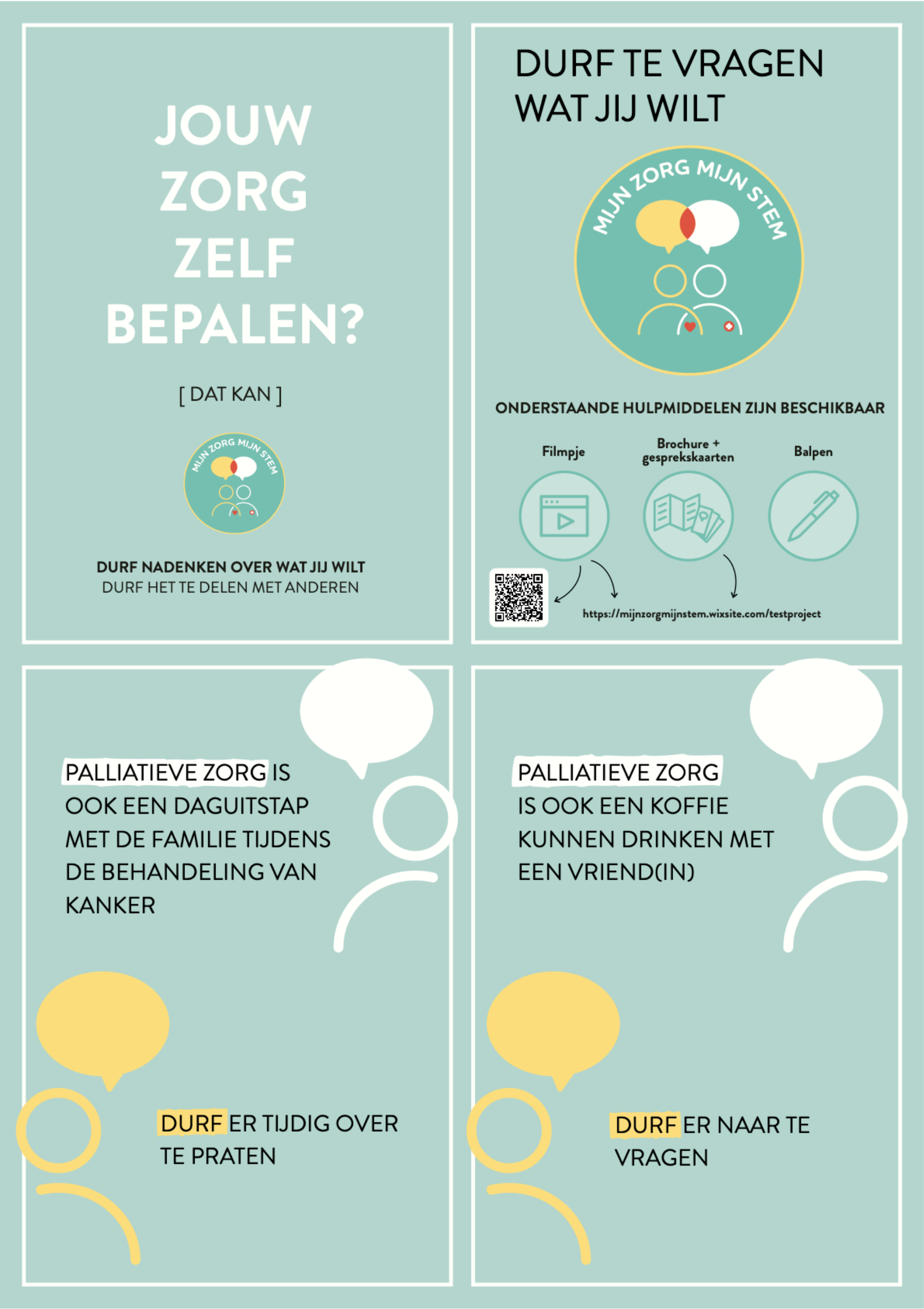
It was important that the slogan appealed to everyone and emphasized the role of patients in care decisions. The planning group chose soft pastel colors. Green symbolizes hope and has a strong emotional correspondence with safety.

The intervention consisted of two components: 1) focused on the patient and 2) focused on the physicians. The intervention will last three months. First, the physicians will be exposed to the posters and will have the time to follow the online training (which introduces the conversation card) (1 month). Following this time period, the people with cancer will be exposed to the introduction movie, poster, flyer, pen and website (2 months – based on the average consultation time). The researcher designed drafts of the intervention materials based on the practical applications (see **Table 1**). The planning group’ feedback was mainly related to the structure and the wording of the flyer. It was opted for a careful introduction of the word palliative care and clear lay language. After session three, all materials developed were agreed up the planning group. All materials are in Dutch.

An overview of the materials to change people with cancer their behavior can be found on the website developed: https://mijnzorgmijnstem.wixsite.com/test. Images are illustrated below.

Introduction movie for people with incurable cancer

Poster for people with incurable cancer



JOUW
ZORG
ZELF
BEPALEN?

[DAT KAN]

MIJN ZORG MIJN STEM

DURF NADENKEN OVER WAT JIJ WILT
DURF HET TE DELEN MET ANDEREN

DURF TE VRAGEN
WAT JIJ WILT

MIJN ZORG MIJN STEM

ONDERSTAANDE HULPMIDDELEN ZIJN BESCHIKBAAR

Filmpje
Brochure + gesprekskaarten
Balpen

https://mijnzorgmijnstem.wixsite.com/testproject

PALLIATIEVE ZORG IS
OOK EEN DAGUITSTAP
MET DE FAMILIE TIJDENS
DE BEHANDELING VAN
KANKER

DURF ER TIJDIG OVER
TE PRATEN

PALLIATIEVE ZORG
IS OOK EEN KOFFIE
KUNNEN DRINKEN MET
EEN VRIEND(IN)

DURF ER NAAR TE
VRAGEN

Flyer for people with incurable cancer

"Bij palliatieve zorg dacht ik aan oudere mensen, mensen die doodgaan. Ik ben over palliatieve zorg beginnen lezen, en weet nu dat het niet gelijk is aan doodgaan. Door erover te praten met de arts weet je waar je aan toe bent en kan je beslissingen nemen voor jezelf"

(patiënt, 65 jaar, longkanker)

"Op een gegeven moment kon ik de zorg voor mijn man niet meer alleen aan. Ik moest toen zelf op zoek naar informatie over palliatieve zorg omdat het ziekenhuis niet over een palliatieve eenheid beschikte. Was er tijdig gesproken over palliatieve zorg, dan was de invulling van de zorg anders geweest. Mijn man zou meer geschikte zorg gekregen hebben en ik zou minder belasting en stress ervaren hebben"

(echtgenote en mantelzorger, 69 jaar)

"De patiënt kan zelf beslissen welke zorg hij of zij nodig heeft. Als arts kan je hier de nodige ondersteuning bieden: een open communicatie helpt om de behoeften van de patiënt te horen en zo goed als mogelijk te vervullen. Dit geeft de patiënt wat extra gemoedsrust"

(huisarts, 33 jaar)

DURF

Vragen?

mijnzorgmijnstem@ugent.be

Meer informatie?

- Kom Op Tegen Kanker:
  https://www.komoptegenkanker.be
  https://www.allesoverkanker.be/palliatievezorg
  0800 35 445
- Federatie Palliatieve Zorg Vlaanderen:
  https://www.palliatief.be
  02 255 30 40
- LevensEinde InformatieForum:
  https://leif.be/palliatieve-zorg
  078 15 11 55
- Video
  Waarom moet je blij zijn als je palliatieve zorgen krijgt?

Palliatieve zorg diensten?

- Palliatieve thuiszorg
  http://www.palliatieve.org/contact
- Gespecialiseerde zorg in voorzieningen zoals ziekenhuizen en dagcentra

fwo
VUB VRIJE UNIVERSITEIT BRUSSEL
UNIVERSITEIT GENT
UZ GENT
palliatieve zorg VLAANDEREN

JOUW
ZORG
ZELF
BEPALEN?

[DAT KAN]

MIJN ZORG MIJN STEM

DURF NADENKEN OVER WAT JIJ WILT
DURF HET TE DELEN MET ANDEREN

ZORG OP MAAT

Wat de beste zorg is voor u, is afhankelijk van uw medische situatie, **wensen en noden**, van **wat u zelf wilt en niet wilt**.

Het is belangrijk om dit **voor uzelf na te gaan**.

De **vragenkaart** kan u hierbij helpen

Uw kankerbehandeling is vooral gericht op uw ziekte of problemen als gevolg van de therapie. Er bestaat ook **een zorg die zich meer focust op uw totale persoon**; lichamelijk, psychisch, sociaal en spiritueel welzijn; **comfort en kwaliteit** van leven; uw familie en vrienden. Deze zorg wordt ook **palliatieve zorg** genoemd.

> *“Palliatieve zorg zorgt ervoor dat er altijd iemand is die een luisterend oor kan bieden”*

> *“Palliatieve zorg zorgt ervoor dat naasten even iets buitenshuis kunnen doen en op adem kunnen komen”*

Met de **test-mijn-kennis kaart** kan u uw kennis over palliatieve zorg testen

PALLIATIEVE ZORG

- Voor iedereen die ernstig ziek is en die noden heeft waaraan de standaardzorg niet tegemoet kan komen
- Op elk moment van het ziekteproces
- **Kan gelijktijdig met kankerbehandeling bedoeld om te genezen**
- Thuis
- In een zorginstelling zoals een ziekenhuis, woonzorgcentrum…
- **NIET ENKEL** voor mensen die op korte termijn kunnen overlijden

EEN GESPREK STARTEN

Het kan nuttig zijn om **tijdig te bespreken wat u wilt en niet wilt**. Ook u kan **een gesprek starten** over **palliatieve zorg** met **uw arts**. Dit gesprek hoeft niet onmiddellijk iets aan uw zorg te veranderen, en zal ook niets aan uw relatie met de arts veranderen.

Mogelijke voordelen

- Uw zorgwensen uitdrukken
- U gerustgesteld of opgelucht voelen
- U emotioneel ondersteund voelen
- Meer controle krijgen over uw zorg
- Meer zorg op maat ontvangen
- Meer comfortabel leven leiden

> *“Het is niet gemakkelijk, maar door er tijdig over te praten ben je beter voorbereid eens het écht nodig is”*

Hindernissen

Het is zeker niet uitzonderlijk indien u hindernissen zou ervaren zoals

- U op dit moment (te) goed voelen
- Het niet durven
- Stress en angst voelen: wat als er tijdsdruk is, ik emotioneel word, ik niet gehoord word, ik vragen vergeet te stellen of de verkregen informatie niet verwerkt krijg…

Mogelijke oplossingen

Dit gesprek is niet altijd gemakkelijk, ook niet voor uw arts. Een voorafgaand **gesprek met een vertrouwenspersoon** (partner, familielid, vriend(in)) **en een goede voorbereiding** (wat wil ik delen/vragen, met wie, wanneer, hoe…) kunnen u mogelijks helpen. Dit kan u vertrouwen geven en het gesprek vlotter laten verlopen.

De **gesprekskaart** kan helpen om u voor te bereiden

Vindt u het gesprek nu nog niet nodig? Voelt u zich nog niet klaar? Leg deze brochure aan de kant en geef het nog wat tijd..

Flyer for people with cancer – question card

VRAGENKAART

Hoe wilt u dat uw toekomst er uitziet?
Denk aan “als (bv. situatie erger wordt) … dan…”. *Het is oké om geen bijzondere (wensen) te hebben.*

1) De komende tijd wil ik deze dingen nog kunnen doen (*denk aan: werk, hobby’s, sport, familie, reis…*)

....

....

2) De komende tijd wil ik dat mijn behandeling ervoor zorgt dat… (*denk aan: ik me goed voel, ik zolang mogelijk leef, ik weinig belemmerd word door mijn ziekte…*)

....

....

3) De komende tijd wil ik dat mijn behandeling er niet toe leidt dat (*denk aan: ik veel tijd in het ziekenhuis doorbreng, ik zware bijwerkingen krijg, ik afhankelijk word van anderen…*)

....

....

MIJN NOTITIES

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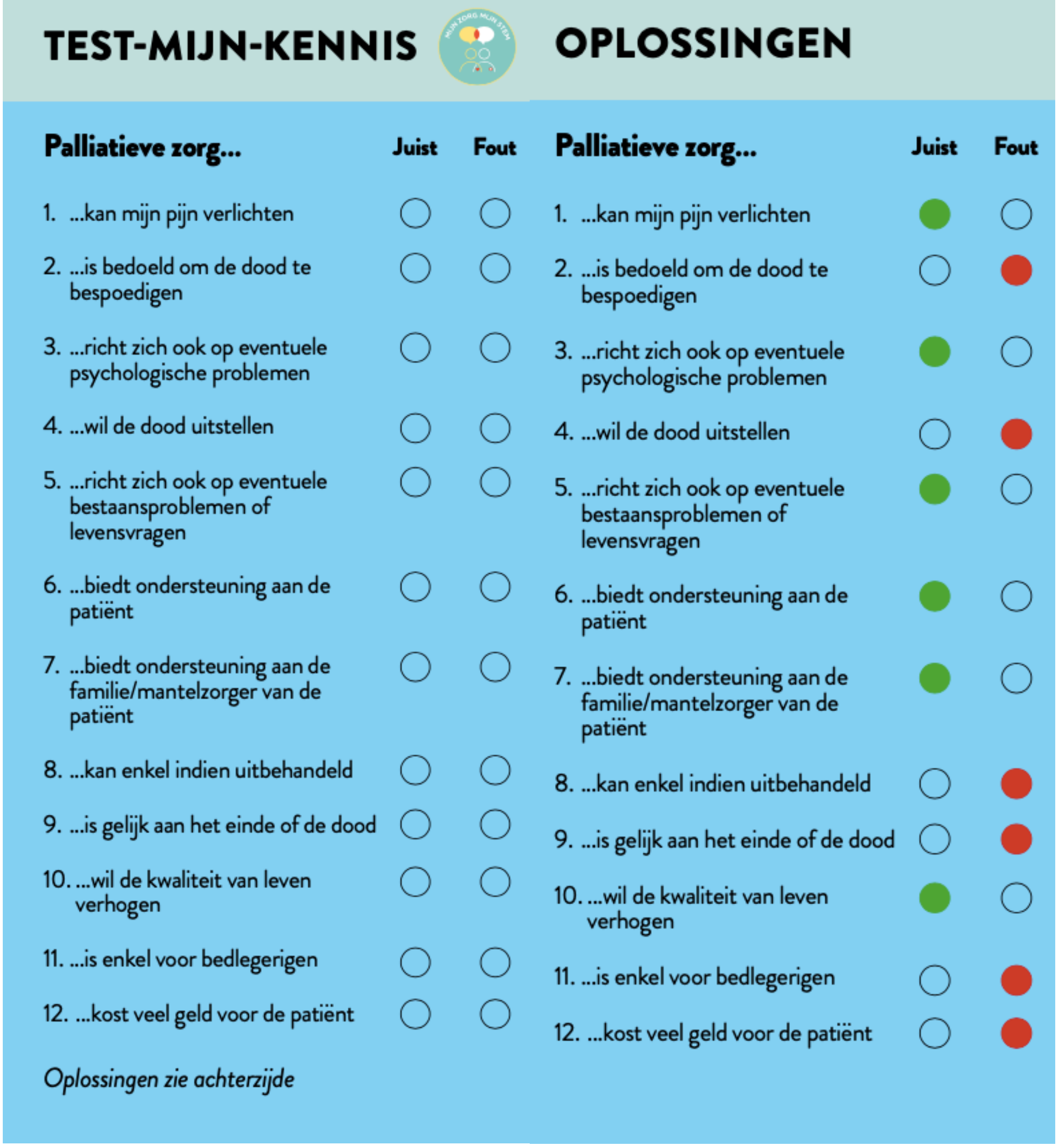
Flyer for people with cancer – palliative care knowledge card



TEST-MIJN-KENNIS

Palliatieve zorg...	**Juist**	**Fout**
1. ...kan mijn pijn verlichten	○	○
2. ...is bedoeld om de dood te bespoedigen	○	○
3. ...richt zich ook op eventuele psychologische problemen	○	○
4. ...wil de dood uitstellen	○	○
5. ...richt zich ook op eventuele bestaansproblemen of levensvragen	○	○
6. ...biedt ondersteuning aan de patiënt	○	○
7. ...biedt ondersteuning aan de familie/mantelzorger van de patiënt	○	○
8. ...kan enkel indien uitbehandeld	○	○
9. ...is gelijk aan het einde of de dood	○	○
10. ...wil de kwaliteit van leven verhogen	○	○
11. ...is enkel voor bedlegerigen	○	○
12. ...kost veel geld voor de patiënt	○	○

Oplossingen zie achterzijde

OPLOSSINGEN

Palliatieve zorg...	**Juist**	**Fout**
1. ...kan mijn pijn verlichten	●	○
2. ...is bedoeld om de dood te bespoedigen	○	●
3. ...richt zich ook op eventuele psychologische problemen	●	○
4. ...wil de dood uitstellen	○	●
5. ...richt zich ook op eventuele bestaansproblemen of levensvragen	●	○
6. ...biedt ondersteuning aan de patiënt	●	○
7. ...biedt ondersteuning aan de familie/mantelzorger van de patiënt	●	○
8. ...kan enkel indien uitbehandeld	○	●
9. ...is gelijk aan het einde of de dood	○	●
10. ...wil de kwaliteit van leven verhogen	●	○
11. ...is enkel voor bedlegerigen	○	●
12. ...kost veel geld voor de patiënt	○	●

Flyer for people with cancer – conversation card

GESPREKSKAART

Wat wil ik meedelen/vragen?

- Wat ik belangrijk vind, mijn wensen en noden, mijn bezorgdheden [nu of later]
- Situaties waarin palliatieve zorg mij zou kunnen helpen [nu of later]
- Hoe denken mijn naaste(n) of arts over palliatieve zorg voor mij? [nu of later]

Bv. Ik vind het belangrijk dat mijn familie ontlast wordt
Bv. Vind jij palliatieve zorg nodig voor mij?

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

Aan wie?

- Vertrouwenspersoon: partner, familielid, vriend, verpleegkundige, maatschappelijk werker...
- Arts: huisarts, oncoloog, andere specialist...

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

GESPREKSKAART

Wanneer?

- Tijdens thuisgesprek
- Tijdens consultatie
- Tijdens opname

……………………………………………………………………

……………………………………………………………………

Hoe?

- Op voorhand de arts op de hoogte brengen (bv. 'reden afspraak')
- Vragen aan iemand om mee te gaan op gesprek
- Neem de (ingevulde) vragenkaart, gesprekskaart, brochure...mee
- Neem eventueel balpen en papier of een geluidsrecorder/gsm mee

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

Zijn er voor mij persoonlijk nog hindernissen? Hoe ga ik hiermee om?

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

Theme pen for people with cancer

Below, an overview of the poster, screenshots from the online training and the conversation card to change the physicians' behavior can be found.

Poster to invite physicians for the online training

WEET JIJ WAT OOK NOG BELANGRIJK IS VOOR JOUW PATIËNT DIE KANKER HEEFT?

ONLINE VORMING

Personen met gemetastaseerde kanker hebben tijdens de behandeling nood aan persoonlijke en ondersteunende zorg. Als arts kan je **meer** bieden **dan** enkel die **medische zorg**. Als arts kan je een sleutelfiguur zijn in het voeren van tijdige gesprekken rond **palliatieve zorg**.

Het project 'Mijn zorg mijn stem' wilt artsen **begeleiden en ondersteunen bij het voeren van gesprekken over palliatieve zorg**. Het gaat om een **online vorming bestaande uit drie modules**. De volledige vorming duurt ongeveer 60 minuten, kan zelfstandig doorlopen worden en per module hernomen worden. Er wordt veel beeldmateriaal gebruikt (bv. videogetuigenissen van collega's, patiënten, mantelzorgers...). Theorie en (casus)oefeningen wisselen elkaar af. Er worden handvaten meegegeven voor de praktijk. Er wordt een gesprekskaart ter beschikking gesteld. In een groepsgesprek is het mogelijk om gedachten uit te wisselen met collega-artsen.

Module 1 (15')
Project 'Mijn zorg mijn stem' + palliatieve zorg (mogelijkheden) voor personen met kanker + sleutelrol arts

Module 2 (25')
Communicatie over gevoelige thema's zoals palliatieve zorg

Module 3 (20')
Als persoon met kanker zelf gesprek start over palliatieve zorg: hoe reageren?

Deelnemen?

Scan QR Code, meld vervolgens aan met UGent adres of registreer kort

Voor wie: artsen (huisartsen, oncologen, specialisten, artsen in opleiding...). Voorkennis palliatieve zorg is NIET nodig.

In samenwerking met Prof. dr. Luc Deliens, Dr. Lore Lapeire, Prof. dr. Peter Pype...

Deelname via QR code. Gratis registratie werd mede mogelijk gemaakt dankzij de steun en medewerking van het FWO, VUB, U(Z)Gent, Palliatieve Zorg Vlaanderen.
Vragen via mijnzorgmijnstem@ugent.be.

Accreditering werd aangevraagd bij het RIZIV

Online training for physicians: QR-code

Online training for physicians: some screenshots

Online Vorming Mijn Zorg Mijn Stem

Online vorming "Mijn Zorg Mijn Stem"

gepost door Jasper Coppens op 27 augustus 2021 11:27 • Bewerkt

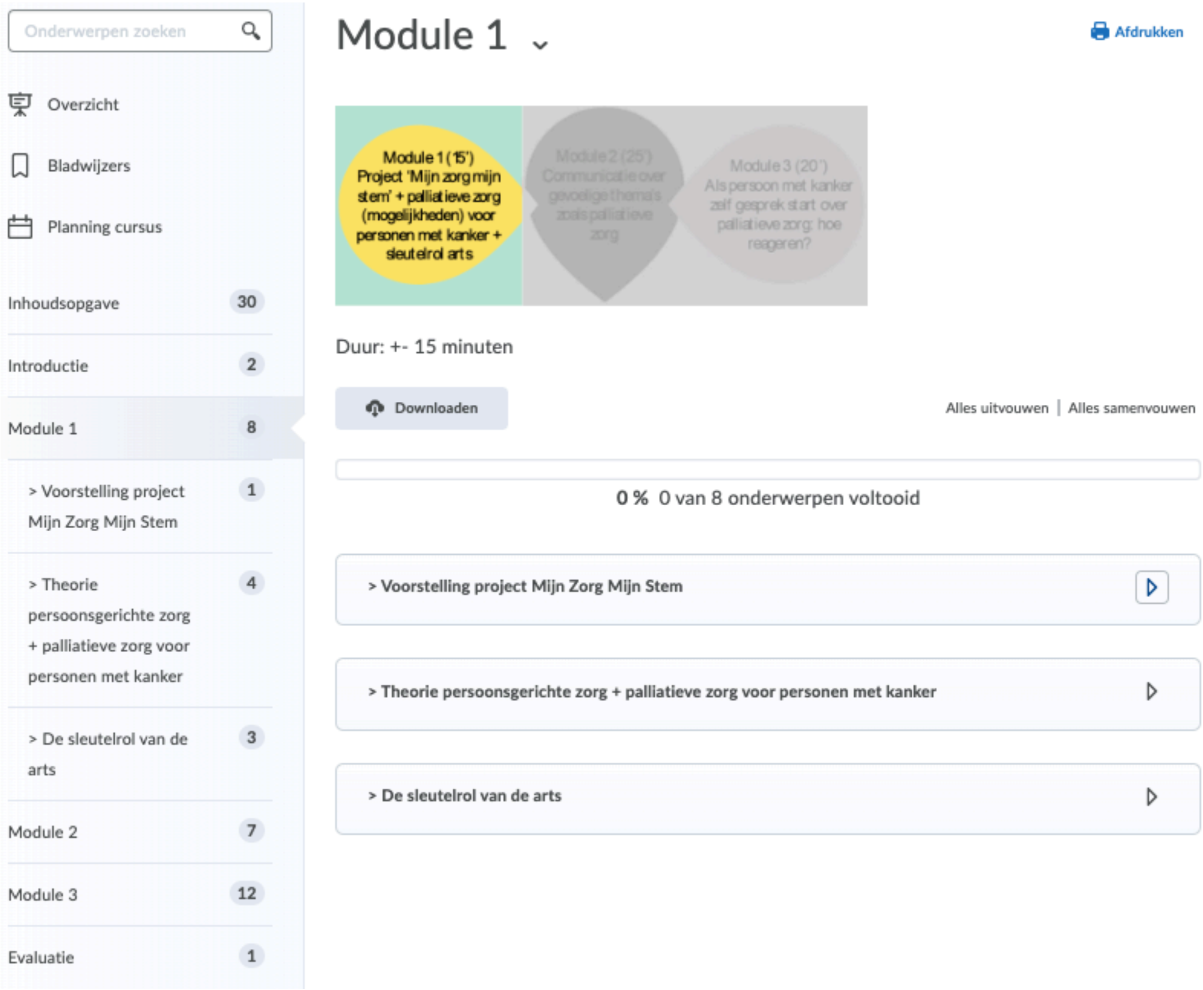
Welkom Anne-Lore op de online vorming "Mijn Zorg Mijn Stem" voor artsen (huisartsen, oncologen, specialisten, artsen in opleiding...).

Personen met gemetastaseerde kanker hebben tijdens de behandeling nood aan persoonlijke en ondersteunende zorg. Als arts kan je meer bieden dan enkel de medische zorg. Als arts is het belangrijk om zicht te krijgen op de leefwereld van de persoon met kanker. Als arts kan je een sleutelfiguur zijn in het voeren van tijdige gesprekken rond palliatieve zorg.

Het project "Mijn Zorg Mijn Stem" wilt u begeleiden en ondersteunen bij het voeren van gesprekken over palliatieve zorg. Theorie en oefeningen wisselen elkaar af. Er worden handvaten meegegeven die direct bruikbaar zijn in de praktijk.

De volledige vorming duurt ongeveer 60 minuten en kan per module hernomen worden. Om in aanmerking te komen voor de accreditering (< RIZIV) dient u alle drie de modules door te nemen.

Klik hier om naar de inhoud van de online vorming te gaan.



Module 1

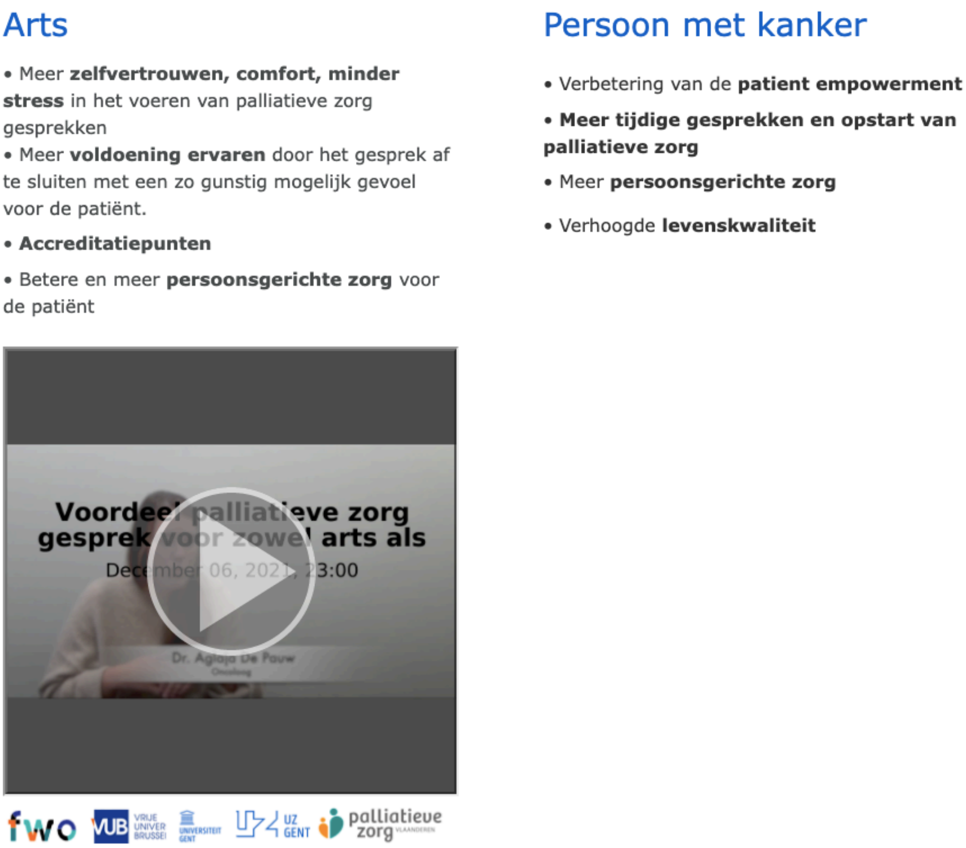
Duur: +- 15 minuten

0 % 0 van 8 onderwerpen voltooid

> Voorstelling project Mijn Zorg Mijn Stem

> Theorie persoonsgerichte zorg + palliatieve zorg voor personen met kanker

> De sleutelrol van de arts



Arts

- Meer **zelfvertrouwen, comfort, minder stress** in het voeren van palliatieve zorg gesprekken
- Meer **voldoening ervaren** door het gesprek af te sluiten met een zo gunstig mogelijk gevoel voor de patiënt.
- **Accreditatiepunten**
- Betere en meer **persoonsgerichte zorg** voor de patiënt

Persoon met kanker

- Verbetering van de **patient empowerment**
- **Meer tijdige gesprekken en opstart van palliatieve zorg**
- Meer **persoonsgerichte zorg**
- Verhoogde **levenskwaliteit**

Communicatie over moeilijke thema's zoals palliatieve zorg(mogelijkheden): algemene communicatieve vaardigheden

Communicatieve aandachtspunten
Webpagina

Presentatie met aan het woord expert in communicatie: toelichting bij communicatieve aandachtspunten
Externe cursustool

Videogetuigenis huisarts: "Leg uw eigen agenda naast die van de patiënt"
Externe cursustool

Getuigenissen patiënt en mantelzorger
Externe cursustool

Identificatie eigen barrières bij gesprek over palliatieve zorg
Test

Casusoefening
Test

Casusoefening module 3

Schatting Lengte: 2:00:00 Anne-Lore Scherrens: Poging 1

Vraag 1 (1 punt)

Een persoon die lijdt aan ongeneeslijke longkanker krijg palliatieve chemotherapie, en gaat ervan uit dat deze behandeling nog kan genezen en zijn/haar leven verlengt. Deze persoon geeft tijdens een consultatie aan dat hij recentelijk iets gelezen heeft over palliatieve zorg toen hij/zij in de wachtzaal zat. Hij/zij geeft aan dat hij niet helemaal begrijpt hoe het van toepassing kan zijn voor hem/haar. U heef slechts 2 minuten de tijd. Hoe kan u hier als arts binnen die 2 minuten tijd gepast op reageren?

○ De hoop niet wegnemen en antwoorden dat palliatieve zorg op dit moment inderdaad nog niet van toepassing is voor hem/haar. Antwoorden dat als het van toepassing kan zijn, dat u hem/haar hier dan wel over zal aanspreken.

○ Aangeven dat het goed is dat men over palliatieve zorg begint tegen u. Antwoorden dat verpleegkundigen gespecialiseerd in palliatieve zorg hen indien gewenst bijkomende informatie kunnen geven.

○ Aangeven dat het goed is dat men over palliatieve zorg begint tegen u. Antwoorden dat verpleegkundigen gespecialiseerd in palliatieve zorg hen indien gewenst bijkomende informatie kunnen geven. Bijkomend aangeven dat jullie er de volgende keer samen op terugkeren indien gewenst: wat kan voor hem/haar van toepassing zijn, nu onmiddellijk of later?

○ Dieper ingaan op wat de patiënt weet en hoe hij/zij zich hierbij voelt. Bijvoorbeeld: Wat heb je ervan onthouden? Wat voelde je toen erover las? Heb je het gevoel dat het van toepassing kan zijn voor u? Wil jij hier graag meer over weten, zo ja, wat dan precies?

Conversation card for physicians

MIJN ZORG MIJN STEM

EEN GESPREK OVER PALLIATIEVE ZORG

Met een kankerpatiënt

STEL U AANSPREEKBAAR OP

- Straal uit dat er over moeilijke onderwerpen zoals palliatieve zorg kan en mag gepraat worden
- Neem een open, actieve luisterhouding aan
- Gebruik steeds duidelijke en eenvoudige taal, geen vakjargon

ZORG VOOR EEN GEPASTE EERSTE REACTIE

Ga voor uzelf na of u tijd heeft en/of u zich voldoende comfortabel voelt - indien niet, plan het gesprek in de nabije toekomst in of volg verder op

Verbaal

- Ga na of u de vraag of de uiting van bezorgdheid van de patiënt goed begrepen heeft
- Exploreer hoe de vraag of bezorgdheid tot stand is gekomen
- Erken de link met palliatieve zorg
- Toon begrip en geef aan dat het goed is dat men hierover nadenkt

Non-verbaal

- Reageer empathisch
- Zorg voor een rustige omgeving en zoveel mogelijk privacy
- Ga zitten, spreek rustig, maak oogcontact
- Geef de patiënt tijd en ruimte om na te denken en emoties te uiten, laat eventueel gepaste stiltes vallen
- Richt u ook op de naaste(n) van de patiënt

VRAAG NAAR WENSEN EN NODEN

- Vraag naar wat de patiënt denkt, voelt en weet
- Vraag naar wat hij/zij belangrijk vindt, hij/zij wenst
  - Wat vind je belangrijk in het leven? Wat wil je zeker kunnen behouden in de toekomst?
  - Wat verwacht je van de zorgverlening tav jezelf?
  - Wat verwacht je van de zorgverlening tav je naaste(n)?
- Let op non-verbale reacties
- Erken emoties die naar boven komen en durf benoemen
- Let op interactie tussen patiënt en naast(en)

INFORMEER OVER GEZONDHEIDSSITUATIE EN PALLIATIEVE ZORG

- Vraag aan de patiënt welke informatie hij/zij wenst
  - Geef correcte, duidelijke en eerlijke informatie
  - Beschrijf de diagnose, prognose…
- Informeer over de behandelmogelijkheden en palliatieve zorg
- Moedig de patiënt aan om bijkomende vragen te stellen
- Vraag of de patiënt het gesprek graag opneemt of graag iets op papier heeft

VOLG OP

- Volg het tempo en ritme van de patiënt: vraag na of hij/zij er nog eens over wilt praten
- Geef een duidelijk beeld van de te verwachten stappen
- Keer er indien nodig bij geschikt moment zelf op terug
- Mits toestemming contacteer andere zorgverleners rond de patiënt

fwo

VUB VRIJE UNIVERSITEIT BRUSSEL

UNIVERSITEIT GENT

UZ GENT

palliatieve zorg VLAANDEREN

PALLIATIEVE ZORG DIENSTEN

Per regio

WEST-VLAANDEREN

- Vzw palliatieve zorgen **Westhoek–Oostende**
  051 51 98 00 - info@palliatieve.be - www.pzwvl.be
- Heidehuis vzw - palliatieve zorg thuis (**Noord-West-Vlaanderen**)
  050 40 61 52 - info@heidehuis.be – www.heidehuis.be
- Palliatieve thuiszorgequipe De Mantel vzw (**Midden-West-Vlaanderen**)
  051 24 83 85 - info@demantel.net – www.pzwvl.be
- Netwerk palliatieve zorg **Zuid-West-Vlaanderen** vzw
  056 63 69 50 - palnet.zwvl@yucom.be – www.pzwvl.be

OOST-VLAANDEREN

- Palliatieve thuiszorg **Gent-Eeklo** vzw
  09 218 94 01 - npz.genteeklo@palliatieve.org - www.palliatieve.org
- Netwerk Levenseinde VZW (**Oudenaarde**)
  055 20 74 00 - info@netwerklevenseinde.be - www.netwerklevenseinde.be
- Netwerk palliatieve zorg **Waasland** vzw
  03 776 29 97 - info@npzw.be - www.palliatieve.org
- Palliatieve thuiszorg **Aalst-Ninove** vzw en palliatieve thuiszorg arrondissement **Dendermonde** vzw
  053 21 40 94 - info@npzadn.be - www.palliatieve.org

ANTWERPEN

- Palliatief netwerk arrondissement **Mechelen** vzw - PNM
  015 41 33 31 – info@pnmechelen.be - www.palliatief-netwerk-mechelen.be
- Palliatieve hulpverlening **Antwerpen** vzw - PHA
  03 265 25 31 - pha@uantwerpen.be - www.pha.be
- Coda-thuiszorg vzw + netwerk palliatieve zorg **Noorderkempen**
  03 432 78 40 - thuiszorg@coda.care - www.coda.care
- Ispahan vzw - palliatieve zorgen **Kempen** + palliatief netwerk arrondissement **Turnhout** vzw
  014 42 66 02 - ispahan@ispahan.be - www.ispahan.be

LIMBURG

- Palliatieve **Limburgse** ondersteuningsequipe van listel (pallion) vzw
  011 81 94 74 - info@pallion.be - www.pallion.be

VLAAMS-BRABANT

- Omega vzw (**Halle-Vilvoorde**)
  02 456 82 03 - info@vzwomega.be - www.vzwomega.be
- Palliatief netwerk arrondissement **Leuven** - PANAL vzw
  016 23 91 01 - vragen@panal.be - www.panal.be
- Forum palliatieve zorg (**Brussel-Halle-Vilvoorde**)
  02 456 82 07 - info@forumpalliatievezorg.be - www.forumpalliatievezorg.be

Er is ook gespecialiseerde zorg binnen enkele ziekenhuizen en dagcentra

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Chapter 6 Supplementary file 1. Matrix with changes objectives related to the patients' target behavior (*In Dutch – not translated yet*)

	Kennis [over pz + gedrag]	**Algemene attitude [over pz + gedrag]**	**Uitkomstverwachtingen (voor- en nadelen)**	**Gedragscontrole + redenen niet (barrières)**	**Subjectieve norm**
PO1 De persoon met kanker denkt na wat hij/zij belangrijk vindt, wat zijn/haar wensen en noden zijn en wat dit kan betekenen voor zijn/haar zorg (heden vs toekomstige stiuaties)	K1.1: legt uit welke programmaterialen ter ondersteuning er beschikbaar zijn K1.2: legt uit dat hun wensen en noden de zorg mee kunnen bepalen	A1.1 De persoon met kanker geeft aan open te staan om na te denken over eigen (toekomstige) situatie (gezondheidstoestand, zorgplan, wensen, noden...)			
PO2 De persoon met kanker informeert zich over de inhoud van palliatieve zorg: wat is palliatieve zorg, wat kan palliatieve zorg zijn, wat is het niet	K2.1: legt uit welke programmaterialen ter ondersteuning er beschikbaar zijn K2.2: legt uit dat er naast de oncologische zorg nog andere zorgopties zijn	A2.1: drukt uit dat het belangrijk is om zich tijdig te informeren over palliatieve zorg	UV2.1: geeft aan dat er meer voordelen verbonden zijn aan zich informeren over palliatieve zorg dan nadelen	G2.1: drukt het vertrouwen uit dat men zich over palliatieve zorg kan informeren, desondanks men zich goed voelt, het taboe, men in eerste instantie geen interesse heeft in palliatieve zorg	SN2.1: erkent dat andere personen met kanker zich ook informeren over palliatieve zorg SN2.2: erkent dat belangrijke anderen (familie, vrienden, de arts…) het belangrijk en nodig vinden dat hij/zij zich informeert over palliatieve zorg
PO3 De persoon met kanker identificeert dat hij/zij baat kan hebben bij palliatieve zorg of identificeert (toekomstige) omstandigheden waarin hij/zij mogelijks baat kan hebben bij palliatieve zorg of maakt voor zichzelf uit dat hij/zij momenteel/nooit palliatieve zorg wenst te krijgen	K3.1: legt uit wat palliatieve zorg is K3.2: legt uit wat zijn of haar zorgwensen en -noden zijn K3.3: somt de (mogelijke) voordelen op van pallatieve zorg voor zichzelf	A3.1: drukt uit dat het belangrijk is om zorg te krijgen in overeenstemming met eigen wensen/noden A3.2: geeft aan dat palliatieve zorg (toekomstig) belangrijk en relevant kan zijn	UV3.1: geeft aan dat palliatieve zorg voor zichzelf meer voordelen biedt dan nadelen	G3.1: drukt zelfzekerheid uit dat men toekomstige situaties kan identificeren waarin men palliatieve zorg zou kunnen nodig hebben, desondanks men zich nu goed voelt	SN3.1: erkent een positieve attitude van belangrijke anderen (familie, vrienden, de arts…) ten opzichte van palliatieve zorg

	Kennis [over pz + gedrag]	**Algemene attitude [over pz + gedrag]**	**Uitkomstverwachtingen (voor- en nadelen)**	**Gedragscontrole + redenen niet (barrières)**	**Subjectieve norm**
PO4 De persoon met kanker denkt na of hij/zij palliatieve zorg wenst te bespreken met een vertrouwenspersoon (partner, familie, vriend, lotgenoot, verpleegkundige, maatschappelijk werker, arts…)	K4.1: somt op met wie men over palliatieve zorg kan praten K4.2: somt de voordelen op van het praten over palliatieve zorg met een vertrouwenspersoon	A4.1: geeft aan dat het belangrijk is om tijdig over palliatieve zorg te praten met een vertrouwd iemand	UV4.1: geeft aan dat er meer voordelen (zorgwensen uitdrukken, zich gerustgesteld voelen) zijn verbonden aan het bespreken van palliatieve zorg met iemand anders dan nadelen (stress, angst)	G4.1: drukt het vertrouwen uit dat men over palliatieve zorg kan praten met iemand anders, desondanks de stress die hiermee gepaard gaat, de ander negatieve gevoelens heeft tov palliatieve zorg, de weerstand bij de ander om over palliatieve zorg te praten	SN4.1: erkent een positieve attitude van belangrijke anderen (familie, vrienden, vpk…) ten opzichte van een gesprek over palliatieve zorg met hem/haar
PO5 De persoon met kanker denkt na om zelf over palliatieve zorg te starten tegen zijn/haar (huis)arts	K5.1: legt uit dat hij/zij als patiënt zelf een gesprek over palliatieve zorg kan starten tegen de arts K5.2: legt uit welke arts hij/zij geschikt acht als gesprekspartner om zelf een gesprek over palliatieve zorg tegen te starten, bij wie hij zich comfortabel voelt K5.3: somt de voordelen op van zelf een gesprek starten over palliatieve zorg tegen de arts	A5.1: drukt positieve gevoelens uit tov patiënteneducatie en – participatie A5.2: drukt uit dat het belangrijk is om tijdig zelf een gesprek over palliatieve zorg te starten met de (huis)arts	UV5.1: geeft aan dat zelf een gesprek starten over palliatieve zorg tegen de arts meer voordelen (bv. meer participatie, meer controle te hebben, zich gerustgesteld te voelen…) biedt dan nadelen (bv vooruit lopen op de zaken)	G5.1: drukt het vertrouwen uit dat men in staat is om zelf een gesprek over palliatieve zorg te starten met de artsen, desondanks men zich goed voelt, stress ervaart, angst voelt, men het gevoel heeft dat de arts weinig tijd heeft, het taboe, …	SN5.1: erkent dat andere personen met kanker ook nadenken palliatieve zorg gesprekken SN5.2: erkent dat belangrijke anderen (familie, vrienden, de arts…) het belangrijk en nodig vinden dat hij/zij een gesprek over palliatieve zorg start met de arts SN5.3: erkent dat de (huis)arts openstaat voor het thema palliatieve zorg

	Kennis [over pz + gedrag]	**Algemene attitude [over pz + gedrag]**	**Uitkomstverwachtingen (voor- en nadelen)**	**Gedragscontrole + redenen niet (barrières)**	**Subjectieve norm**
PO6 De persoon met kanker bereidt zich praktisch voor om zelf een gesprek te starten over palliatieve zorg tegen zijn/haar (huis)arts en maakt indien nodig een afspraak met de arts (hoe wilt men het gesprek starten, wat wilt men zeker aanhalen (welke vragen wilt hij/zij zeker stellen, welke bezordgheden wilt men zeker uiten, welke wensen wilt hij/zeker uiten), wenst hij/zij iemand mee te nemen op gesprek, formuleren waar de (huis)arts hem/haar mee kan helpen, hoe reageren als iets niet begrepen wordt door hij/zij…)	K6.1: somt op wat de voordelen zijn van een goede voorbereiding op het zelf starten van een gesprek over palliatieve zorg met de arts K6.2: legt uit wanneer een geschikt moment zou zijn om dit gesprek over palliatieve zorg zelf te starten met de (huis)arts (bv. tijdens volgende consulatie, tijdens volgende ziekenhuisopname, bij nieuwe diagnosestelling…) K6.3: somt op welke situaties het voor zichzelf moeilijk zouden maken/welke factoren zouden helpen om effectief zelf een gesprek over palliatieve zorg te starten met de arts	A6.1 Drukt positieve gevoelens uit ten opzichte van zich goed voor te bereiden, instructies te doorlopen, om zelf een gesprek over palliatieve zorg te starten met de arts	UV6.1: drukt uit dat een goede voorbereiding zal leiden tot een beter en vlotter gesprek over palliatieve zorg met de arts UV6.2: drukt uit dat er meer voordelen (zekerheid, verwachtingskader) zijn dan nadelen (tijd) van de voorbereiding om zelf een gesprek over palliatieve zorg te starten tegen de arts	G6.1: drukt het vertrouwen uit over zichzelf goed voor te kunnen bereiden om zelf een gesprek over palliatieve zorg te starten, ondanks men het moeilijk vindt, dit hem/haar stress of angst bezorgt… G6.2 demonstreert hoe men moeilijke omstandigheden (bv. emotionele stress voorafgaand aan consultatie, afwezigheid mantelzorger, arts die niet niet wil ingaan op pt die over pz begint…) facilitatoren (bv. wat kan hen persoonlijk helpen) kan identificeren om zelf een gesprek over palliatieve zorg te starten met de arts G6.3: drukt uit hoe men zal omgaan met deze moeilijke situaties en hoe men de faciliterende situaties zelf zal creeëren	SN6.1: erkent dat andere personen met kanker zich ook voorbereiden op het zelf starten van een gesprek over palliatieve zorg met de arts SN6.2: erkent dat artsen het gemakkelijker vinden om te communiceren met iemand die goed is voorbereid

	Kennis [over pz + gedrag]	**Algemene attitude [over pz + gedrag]**	**Uitkomstverwachtingen (voor- en nadelen)**	**Gedragscontrole + redenen niet (barrières)**	**Subjectieve norm**
PO7 De persoon met kanker start effectief een gesprek over palliatieve zorg met zijn/haar (huis)arts	K7.1: beschrijft hoe hij/zij het gesprek over palliatieve zorg tegen de arts zelf zal starten		UV7.1: drukt uit dat er meer voordelen (zorgwensen kunnen uitdrukken, informatie krijgen over palliatieve zorg, zich gerustgesteld voelen, de arts kent zijn/haar zorgwensen…) zijn dan nadelen (stress en angst voelen, vooruitlopen op de zaken…) bij het effectief zelf starten van een gesprek over palliatieve zorg met zijn/haar arts	G7.1: drukt het vertrouwen uit dat men in staat is om effectief een gesprek over palliatieve zorg met zijn/haar arts te starten, desondanks men zich goed voelt	SN7.1: erkent dat de arts minimaal tijd zal vrijmaken SN7.2: erkent dat belangrijke anderen (familie, vrienden) het belangrijk vinden dat men effectief een gesprek over palliatieve zorg met zijn/haar arts start

Chapter 6 Supplementary file 2. Matrix with changes objectives related to the physicians' target behavior (*In Dutch – not translated yet*)

	Kennis en attitude	**Subjectieve norm**	**Eigen-effectiviteit**
PO1: de arts informeert zich over alle mogelijkheden binnen palliatieve zorg, en meer specifiek bij personen met kanker	K1.1 legt uit hoe (kanalen?) men zich beter kan informeren over palliatieve zorg mogelijkheden A1.1. drukt uit dat het nuttig is om eigen expertise tav palliatieve zorg te vergroten om nog betere zorg te kunnen verlenen A1.2. drukt uit dat hij/zij een belangrijke rol speelt in tijdige opstart van palliatieve zorg voor personen met kanker	SN.1.1 erkent dat collega's zich ook informeren over palliatieve zorg bij personen met kanker SN1.2 erkent dat personen met kanker en mantelzorgers het belangrijk vinden dat de arts over palliatieve ozrg expertise beschikt	EE1.1 drukt zichzelf in staat om zich te informeren over palliatieve zorg gesprekken, desondanks de werkdruk, gebrek aan tijd…
PO2: de arts ontwikkelt zijn/haar communicatieve vaardigheden verder tav een gesprek over palliatieve zorg gestart door de patiënt	K2.1 legt uit wat palliatieve zorg is K2.2 legt uit hoe hij/zij communicatieve vaardigheden mbt palliatieve zorg kan aanscherpen K2.3 legt uit dat ook personen met kanker zelf een gesprek over palliatieve zorg kunnen starten tegen hem/haar A2.1 drukt uit wat de voordelen zijn van het hebben van communicatieve vaardigheden in gesprek over palliatieve zorg gestart door de persoon met kanker A2.2. drukt uit dat het belangrijk en nuttig is om tijdig gesprekken te voeren over palliatieve zorg met personen met kanker	SN.2.1 erkent dat collega's ook hun communicatieve vaardigheden verder aanscherpen tav gesprekken over palliatieve zorg met personen met kanker SN2.2. erkent hoe fijn het is voor de persoon met kanker en zijn/haar mantelzorger als de arts een goede communicatie hanteert mbt het thema palliatieve zorg	EE2.1 Drukt uit vertrouwen te hebben om te groeien in gesprekken over palliatieve zorg met personen met kanker, desondands het gevoelige thema, het ontwikkelen van communicatieve vaardigheden een proces is die tijd en geduld kost EE2.2 Demonstreert hoe men communicatieve vaardigheden kan toepassen in gesprek met personen met kanker over palliatieve zorg, desondanks weinig zelfvertrouwen, de stress, het oncomfortabel gevoel…

	Kennis en attitude	**Subjectieve norm**	**Eigen-effectiviteit**
PO3: de arts straalt non-verbaal (cf houding) tov de patiënt en zijn/haar omgeving uit dat er over moeilijke thema's als palliatieve zorg kan en mag gepraat worden	K3.1 legt uit wat (een) palliatieve zorg (gesprek) kan betekenen voor personen met een ongeneeslijke kanker K3.2 Beschrijft hoe duidelijk gemaakt kan worden aan de persoon met kanker dat over moeilijke onderwerpen kan gesproken worden A3.1 drukt uit dat palliatieve zorg belangrijk en nuttig is A3.2. drukt uit dat het belangrijk en nuttig is om tijdig gesprekken te voeren over palliatieve zorg met personen met kanker A3.3 drukt uit dat ook personen met kanker zelf een gesprek over palliatieve zorg kunnen starten tegen hem/haar als hij/zij dit wenst	SN3.1 erkent dat er moeilijkheden eigen aan de arts (cf te weinig tijd, perceptie niet open te staan voor palliatieve zorg) kunnen zijn voor de patiënt om een gesprek over palliatieve zorg te starten met hem/haar SN3.2 erkent dat het voor de persoon met kanker een gerustelling en hulp kan zijn als men weet dat de arts opstaat voor de persoon met kanker die gesprek over palliatieve zorg begint	
PO4: de arts erkent dat de persoon met kanker een gesprek wenst te starten over palliatieve zorg	K2.1 legt uit wat palliatieve zorg is K2.3 legt uit dat ook personen met kanker zelf een gesprek over palliatieve zorg kunnen starten tegen hem/haar K4.2 somt signalen op van personen met kanker die erop kunnen wijzen dat men een gesprek over palliatieve zorg wenst te starten A4.1 drukt uit ervoor open te staan dat de persoon met kanker initiatief neemt in het starten van een gesprek over palliatieve zorg		EE4.1: drukt uit zichzelf in staat te zien om de achterliggende reden van bepaalde uitspraken/vragen van de pt te achterhalen en te linken aan het referentiekader palliatieve zorg

	Kennis en attitude	**Subjectieve norm**	**Eigen-effectiviteit**
PO5: de arts maakt minimale tijd vrij en helpt de patiënt verder: stelt zich empathisch op, luistert actief en exploreert wat de patiënt ermee bedoelt	K5.1 legt uit wat actief luisteren is A5.1 drukt uit dat het belangrijk is dat er minimale tijd wordt vrij gemaakt voor een persoon met kanker die de moed vindt om zelf een gesprek over palliatieve zorg voor hem/haar te beginnen A5.2 drukt uit dat het belangrijk is om de persoon met kanker goed te begrijpen, een vertrouwensband (verder) op te bouwen… A5.3 drukt uit dat gesprekken over palliatieve zorg tot zijn/haar kerntaken toebehoren	SN5.1 erkent dat de persoon met kanker zich goed begrepen wilt voelen	EE5.1 Drukt uit vertrouwen te hebben in zichzelf om actief te luisteren desondanks tijdsdruk tijdens een contactmoment, mogelijks snel afgeleid te zijn tijdens een contactmoment (bv. inkomende telefoon) EE5.2 Drukt uit vertrouwen te hebben in zichzelf om empathisch te kunnen reageren desondanks tijdsdruk tijdens een contactmoment, mogelijks snel afgeleid te zijn tijdens een contactmoment (bv. inkomende telefoon)
PO6: de arts gaat na wat de individuele verwachtingen, wensen en noden zijn met betrekking tot palliatieve zorg, op fysiek, psychisch, sociaal en spiritueel vlak	K6.1 legt uit hoe men naar de individuele palliatieve zorg wensen en noden kan vragen A6.1 drukt uit dat het belangrijk is om de persoon met kanker goed te begrijpen, het contact te verbeteren… A6.2 drukt uit dat goede zorg overeenstemt met individuele wensen en noden en niet enkel is wat hij/zij denkt dat nodig en goed is	SN6.1 erkent dat personen met kanker zich als individu met zijn/haar eigenheden benaderd wilt voelen	EE6.1 Drukt uit vertrouwen te hebben in zichzelf om op een goede manier naar wensen en noden van personen met kanker te vragen desondanks tijdsdruk tijdens een contactmoment, mogelijks snel afgeleid te zijn tijdens een contactmoment (bv. inkomende telefoon), hevige emotionele reacties bij de persoon met kanker
PO7: de arts geeft indien nodig duidelijke en eerlijke informatie over gezondheidsituatie en de mogelijke ondersteuningsvormen, waaronder palliatieve zorg, voor zowel patiënt als mantelzorger	K2.1 legt uit wat palliatieve zorg is K7.1 legt uit hoe zich op voorhand te informeren over de gezondheidstoestand, zorgnoden, mogelijks nut van palliatieve zorg voor specifiek die pt… K7.2 beschrijft welke informatie de persoon met kanker wel/niet wilt		EE7.1 Drukt uit in staat te zijn om extra informatie over de gezondheidstoestand en palliatieve zorg te geven in lekentaal, desondanks men zich er niet geheel comfortabel bij voelt en men niet steeds goed voorbereid is

	Kennis en attitude	Subjectieve norm	Eigen-effectiviteit
	A.7.1 drukt uit dat extra informatie geven meer voordelen (bv. hoger bewustzijn zorgnoden, betere inschatting 'ernst' van de gezondheidstoestand, meer kennis over palliatieve zorg) biedt dan nadelen (bv. angst, stress bij de pt)		
PO8: de arts biedt de mogelijkheid aan tot registratie van het gesprek (vraagt of de patiënt het gesprek graag opneemt – opname, of er zaken op papier geschreven moeten worden – notities of als er iets afgedrukt moet worden	K8.1 Somt de mogelijkheden rond registratie van het gesprek op A8.1 Erkent dat personen met kanker steeds veel (nieuwe) informatie moeten verwerken, er niet steeds in slagen om alles onmiddellijk te begrijpen en dat een verslag een houvast kan betekenen voor zowel patiënt als mantelzorger		
PO9: de arts zorgt ervoor dat dit gesprek wordt opgevolgd (vervolggesprek inplannen of correct doorverwijzen)	K9.1 beschrijft hoe hij/zij zelf een extra contactmoment kan vastleggen of wie hij/zij daarvoor kan contacteren K9.2 somt op waar en bij wie er expertise aanwezig is omtrent het thema palliatieve zorg A9.1 drukt uit het relevant te vinden dat een eerste gesprek een aanzet is voor een reeks van gesprekken die volgen A9.2 drukt uit het belangrijk te vinden dat er voldoende tijd wordt vrijgemaakt voor een gesprek over palliatieve zorg (wensen en noden) A5.3 drukt uit dat gesprekken over palliatieve zorg en het doorverwijzen tot zijn/haar kerntaken toebehoren.		

PART IV

USING HEALTH BEHAVIOR THEORIES TO IDENTIFY AND UNDERSTAND FAMILY CARERS' BEHAVIORS AND ITS FACTORS TO PALLIATIVE CARE UTILIZATION BY PEOPLE WITH INCURABLE CANCER

Chapter 7

PALLIATIVE CARE UTILIZATION: A QUALITATIVE INTERVIEW STUDY ON FAMILY CARERS' BEHAVIORS AND DETERMINANTS

Scherrens A, Beernaert K, Magerat L, Deliens L, Deforche B* & J Cohen*. (2021). Palliative care utilisation: family carers' behaviors and determinants: a qualitative interview study. *BMJ Supportive and Palliative Care.*

[Published]

Abstract

Objectives - Most research on starting palliative care focuses on the role of healthcare services and professional carers. However, patients and their family carers may also play a role. Especially opportunities for starting palliative care might exist among family carers. This study focused on family carers by identifying their behaviors and underlying determinants that might contribute to starting palliative care.

Methods - A qualitative study with sixteen family carers of deceased persons who used palliative care was conducted using semi-structured, face-to-face interviews. Constant comparison analysis was used to identify groups of behaviors that influenced starting palliative care and related determinants. The behavioral determinants were matched with concepts in existing behavioral theories. A preliminary behavioral model was developed.

Results - Most reported behaviors regarding starting palliative care were related to communicating with the seriously ill person, other family members and professional carers; seeking information and helping the seriously ill person process information from professional carers; and organizing and coordinating care. Determinants facilitating and hindering these behaviors included awareness (e.g. of poor health); knowledge (e.g. concerning palliative care); attitudes (e.g. negative connotations of palliative care); and social influences (e.g. important others' opinions about palliative care).

Conclusions - This study identified relevant family carers' behaviors and related determinants that can contribute to starting palliative care. As these determinants are changeable, the palliative care behavioral model that resulted from this study can serve as a basis for the development of behavioral interventions aiming at supporting family carers in performing behaviors that might contribute to starting palliative care.

Keywords

Qualitative research, family caregivers, palliative care, terminal care, behavior, behavioral theory

7.1 Introduction

A possible approach that could improve the quality of life of people with cancer is palliative care[1–3]. However, palliative care is often started late or not at all[1,4,5], resulting in poorer quality of life and quality of care[4,5]. This might be an indication that patients do not receive the care they need or receive it too late. The timing of palliative care should be consistent with patient's preferences, needs and values. Studies focusing on timely palliative care frequently do so from a health service or professional carer perspective[2,6]. Results showed that professional carers display relevant behaviors that contribute to timely palliative care[7]. In contrast, it seems that perspectives of patients and their family carers are studied to a limited extent, especially those of family carers. It is nevertheless clear from previous literature that, next to those for professional carers and patients, also specific barriers, and hence opportunities for starting palliative care might exist among family carers. Family carers share the experience of illness with the patient with whom they have a close relationship[8] and have the potential to play an important role in caring for them[9,10], e.g. taking medical end-of-life decisions[11]. Therefore the family carer also displays important behaviors, such as providing information and communicating the seriously ill person's wishes[12–14] about starting palliative care. Many family carers are willing to fill in this supporting role in palliative care, but are unprepared to do so[15].

A health promotion approach, i.e. enabling people to make informed choices and adopt behaviors supporting the use of palliative care consistent with patients' needs and wishes, might be appropriate to help family carers in filling in the supporting role and displaying behaviors that can contribute to starting palliative care. Behavioral theories are often used within healthcare, providing a meaningful framework to understand people's behavior better by identifying underlying determinants and to change behaviors by targeting changeable determinants[16–18]. Previous research has shown that interventions using behavioral theories are more successful and effective than those lacking a theoretical base[19]. The Theory of Planned Behavior is the most widely used theory, positing that behaviors are immediately determined by intentions, determined in turn by attitude, subjective norms and perceived behavioral control[16]. Several studies have identified critical behaviors affecting the start of palliative care[12–14] and influencing factors (e.g. attitude towards palliative care)[20], but a recent review showed that the use of behavioral theories in palliative care research is limited: no studies so far have used a behavioral theory to investigate the underlying determinants influencing family carers' behaviors in palliative care[7].

The aim of this study was 1) to identify relevant behaviors of family carers that they perceive as influencing the seriously ill persons starting to use palliative care 2) to better understand these behaviors by identifying factors perceived by family carers as influencing their behaviors contributing to the start of palliative care and 3) to develop a preliminary behavioral model that provides an overview of factors explaining why family carers do or do not display behaviors that might contribute to seriously ill people starting to use palliative care. This behavioral model will be used to design and evaluate effective interventions aiming at supporting family carers in performing these behaviors[21].

7.2 Methods

7.2.1 Study design

A qualitative study was conducted using semi-structured, in-depth, face-to-face interviews with family carers. Qualitative research was deemed most suitable for this explorative study because, in the absence of previous research, we were primarily interested in gaining better understanding of family carers' behaviors and related determinants[22]. Individual interviews at the participant's preferred place were chosen because of the sensitive topic and the possibility to get more in-depth information about their beliefs and experiences. The outcome of this study, the seriously ill starting to use palliative care, refers to receiving generalist palliative care (i.e. palliative care provided by the regular professional carers) and/or specialized palliative care services (i.e. services dedicated to palliative care, whose professional carers are specially trained in palliative care)[23]. The criteria for reporting qualitative research in the COREQ guidelines were used[24]. The study was conducted in Flanders, Belgium and approved by the ethics committee of Ghent University Hospital (registration number B670201731675).

7.2.2 Participants

Inclusion criteria for family carers were: aged 18 or older; an important supporting role in caring for a seriously ill family member/friend (18 or older) who used generalist and/or specialized palliative care and died in the 18 months before the interview[8]; able to participate in an interview in Dutch.

7.2.3 Recruitment

Family carers were recruited firstly through purposefully selected key informants. These were professional carers (e.g. Life End Information Forum physicians[25] or palliative care nurses) who frequently dealt with family carers for seriously ill people using palliative care. Twenty-four key informants were invited by email and phone; thirteen participated. The participating key informants explained the study to eligible family carers or spread the call. The key informants gave the contact details of those willing to participate to AS (a nurse; MSc in Health Education and Health Promotion) and LM (an occupational therapist; MSc in Health Education and Health Promotion). However, it was difficult to reach enough family carers, possibly because of the professional carers' high workload. Therefore, other family carers were recruited through the researchers' personal networks. Interested parties without overly close ties to the researchers were approached. Seven eligible family carers declined participation because of the sensitive theme.

7.2.4 Data collection

A topic guide was developed by a multidisciplinary team including experienced researchers in end-of-life care and health promotion (**Appendix 6**). The interviewer briefly explained palliative care to the participants as a holistic approach addressing physical, psychological, social and spiritual needs and as care that can be pursued by both regular professional carers (e.g. primary carers, oncologists, geriatricians, nurses) or carers specially trained in palliative care simultaneously with curative and lifeprolonging care. Prompts were used to stimulate reflection and responses concerning palliative care. These prompts were based on the determinants of the Theory of Planned Behavior with an opportunity to identify other determinants not included in this theory. A questionnaire collected socio-demographic data about the family carer and seriously ill person. Data was collected between March and December 2017 by LM.

7.2.5 Data analysis

Data collection and analyses were undertaken in a cyclical, iterative process. Interview recordings were transcribed verbatim. The data was structured with Nvivo 11 and constant comparison analysis was used for data analysis. Two researchers independently and openly coded the interviews. Coding of the behaviors and related determinants was partially inductive and deductive. Firstly, inductive open coding searched for behaviors relating to starting palliative care use and influencing facilitating and hindering factors. Data saturation would be established if no new family carers' behaviors and related factors emerged from the interviews. We achieved data saturation after 12 interviews and performed two more interviews for confirmation. Then identified behaviors were grouped in categories of similar behaviors and determinants were deductively matched with concepts in behavioral theories (e.g. 'attitude' defined by the Theory of Planned Behavior). These concepts were defined in **Table 1.** The coders compared and debated their code nodes and trees. Where coding discrepancies occurred, consensus was sought. The final model developed was agreed upon by all authors.

Table 1. Definitions of the concepts of behavioral theories

Concept	**Definition**
Awareness and risk perception	Need recognition or problem appraisal (e.g. health condition, care needs etc.). To be aware of a risk for themselves[16].
Knowledge	The understanding one has of a key concept or the behavior[21].
Attitude	The individual's positive or negative evaluation of performing the particular behavior of interest[16,21] Attitude consists of behavioral beliefs: outcome beliefs (outcome of the behavior, for example benefits or disadvantages) and evaluation beliefs (how important are these outcomes)[16].
Perceived behavioral control (self-efficacy)	Subjective probability that a person is capable of executing a certain course of action (ability to perform the behavior and to overcome barriers)[16,26] Perceived behavioral control consists of control beliefs[16].
Anticipated regret and moral duty	Anticipated regret: Having people imagine how they would feel after they behaved in a risky way contrary to their own intentions or after they did not perform a given behavior. Personal moral duty: People's judgments as to whether they themselves think should or should not perform a certain behavior[16].
Perceived social norm and social influence	Perceived social expectations. Beliefs about whether key people (e.g. family or friends) approve or disapprove of the behavior (normative beliefs) and motivation to behave in a way that gains their approval (motivation to comply)[16]. The social support/pressure to perform or not to perform a given behavior[27]

All definitions are mainly based on Eldredge et al. (2016). Planning Health Promotion Programs: An Intervention Mapping Approach.

7.3 Results

Fourteen interviews with 16 family carers of deceased persons who used palliative care were conducted. Twelve interviews took place individually and two were taken with married couples. Patients suffered from cancer (n=10), dementia (n=1), lung disease (n=1) or general fragility (n=2). All family carers reported that the start of palliative care was rather late, i.e. close to the patient's death. They estimated the period when palliative family care was provided as ranging from three months to six days before death. Characteristics of family carers and seriously ill persons are presented in **Table 2**.

Table 2. Characteristics of family carers and seriously ill persons

Characteristics of participating family carers (N=16)	Total (N =)
Number of interviewed family carers[a]	16
Number of interviews[a]	14
Sex	
Male	8
Female	8
Relationship between family carer and deceased person	
Partner	4
Child	2
Parent-in-law	1
Parent	7
Aunt	1
Friend	1
Care intensity of family care (number of days per week)[b]	
One	0
One to two[b]	2
Two to three[b]	2
Seven	12
Care intensity of family care (number of hours per week)	
Less than ten	2
Ten to twenty	0
More than twenty	14
Characteristics of the seriously ill person (N=14)	
Disease of the seriously ill person	
Cancer	10
Dementia	1
Lung disease	1
General fragility	2
Place of death of the seriously person	
Home	3
Hospital	3
Palliative care unit	7
Care home (residential home, nursing home…)	1
Mean age (SD) (yrs.) of the seriously ill person	70.5 (16.4)
Minimum age	37
Maximum age	91

[a] 12 interviews took place individually. Two interviews were taken with married couples, namely a mother and father; and a son and daughter-in-law.

[b] Three choices of answer: one, seven (daily) or others (free to fill in)

7.3.1 Family carers' behaviors that may have contributed to the start of palliative care

Family carers mentioned three behaviors that may have contributed to the start of palliative care: communicating about palliative care (i.e. initiating the theme of palliative care in a conversation), searching for information and helping the seriously ill person process medical information from professional carers and organizing and coordinating care.

Communicating behaviors

Each family carer identified communication as an important behavior. Participants reported contacting professional carers about palliative care services or making appointments to discuss palliative care, having conversations about palliative care with the seriously ill person, other family carers, professional carers and palliative care experts, asking professional carers questions about palliative care such as ‘how does palliative care work?’ and asking the seriously ill person about their wishes and needs. Multiple family carers initiated such conversations about palliative care.

> All of us children got together in February to discuss palliative care for the first time. So that was actually the beginning of ‘ok, how are we going to handle this… the end is coming’. Yes, how are we going to do this, because we all have work too? (Daughter, who cared for her father (cancer; † 84 years))

> At that point (hospital admission due to serious health deterioration) I said to the physician: 'Is it too early, or should we start thinking about palliative care now?’ (Son, who cared for his father (cancer; † 80 years).

Seeking information and helping the seriously ill person process medical information from professional carers

On the one hand, respondents stated that they had to seek information independently about palliative care possibilities and meaningful documents about starting palliative care use. On the other hand, they had to help the seriously ill person process medical information from professional carers, accompanying them to consultations and visiting a palliative care unit for a first introduction to the unit and its care services.

> There was never really concrete communication about the options of palliative care or euthanasia. In the end, we had to look for these options ourselves […] You suddenly get the news that curative treatments are no longer effective and then all of a sudden you have to process that news and say that ... we do not really know, and then yes, you have to find information and to look into what has to be done soon to be a little bit prepared. (Daughter, who cared for her mother (died of cancer; † 59 years))

Organizing and coordinating behaviors

Family carers reported that organizing and coordinating behaviors contributed to palliative care: starting the intake procedure for a stay at a palliative centre; filling in forms (e.g. for official palliative care status to receive increased healthcare reimbursements); giving permission (i.e. for the intake procedure to stay at a palliative centre, for palliative sedation); and passing care to other family members etc.

> […] all of a sudden you have to take care... you have to fill in all sorts of papers, you have to ... what do you have to do, request health insurance, request support for palliative care... Actually, we got everything sorted out with the health insurance fund fairly quickly. So, the first thing I did was go to the health insurance fund... I explained the situation and those people actually... reserved a bed and … (Mother and father, who cared for their daughter (died of cancer, † 37 years))

7.3.2 Determinants of family carers' behaviors surrounding the start of palliative care

Family carers reported different determinants facilitating and hindering the aforementioned behaviors surrounding palliative care. **Table 3** shows all identified determinants (individual and perceived environmental determinants) related to these family carers' behaviors. The description below focuses on the determinants reported in the literature as most easily changed in behavioral interventions[21].

Awareness and risk perception (individual level)

Family carers mentioned awareness of the poor health condition, palliative care needs and end-of-life wishes as a facilitating factor for communicating and information seeking behaviors. The respondents became aware of the seriously ill person's worsening health, e.g. as curative treatments had to be discontinued and other treatments (e.g. palliative sedation) had to be started. This made the family carers aware of the need for palliative care. They also reported limited awareness of the poor health condition (e.g. where the health condition worsened quickly) and the need for palliative care as factors hindering the search for information about palliative care and communication with professional carers about palliative care.

Awareness of an increasing need for care led to a first conversation about palliative care between the family members:

> Uh, we were prepared for a long time. For him to die, because his illness lasted for at least 15 years. So we knew that the end was coming. But you never want to believe it. That is always very difficult. But I felt that his health condition was deteriorating. Every time he climbed the stairs. He couldn't do this anymore, he couldn't do that anymore, at the end he could hardly walk anymore. He could no longer

> get out of his chair. I had to help him with everything. (Wife, who cared for her husband (died of general fragility; † 81 years))

Limited awareness of the poor health condition hindered communication with professionals about palliative care:

> At a palliative care unit you can discuss everything, of course. All the questions you have can be answered. But not before [refers to another hospital unit]. Yes, there is a brochure about palliative care that you have to read. You read it five times and think 'what is that?' 'How long does it take?' And, listen, I knew my mom was getting worse. That was very clear. But still you don't realize how bad it really is, or how suddenly it all can get much worse. I didn't understand that. (Daughter, who cared for her mother (cancer; † 77 years))

Knowledge (individual level)

Lack of knowledge about palliative care possibilities due to inadequate communication and information (e.g. no information at layman's level and no available contact details for a palliative care centre) are indicated by the respondents as having had a negative influence on all behaviors contributing to palliative care. Lack of knowledge as a hindering determinant was demonstrated by participants who believed palliative care would incur a high cost, whereas the costs of palliative care in Belgium are very limited compared to the costs of acute care.

> They assume that people have information. Maybe they assume that we have information about palliative care, but I don't think we do. No one in our family is medically trained...How should we know? So I said: maybe it is up to me, it is up to us. (Daughter, who cared for her mother (cancer; 59 years))

The respondents indicated that having knowledge about prognosis and palliative care possibilities – partly thanks to timely, clear and sufficient communication from the professional carers – enabled to inform themselves further about palliative care, start discussions about palliative care and make practical arrangements.

> The explanation from the oncologist helped me. He actually gave us good information. And yes, I had already heard about it [refers to palliative care] and thought why not. (Daughter, who cared for her mother (general fragility; † 72 years))

Attitude (individual level)

Respondents who found palliative care important and those who associated it with better quality of life, greater comfort etc. were more likely to communicate about palliative care.

> I think it is better to start palliative care early than too late. Because palliative care remains a taboo... (Son, who cared for his father. (died of cancer; † 80 years))

Other participants reported palliative care as stigma with a negative connotation. They associated palliative care with terminal care, death, giving up etc., which hindered communication with professional carers about (the start of) palliative care.

> We asked the oncologist to not transfer her to the palliative care unit. We asked him [the oncologist] to keep her at the oncology unit, because that is not the death unit. (Husband, who cared for his wife (died of cancer; † 41 years)).

Wanting to do ‘everything’ (e.g. wanting to participate in medical studies after being told that other medical treatments were no longer working) before ‘giving up’ was another hindering attitude.

> It may also be that these medical studies do nothing at all, and we will see how long it will take. But we have participated in all studies, because we wanted to have done everything before giving up on our mother. (Daughter, who cared for her mother (died of cancer; † 59 years))

Perceived behavioral control (individual level)

Participants identified (lack of) skills and ability to provide care as influencing. Experiencing a care burden which was too high for them and recognizing the need for professional care support was indicated as facilitating. Feeling one could handle the care and considering their own care as sufficient was mentioned as hindering.

> I did not know any more, I had no other choice. Those bedsores had to be treated, and it was no longer feasible for me to do at home. There was only one solution, palliative care. (husband, who cared for his wife (died of dementia; †84 years))

Social norm and influence (perceived environmental level)

The participants mentioned influential factors linked to other people involved in the care for the seriously ill person (e.g. other family members, professional carers) and the seriously ill himself. Other family carers agreeing that the seriously ill person needed palliative care was one of the facilitating factors. Participants also experienced that a good relationship with both their treating professional carers and the seriously ill encouraged them to contribute to the start of palliative care. Support from important others or initiatives by the oncologist or social worker (e.g. starting a conversation about palliative care, seeking admission to a palliative care unit/centre) had a positive effect on family carers' behaviors, and especially on starting conversations about palliative care.

> Support from each other is very important. Being on the same wavelength with your partner. It is not easy to deal with it in the same way, but with us this was the case (Mother and father, who cared for their daughter (cancer; † 37 years))

Negative social norms were that participants perceived that other family members or the seriously ill had different preferences (e.g. persistent hopes or wanted other treatment options). Perceived lack of support from professional carers did also negatively affect the family carers' behaviors. This was related to limited information about palliative care from and perceived lack of communication between the professional carers.

> If I had been an only child, I think palliative care might have been started two weeks earlier. If my brother had been an only child, palliative care would not have been started at all. (Son, who cared for his father (cancer, † 80 years))

The family carers also reported the following determinants as influencing behaviors regarding the start of palliative care: anticipated regret and moral duty, such as stimulating the start of palliative care to prevent regret afterwards or feelings of guilt; and other perceived environmental determinants (e.g. availability of palliative care).

Table 3. Overview of the determinants of family carers' behaviors related to starting to use palliative care

Determinant	Facilitating factors	Hindering factors
Individual level		
Awareness and risk perception	- Sufficient awareness (e.g. of the poor health condition; of the palliative process; of a palliative centre as the place offering the best care etc.) - The acceptance that the situation is getting worse and that additional help is needed - Awareness that palliative sedation is needed for quiet breathing - Awareness that they can no longer provide the care that is needed	- Limited awareness (e.g. of the palliative situation) - Wrong estimate of the prognosis (wrongly thinking that there is still a lot of time left)
Knowledge	- To know people who are specialized in palliative care - To know palliative services (e.g. a palliative centre) - To have background knowledge about palliative care - To have experience with palliative care support	- No knowledge about palliative care - No knowledge about who is qualified to help and support them - Financial costs associated with palliative care
Attitude	- To associate palliative care with qualitative care, the best care, more qualitative days, more comfort etc. - To be convinced palliative care is important - To be convinced palliative care must be started in good time - To be convinced there is no other choice - To be convinced quality of life is important - To be prepared for the palliative care process - To accept the end of life - To consider the onset of palliative care as expert care support that offers reassurance - Not wanting to unnecessarily prolong life	- Connotation of palliative care: association of palliative care with death, the last step, life-shortening etc. (e.g. procrastination because of association of palliative care with the last step) - To perceive palliative care as a taboo - The feeling that start using palliative care is 'not done' - To be reluctant to use palliative care - To be convinced that the timely onset of palliative care has no added value - To be convinced it is not necessary as family carer to be involved in care - To want to protect oneself from the medical aspect of care

Determinant	Facilitating factors	Hindering factors
Individual level		
Perceived behavioral control	- To feel able to care intensively for someone you know well	- Not being able to pass on control of care - Not being able to communicate about palliative care - Not being able to propose other care options in conversation with a physician - Not being able to interrupt daily functioning - Not being able to process bad news or seek more information due to experiencing a lot of emotions
Anticipated regret and moral duty	- To prevent regret afterwards (e.g. regret not having done everything that one could do for high quality end-of-life care) - To avoid a death battle - Believe that the seriously ill person had already sufficient problems - Duty and wish to choose all the best for the seriously ill person	- Feeling of guilt by start using palliative care - To exhaust all treatment options to prolong the lifetime before giving up on the seriously ill person
Perceived environmental level		
Social norm and social influence		
Social norm	- Other family members indicate that the seriously ill person needs palliative care	- Other family members have different attitudes or wishes (e.g. they do not want to accept start using palliative care, they want other therapies such as immunotherapy, they maintain hope regarding lifespan etc.)

Determinant	**Facilitating factors**	**Hindering factors**
Perceived environmental level		
Social influence	- Good connection with professional carers (e.g. oncologist, nurses, family physician) - Good connection with the seriously ill person - The conviction that the family physician is making an effort to understand the individual - Family physician or oncologist acknowledges pain and needs - Support from important others (e.g. support from other family members by making time; from professional carers such as the family physician and home care by starting-up palliative care after receiving signals from the family carer etc.) - Initiative by the oncologist or social assistant to start using palliative care (i.e. to start a conversation about palliative care, to increase the pain medication, to look for admission to a palliative care unit/palliative care centre) - Conversation between the seriously ill person and a professional carer - Continuous follow-up of the health status and situation by the residential care centre	- Absence of a good relationship with the treating (family) physician - The (family) physician does not share the bad feeling of the family carer (e.g. recognition of bad condition due to certain symptoms) - Limited contact with professional carers (e.g. oncologist, family physician etc.) - Little support from the professional carers (e.g. professional carers from the hospital unit do not make many arrangements when it comes to palliative care to support the family carer) - Kind of (false) hope created by the professional carers - The professional carer wants to hear the seriously ill person' wishes himself, but cannot come home to visit quickly or the seriously ill person is not awake enough to have a conversation - Concern of the family physician that increasing pain medication will be life-shortening - The oncologist promotes immunotherapy at the expense of palliative care - Struggles, tension and disagreement between the different family members
	- Timely communication from the professional carer (e.g. soon after diagnosis) about the care and the possibilities - Clear communication from the professional carer about the prognosis and the possibilities (e.g. the physician clearly says what the situation is) - Sufficient communication about palliative care from the professional carer (e.g. by conversation or by leaflet)	- Another family carer thinks that the seriously ill person is still coming home for recovery - Difference in wishes between the family carer and the seriously ill person - Generally inadequate communication from the professional carers and between the family carer and the seriously ill person - Limited information (about the prognosis, about palliative care)

Determinant Perceived environmental level	Facilitating factors	Hindering factors
Physical environment	- Easy transfer from the oncological unit to the palliative unit	- No free place in palliative day centre
Related to the seriously ill person	- Diagnosis with an incurable disease - Increasing need for care (e.g. because of increasing pain, loss of all kinds of functions, no longer being able to get out of bed, poorer general condition, a fall, wound care, presence of fluid in the lungs) - The seriously ill person openly and broadly communicates about the situation and his/her wishes - The seriously ill person has an explicit wish (e.g. wish for the most comfortable possible end of life; wish to go to a palliative centre) - The seriously ill person is aware of palliative condition - The seriously ill person poses questions him/herself - The seriously ill person has experience with palliative care among friends, acquaintances etc.	- Disease trajectory with gradual decline - Cognitive inability of the seriously ill person - The seriously ill person shows resistance - The seriously ill person maintains hope - The seriously ill person does not know or realize that the disease is incurable - The seriously ill person does not expect that life will end in 2 months - The seriously ill person wants to continue the treatments - The seriously ill person is afraid of loneliness - The seriously ill person is afraid of the unknown - The seriously ill person takes no initiative - The seriously ill person does not want to talk about palliative care
Care environment	- Someone the family carer knows/the nursing team has taken palliative training - Availability of contact details to know who they can contact	- Incorrect care assessment by the professional carers (e.g. sending the patient back to nursing home when other and more specialized care is needed) - No continuity of care - No financial compensation for the family carer - No referral between the different hospital units involved - The professional carers do not involve the family carer in the care - The professional carers are understaffed

The behaviors above and related determinants were combined in one behavioral model (see **Figure 1**).

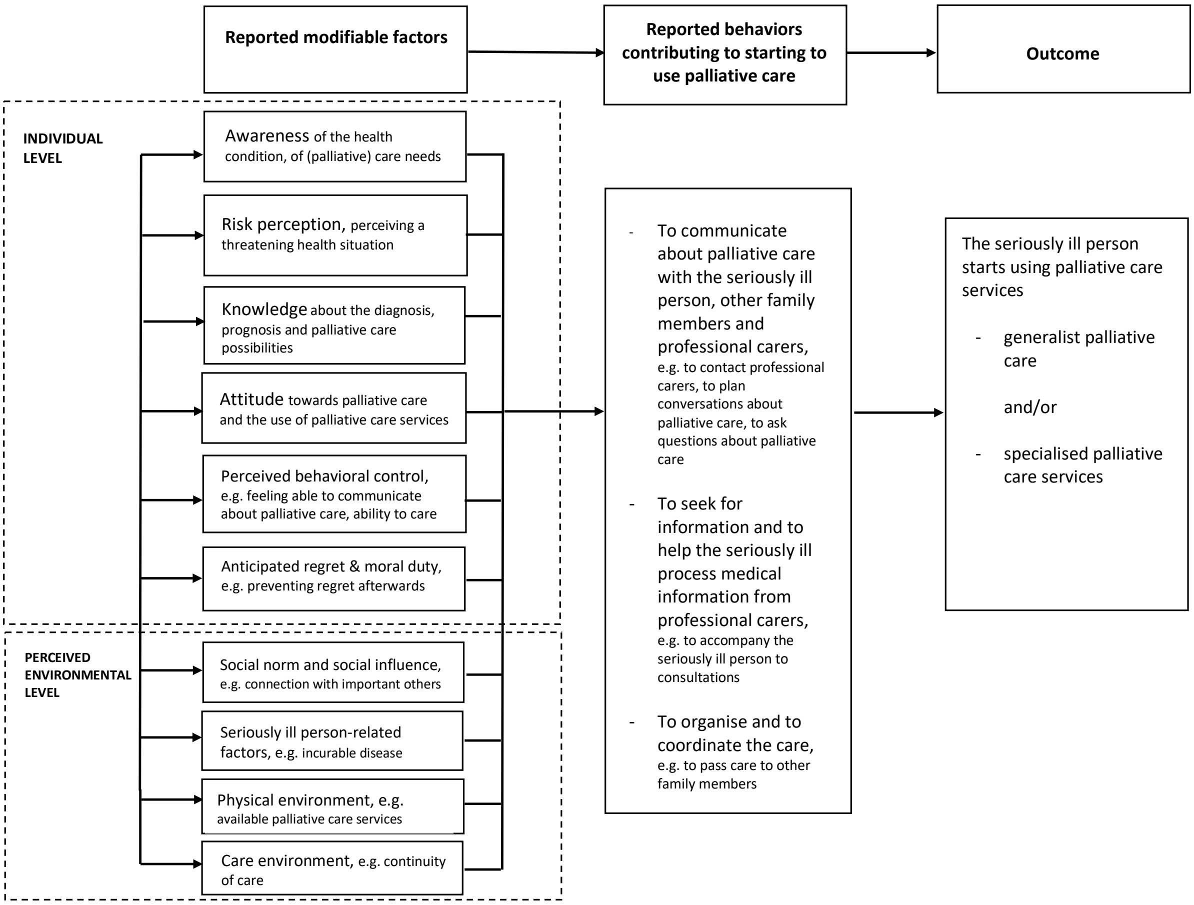

Figure 1: behavioral model developed

7.4 Discussion

This qualitative study with family carers identified three overarching behaviors that may have contributed to starting palliative care: (1) communicating about palliative care, (2) seeking information about palliative care and helping the seriously ill person process information from professional carers, and (3) organizing and coordinating, with the first as recurrent behavior. Attitude, social norm and influence, perceived behavioral control; awareness and risk perception, knowledge, anticipated regret and moral duty, and other perceived environmental determinants were identified as facilitating and hindering determinants related to these behaviors.

7.4.1 Strengths and limitations of the study

This study is highly innovative because it uses behavioral theories to identify and model determinants related to family carers' palliative care behaviors. This study uniquely focuses on the family carers' perspective, which is next to the professional carers' and patients' perspective, important to have a full understanding of starting palliative care. Certain limitations need to be acknowledged. The developed model is a preliminary model that needs to be further elaborated, but we believe that our study findings can be theoretically generalised in countries with a similarly developed healthcare context where palliative care is accessible to everybody. In many countries the family carer(s) plays an important role in the (palliative) care of the patient and therefore our findings are of added value to gain insights into which behavioral cognitions and motivations will hinder or facilitate family carers in performing behaviors that can contribute to the start of palliative care. We cannot provide medical information about the time period between the start of palliative care and the patients' death, but all family carers experienced rather late start of palliative care and reported that they displayed these behaviors late in the disease trajectory. Interviewing family carers who experienced timely start of palliative care could have led to the identification of other behaviors or determinants. However, it was not our aim to look for differences between timely and late start of palliative care and we wanted to include participants reflecting current practice, which is generally a late start of palliative care in Belgium and many other countries[9].

7.4.2 Interpretations of the main findings

All pre-established determinants (attitude, subjective norm and perceived behavioral control) of behaviors as derived from the Theory of Planned Behavior[16] were identified. However, also factors that could not be matched within these determinants but in determinants of other behavioral theories (awareness and risk perception, knowledge, anticipated regret and moral duty, social influence and other perceived environmental determinants) were found. The model demonstrates on which combination of determinants focus might be needed to bring about behavioral changes. This is an added value compared to obstacles to palliative care previously found in literature from professional carers' perspectives (e.g. family disputes as an obstacle to discussing palliative care[20]).

Family carers' awareness of the poor health condition and the need for palliative care are important determinants for communicating about palliative care with the seriously ill person (awareness and risk perception). There might be lack of knowledge about the patient's condition and palliative care possibilities and their relevance[28,29]. We also found that the seriously ill having persistent hopes of curative treatment options could be a factor hindering the closest carer from talking about palliative care (social influence). Even though research shows the benefits of timely palliative care, regardless of the prognosis but based on care needs[1,2], the respondents, other family members and the seriously ill still perceive palliative care as giving up, care only needed when all other treatments were no longer effective and when death was approaching (attitude). Family carers want to exhaust all treatment before giving up (anticipated regret and moral duty). This might explain why participants said that awareness of the poor health condition (or the short prognosis or terminal condition) of the seriously ill person was an important determinant. These attitudes are consistent with recent qualitative studies showing that family carers and the general public associate palliative care with diminished care[30] and death[31,32]. The belief that palliative and curative care cannot be provided simultaneously is in contrast with the prevailing paradigm that palliative care can be provided concordantly with all other disease-modifying treatments[23,33]. This negative connotation can be related to lack of knowledge. We indeed found that family carers often did not know that palliative care was an option, what palliative care could mean to the seriously ill person and what it would cost (knowledge), which hindered them from being prepared for conversations about palliative care. The family carers assumed that palliative care would create big changes in the care process and that their daily routines would be interrupted, which made them feel unable to communicate about palliative care (perceived behavioral control).

In all narratives, professional carers' social support (social norm and influence) was a recurring theme. We found that professional carers played important roles in influencing many factors. Their role was mainly related to the provision of (palliative care) information. Previous studies have emphasized the family carers' need for information[34] and also found this need is often unmet[35,36]. Family carers may not always be involved in the communication about palliative care as professional carers consider them as a barrier to initiating a conversation about palliative care (e.g. protection of the patient, unrealistic expectations)[20]. In contrast, family carers in our study wanted to be involved early in palliative care discussions with professional carers such as the physician, nurse or psychologist. Family carers are currently not enabled enough to behave in ways that contribute to (timely) palliative care, which is in contrast with the health promotion principles[1,4,5]. This implies that behavioral change might be needed amongst professional carers.

The model developed is useful for 1) researchers (e.g. health promoters) who aim to achieve behavior change in family carers and 2) professional carers caring for seriously ill people and their family carers. If we want to promote the family carers' behaviors, interventions should strengthen the facilitating determinants and change the hindering ones. Family carers need more accurate knowledge of palliative care to enable them to take initiative in palliative care. Knowledge can be increased through accessible information about palliative care for lay people (e.g. media education sessions, public websites)[37,38] and timely information from professional carers (e.g. a short 'readiness to engage in palliative care discussions' questionnaire to use during consultations[38]). Furthermore, family carers would benefit from skill-training, to assist them in facilitating timely palliative care as consistent with patients' preferences. Professional carers can also play a role in augmenting the ability of family carers to support the patient. It will be necessary to change the attitude that palliative care is only terminal care and the belief that it is necessary to know the prognosis in order to communicate about palliative care or start using palliative care. However, this is an explorative study focusing on the family carer, who is only one of the environmental agents related to timely use of palliative care, resulting in a preliminary model. Further research is needed on determinants related to specific sub-behaviors. For example, other perceived benefits related to motivation and palliative care needs of family carers themselves could be important, although not mentioned in the present study. A lot of the barriers identified relate to external factors, out of family carers' control. Therefore, comparable individual behavioral models from professional carers' and patients' perspectives need to be developed. The models, or a combination of these models, can be used as a basis for development of effective interventions[39].

7.5 Conclusion

This study identified family carers' behaviors that may contribute to starting palliative care and related facilitating and hindering determinants, which were combined in one behavioral model. This model makes it possible to better understand why family carers do or do not display these behaviors. Considering the changeability of the identified determinants, this model can be can serve as a basis for the development of behavioral interventions to empower family carers in their efforts to start palliative care.

Licence for publication

Competing interests

None declared.

Contributorship statement

All authors, A.S., K.B., L.M., L.D., J.C. & B.D. were responsible for the literature search, planning and design of the study. L.M. was responsible for data collection. L.M. and A.S. were responsible for data analysis. All authors contributed to the interpretation of the data. A.S. and K.B. wrote the first draft of the manuscript and critically revised the manuscript after receiving comments from all authors. K.B., L.D., B.D. and J.C. supervised the study. K.B., B.D. and J.C. contributed to acquisition of funding. A.S. was responsible for final submission and as guarantor of content.

Funding

This work was supported by grants from the Vrije Universiteit Brussel (HOA24) and Ghent University (BOF). A.S. is a Predoctoral Fellow and K.B. a Postdoctoral Fellow at the Research Foundation Flanders (FWO).

Acknowledgements

The authors wish to thank the professional carers for recruiting family carers in this study. We are very grateful to the family carers for participating in this study and for sharing their story with us. We further thank Helen White for help with linguistic editing of the text.

Data availability

All data relevant to the study are included in the article.

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PART V

GENERAL DISCUSSION AND CONCLUSIONS

Chapter 8

GENERAL DISCUSSION AND CONCLUSIONS

8.1 Introduction

The aim of this dissertation was to better understand behaviors to initiate palliative care in patients and family carers confronted with serious illness, through a health promotion and behavioral theories lens. I described the state of science by systematically reviewing the studies in end-of-life care and palliative care that used a behavioral theory. Next, I described how behavioral theories can be used in end-of-life care and palliative care research (**Part II)**. Applying a behavioral theory, I then sought to understand the factors facilitating and hindering people with incurable cancer in starting a conversation about palliative care with the physician and to examine the contribution of different factors to this behavior. Then, I developed a behavioral intervention aimed at helping people with incurable cancer to start a conversation about palliative care with their physician (**Part III**). Finally, the behaviors of family carers that might contribute to the initiation of palliative care for people confronting serious illness were explored **(Part IV).**

In this discussion section, I will first briefly summarize the main findings of this dissertation (paragraph 8.2). Following this, I will elaborate on the methods used in this work and discuss strengths and weaknesses (paragraph 8.3). In paragraph 8.4, the findings will be discussed in light of current challenges and state of affairs within research on timely communication about and initiation of palliative care. Finally, implications and recommendations for practice, policy and future research will be formulated (paragraph 8.5).

8.2 Summary of the main findings

Chapters 2-7 addressed the three main objectives of this dissertation. Before going into a discussion about the methodological considerations, strengths and weaknesses of these studies and an overall interpretation in light of the state of knowledge, I provide a brief summary of these different parts.

8.2.1 Limited use of behavioral theories in previous palliative and end-of-life care studies (Chapter 2)

Our systematic review showed that 31 studies on palliative or end-of-life care related themes had used behavioral theories - 27 used quantitative designs -of which four (quasi-)randomized controlled trials- and four used qualitative designs. Most were published after 1990. In total, 13 different behavioral theories were identified. More than half of the studies used the Theory of Planned Behavior (TPB) (n=9), the Theory of Reasoned Action (n=4) or the Transtheoretical Model (n=8). Three studies combined two theories. In only 9 of the 31 studies, the behavioral theory was fully used and all factors of the theory were explored, operationalized and/or measured. However, the use of behavioral theories was not always described in detail. In terms of populations, most of these studies focused on the general public (n=14) and professional carers (n=12). Only a limited number of the studies focused on behaviors of people confronted with serious illness, i.e. patients (n=4) or family carers (n=1). In terms of topics, most (16 of the 31) studies focused on behavioral outcomes related to advance care planning.

8.2.2 A step-wise approach to use behavioral theories to better understand and gain deeper insight into factors of health-promoting behavior in people confronted with serious illness (Chapter 3)

We used a step-wise approach. We selected the TPB (step 1). Through qualitative interviews we found that this theory was applicable to the target behavior, but needed extending (step 2). Our final questionnaire developed to quantitatively test the palliative care behavioral model for starting a conversation about palliative care with the physician in people with cancer included 131 items (step 3). The last and fourth step showed that in particular attitudinal factors were associated with starting a conversation about palliative care with the physician in people with incurable cancer (step 4) (*see paragraph 8.3.3 – mixed methods*).

8.2.3 Behavioral factors identified as hindering and facilitating starting a conversation about palliative care with a professional carer in people with incurable cancer (Chapter 4)

Using a qualitative interview study among 25 people with incurable cancer we explored which factors hindered or facilitated the starting of a conversation about palliative care with a professional carer. The TPB was used as a deductive framework while allowing room for inductive identification of other determinants not included in this theory. Identified psychological factors that hindered or facilitated the starting of a conversation about palliative care with the physician included awareness (e.g. about their illness being life-threatening), knowledge (e.g. about palliative care and its possibilities), attitude (e.g. towards palliative care, perceived benefits and disadvantages related to starting a conversation about palliative care) and perceived behavioral control (e.g. self-confidence). Identified perceived socio-environmental factors included perceived subjective norm (e.g. perceived attitude towards palliative care in people around them) and perceived social influence (e.g. relationship with the professional carer). Next to these modifiable factors, a series of non-modifiable factors were identified: for example, character traits and past experiences with palliative care.

This qualitative study resulted in a preliminar palliative care behavioral model, including the factors related to the behavior of starting a conversation about palliative care with a professional carer in people with incurable cancer. This model helps to better understand and explain why people with incurable cancer do or do not start that conversation and can provide guidance for intervention aimed at improving timely communication about palliative care and timely initiation of it from the patients' perspective.

8.2.4 The quantitative importance of the psychological and perceived socio-environmental factors associated with starting a conversation about palliative care with the physician in people with incurable cancer (Chapter 5)

The palliative care behavioral model developed in Chapter 4 was then quantified into a cross-sectional interview survey among 80 people with different types of incurable cancer. This survey study showed that both psychological and perceived socio-environmental factors were moderately to strongly associated with starting a conversation about palliative care with the physician in people with incurable cancer. The patients' attitude towards the behavior was the most important factor associated with starting the palliative care conversation or intending to do so, followed by perceived barriers, perceived benefits, perceived attitude towards the behavior in the physician and family or friends and perceived disadvantages. People holding a positive attitude towards this behavior (OR

4.74; 95%CI 2.35-9.54), perceiving more benefits of it (OR 2.60; 95%CI 1.37-4.96) and perceiving a positive attitude towards the behavior in the physician (OR 2.19; 95%CI 1.39-3.45) and family/friends (OR 2.07; 95%CI 1.26-3.41) were more likely to starting the palliative care conversation or intending to do so; people perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI 0.15-0.63) were less likely to starting the palliative care conversation or intending to do so. These factors together explained 64% of the variance, which is rather high as application of the TPB averagely results in 41% of explained variance in behavior[1,2].

These findings show that the palliative care behavioral model developed (Chapter 4) and quantitatively evaluated (Chapter 5) is useful to better understand starting a conversation about palliative care with the physician in people with incurable cancer. Interventions targeting these associations will empower people with cancer in taking initiative in communication about palliative care.

8.2.5 A theory-based behavioral intervention to help people with cancer to start a conversation about palliative care with their physician (Chapter 6)

A theory-based behavioral intervention aimed at helping people with incurable cancer to start a conversation about palliative care with their physician themselves and at supporting physicians in reacting appropriately was developed together with the end-users. This resulted in the My care my voice intervention. To help people with cancer, the planning group selected the following five applications: a short introduction movie, poster, flyer, theme pen and website. To support physicians, the planning group selected three applications: a poster, online training and conversation card. This study is still ongoing.

8.2.6 Family carers' behaviors contributing to the initiation of palliative care (Chapter 7)

A qualitative interview study with 16 family carers of deceased persons who used palliative care explored what behaviors of family carers might influence the initiation of palliative care and what factors might be related to these behaviors. One of the key overarching behaviors reported by the family carer was communicating about palliative care and its possibilities with the seriously ill person, other family members and professional carers. Another key overarching behavior reported was related to seeking information and helping the seriously ill person process the information from professional carers. Organising and coordinating the care was also reported as an important behavior. Again, the TPB was used as a deductive framework while allowing room for inductive identification of other determinants not included in this theory. Reported behavioral factors facilitating and hindering these behaviors included awareness (e.g. of poor health of the seriously ill person), knowledge (e.g. about palliative care and its possibilities), attitudes (e.g. towards palliative care), perceived behavioral control (e.g. feeling (un)able to perform the behaviors), anticipated regret and moral duty (e.g. wanting to exhaust all treatment before giving up) and social influences (eg, important others' opinions about palliative care).

This qualitative study among family carers resulted in a preliminary model behavioral model including the factors related to family carers' behaviors perceived as contributing to the initiation of palliative care for the seriously ill people such as communicative behaviors. This model helps to better understand why family carers do or do not display these family carers' behaviors. The model can serve as a basis for the development of behavioral interventions aimed at empowering and supporting family carers in performing behaviors that might contribute to the initiation of palliative care.

8.3 Methodological considerations, strengths and limitations

In this dissertation, three different types of study designs were used in order to perform our study objectives and answer our research questions: a systematic review, three qualitative studies (one study with people with incurable cancer, one study with end-users of the intervention and one study with family carers) and one cross-sectional survey study. For all studies, guidelines such as PRISMA[3] (Chapter 2) and COREQ[4] (Chapters 3, 4 and 7) and STROBE[5] (Chapter 5) were used for defining the protocol and reporting, which enhances overall rigour and trustworthiness. In the following section, I further elaborate on important methodological considerations, strengths and limitations.

8.3.1 Behavioral theories – in particular the TPB – to better understand palliative care behaviors of patients and family carers

The TPB does not take into account past experiences and habits, but is open to the inclusion of additional factors

A methodological strength across all studies in this dissertation, was the use of behavioral theories as theoretical framework[6,7] to better understand palliative care behaviors. A strength of the TPB is that it is open to the inclusion of additional factors[8]. In the qualitative study aimed at better understanding the patient behavior of starting a conversation about palliative care with the physician (Chapter 4), awareness, knowledge, and perceived social influence were added to the TPB. In the qualitative study to better understand family carer behaviors contributing to the initiation of palliative care (chapter 7), awareness, knowledge, anticipated regret and moral duty and perceived social influence were added to the TPB. A limitation of the TPB is that it does not take into account past experiences and unconscious or automatic processes involved in habitual behavior[9]. Past experiences with palliative care were reported as influencing factor (chapter 4 and 7), but were not assumed to be changeable. The quantitative survey study only tested the modifiable factors related to starting the palliative care conversation. Adding past experiences or other non-modifiable factors to the quantitative palliative care behavioral model could have resulted in a higher predictive value of the model[9], but could not be targeted through a behavioral intervention.

The TPB results in a high explained variance, but an intention-behavior gap can not be ruled out

Evidence shows the use of the TPB results in high numbers of explained variance in intention (39-50%) and behavior (19-38%)[10,11]. Our final multivariable model with modifiable factors associated with starting the conversation about palliative care with the physician or intending to do so showed with 64% an even higher explained variance. This high explained variance shows that the palliative care behavioral model of Scherrens et al.[12], based on the TPB, is useful to better understand why people with incurable cancer start a conversation about palliative care with the physician (or not). As a critical consideration, the higher percentage may be slightly affected by the methodological choice to include the intention in the behavioral outcome. In most previous research, these are included as two dependent variables or behavioral intention was included as predictor of the behavioral performance[11]. Other behavioral factors, i.e. independent variables, are often better predictors of intention than behavior[1]. Despite of how well our multivariable model seem to predict starting a conversation about palliative care with the physician, it does not indicate how much change in behavior will accrue from changing the targeted factors. There might be a gap between intention and the actual behavior performance[6,13]. There is limited empirical data about factors influencing this gap and the magnitude of this gap. Therefore, more empirical longitudinal studies are needed[14]. In our behavioral intervention developed (Chapter 6), the flyer and conversation card might bridge the intention-behavior gap by targeting perceived behavioral control and barriers. For example, people with cancer are stimulated to form if-then plans and to plan their palliative care conversation: what are their questions or concerns, when they want to start that conversation, with which physician, etc.

The TPB is suitable to understand and change individual palliative care behaviors of patients and family carers, but other environmental factors may be important as well

We found that the TPB was the most common individual theory used in the field of health care[15] and the fields of end-of-life care and palliative care (cfr. Chapter 2). Furthermore, we found that the TPB was suitable to understand patient palliative care behavior (Chapters 4 and 5) and family carer palliative care behaviors (Chapter 7). The extended TPB was useful (Chapters 3-5) in developing a behavioral intervention, that aims to help people with cancer in starting the conversation about palliative care with the physician, and that is perceived as an appropriate intervention by the various stakeholders (Chapter 6). By using the TPB this intervention has high potential to obtain behavioral change[16,17], as strong evidence shows that behavioral interventions based on behavioral theories are effective in understanding and changing behavior across contexts, populations and behaviors[16,17]. However, the dissertation results stressed the importance of the direct environment (family carers, physician) in better understanding patient palliative care behavior. Furthermore, we are interested in obtaining long-term behavioral change[18]. Therefore, additional changes in the social and physical palliative care environment are needed as well. We should consider applying the TPB with a socio-ecological approach[6]. However, individual behavioral theories can also be used to better understand the behaviors of environmental agents who are responsible for environmental factors influencing people with serious illnesses[6].

8.3.2 A qualitative study design to explore palliative care behaviors

Considering the design in Chapters 4 and 7, a qualitative study deemed most suitable for these explorative studies aimed at developing a new palliative care behavioral model. The design made it possible to get more in-depth information about and understanding of the participant's perceptions and beliefs[19,20].

8.3.3 A cross-sectional design to assess factors associated with a patient behavior

We used a cross-sectional design to assess the factors associated with starting a conversation about palliative care with the physician in people with incurable cancer (Chapter 5). Cross-sectional designs are highly used in palliative care research, for example to understand prevalences of conditions, treatments and services or factors associated with such outcomes[21]. This design is also used to assess the association between professional carers' characteristics and behaviors[21]. A cross-sectional design in a population of incurable cancer patients was suited for the purpose of this study[22], and is an important step in order to develop effective and tailored behavioral interventions in people with incurable cancer[6].

Limitations of using a cross-sectional design

We have measured the factors associated with starting a conversation about palliative care with the physician and the intention/behavior at a single time-point. Based on reflections on the use of the TPB, cognitions and thoughts of people with incurable cancer might change over time[8]. For example, these may be influenced by contextual factors (e.g. hospital). We included participants in different phases of their illness and this illness factor was not related to intending to start or starting a conversation about palliative care. However, using a cross-sectional design limits the possibility to make causal claims about what factors influence the behavior due to a large potential residual confounding[23]. Additionally, it does not allow the study of temporality and reverse causation, such as whether a pre-existing attitude influenced intended behavior at a later time point (rather than attitudes being the result of post-hoc rationalization of an intention)[23]. The cross-sectional design might affect the validity of our results. Longitudinal studies might be needed to provide better evidence. With a longitudinal design, we could examine the change of the factors, intention and behavior over time[24] and detect the confounding factors affecting the associations between the factors and the intention/behavior. Longitudinal studies are more frequently used in other health care domains in healthy people (e.g. physical activity in general public). A longitudinal design also gives the opportunity to get insight into the intention-behavior gap[25,26]. For example, unforeseen barriers could emerge[25]. However, a longitudinal design in studies with people with incurable cancer is extremely challenging and resource intensive. Sample size may change as people with incurable cancer drop-out because of deteriorating health or death[27].

What terms to use if interested in determinants, but a cross-sectional design was used?

In this dissertation we were interested in behavioral determinants or predictors of starting a conversation about palliative care with the physician. However, due to the cross-sectional design and risk for confounding bias, in Chapter 5 we opted to use other terms than determinants or predictors conveying a similar meaning but not implying causality. We used terms such as factors or correlates and associations. However, the discussion about what terms to use and when these terms are mis-used is recently re-introduced and ongoing[28].

8.3.4 Mixed-methods

A methodological strength was the use of a mixed-method design in using behavioral theories to better understand why people with cancer start a conversation about palliative care with their physician or not (Chapters 4-5). In recent years, a combination of qualitative and quantitative designs is increasingly used to develop and evaluate complex palliative care and end-of-life care interventions (e.g. to better understand how an intervention works)[29,30]. In this dissertation, a two-phase exploratory design was used, because the behavioral factors determining the specific patient behavior were unknown and we wanted to develop a palliative care behavioral model. In a first phase, we performed qualitative interviews with the target population to explore the factors related the specific patient behavior. Next, we matched these findings with behavioral factors of behavioral theories (e.g. attitude, perceived social norm). Based on this data-analysis, we developed a specific palliative care behavioral model. In a second phase, we developed a questionnaire based on this palliative care behavioral model. After, we performed a cross-sectional survey study to quantitatively test the palliative care behavioral model[31]. These quantitative results showed the most important factors associated with starting a conversation about palliative care with the physician to target on with a behavioral intervention. This mixed-method strategy ensured that the most important, relevant and domain-specific factors[32] related to the specific patient behavior were assessed[6]. This might have contributed to the high predicted value of the palliative care behavioral model developed[33,34]. However, we should bear in mind that a behavioral model will only ever explain a proportion of variance in (the intention to perform) a behavior and other unmeasured and unknown factors play a role[35]. A limitation of using this mixed-method strategy was that it required efforts and unique skills for each method[29,31].

This dissertation shows that this mixed-methods – in particular the exporatory design - used is also effective in understanding a palliative care behavior and developing a palliative care behavioral model warranted to develop a theory-based behavioral intervention in palliative care research. This methodology is detailly described in Chapter 3 and could also be used for other (palliative care) behaviors in seriously ill people (e.g. to make a living will). More detailled description of how mixed-methods were used in palliative care research is needed as current papers often lack quality of reporting[30].

8.4 Discussion of the findings in the light of current challenges and state of affairs within research on timely initiation of palliative care and timely communication about it

8.4.1 Why palliative care researchers should use a health promotion approach and behavioral theories and what to watch out for

Throughout this dissertation (chapter 3-7), a health promotion approach and behavioral theories were innovatively used. Furthermore, we fully used the TPB (chapter 4-5), meaning that we explored, operationalized and measured all behavioral factors of the TPB. Compared to the studies included in our systematic review (Chapter 2), only 9 out of 31 studies fully used a behavioral theory. We recommend to fully use a behavioral theory or to combine two complementary theories to ensure a high predictive value. A high predictive value is accompanied by a more full understanding of the behavior and a higher chance to obtain behavioral change[6,36]. Chapters 3-7 of this dissertation focused on palliative care behaviors, whereas the systematic review (Chapter 2) showed that only few studies focused on palliative care behaviors[37–45].

Health promotion versus pathogenesis

By using a health promotion approach, we focused on (modifiable) factors influencing palliative care behaviors in patients (Chapters 4-5) and family carers (Chapter 7) confronted with serious illness. There is sufficient evidence in other health care domains showing that targeting these factors in an intervention (Chapter 6) may contribute to the improvement of patient empowerment and patients' initiative in palliative care communication, patient-centred care, timely initiation of palliative care and quality of life in both patients and their families[6,15,46]. Therefore, using a health promotion lens forms an eye-opening effect in palliative care research[6,7] as palliative care research is mainly dominated by the paradigm of pathogenesis, i.e. approaches that react to problems rather than prevent them prophylactically[46].

Challenges

Despite the potential benefits of using behavioral theories, some challenges occurred when using these theories to better understand and explain palliative care behaviors. A first challenge was to select an appropriate theory, seeing literature reveals a wide range of different theories[35]. Other behavioral theories than the TPB may also be applicable to palliative care behaviors. For example, the systematic review (Chapter 2) showed that the Transtheoretical Model was applicable to advance care planning behaviors[47–54] and that Health Belief Model[44,55–58] was applicable to advance care planning and communicative behaviors. Empirical evidence is lacking concerning which theories are more appropriate in palliative care research, but socio-ecological models taking into account environmental factors may also be applicable to palliative care behaviors[35]. As a strength, behavioral theories are by nature abstract and not content- or topic-specific[59]. They can be generalized over behaviors and populations, but the weight of each behavioral factor can vary[6]. We suggest to choose a theory based on study purpose and population.

Another challenge was the lack of experience and expertise in using behavioral theories in the domain of palliative care, seeing no clear examples or guidelines were available. Previous studies in end-of-life care and palliative care research that used behavioral theories (Chapter 2), failed to detailly describe how behavioral theories were used[60,61]. This may have been a previous barrier for researchers to use them. The step by step detailed description of our use of behavioral theories in better understanding a palliative care behavior and our illustration with a case example (Chapter 3) may address this need.

In Chapters 4-5, people confronted with incurable cancer often experienced difficulties to think hypothetically and to imagine themselves talking about palliative care (if they would do so or not, or why). They often perceived that palliative care was a long way off and something to be happening in the future (cfr. due to lack of awareness, lack of knowledge, negative attitudes). This may have introduced hypothetical bias, i.e. what people with cancer said they would hypothetically do was not necessarily what they would do in reality[62,63]. Furthermore, question items related to a rather complex and abstract behavior made this imagination process even more challenging. It seemed that some cognitive skills from the participants were required. In this regard, it might be more difficult to question palliative care behaviors and identify its factors compared to other well-known health behaviors that are easily to imagine such as physical activity and quit smoking[15]. However, this challenge can be partially tackled by using face to face interviews and providing more information and by stimulating participants' hypothetical thinking with 'if… then' scenarios.

Another challenge is related to the current limited empirical knowledge about what key palliative care behaviors and factors are. In particular, advance care planning behaviors are studied as key behaviors that contribute to better palliative care and end-of-life care. Advance care planning behaviors may create opportunities for other palliative care behaviors. For example, advance care planning (i.e. reflecting on goals and preferences for future medical treatment and care) may enable patients to start a conversation about palliative care with the physician[64].

In conclusion, this dissertation illustrates that the challenges of using behavioral theories to gain better understanding of factors related to palliative care behaviors do not outweigh the added value. Researchers may need more knowledge and skills to use behavioral theories in palliative care research. Future (empirical) research and wide dissemination of study findings is needed to further integrate a health promotion approach and the use of behavioral theories in palliative care research (see *recommendations for future research*).

8.4.2 Patients' perspective

This dissertation uniquely focused on the perspective and behaviors of patients and family carers (Chapters 3-7), whereas most previous studies in the domain of timely initiation of palliative care focused on professional carers' behaviors and perspectives[46]. The systematic review (Chapter 2) showed that out of the 31 included studies that used behavioral theories in palliative care and end-of-life care studies, most focused on the perspectives of the general public (n=14) and professional carers (n=11). Only four focused on the perspective of patients[44,58,65,66] and two on the perspective of family carers[45,58].

The theory-based behavioral intervention (Chapter 6), underpinned by the previous qualitative interview (Chapter 4) and quantitative survey study (Chapter 5), wants to empower people with cancer in taking initiative in starting a conversation about palliative care with their physician. Patient empowerment ensures that patients reach their personal goals[67] and receive patient-centred care, i.e. care according to their wishes, needs and preferences[67–69].

How well is patient-empowerment currently established in palliative care practice?

The qualitative interviews revealed that a small group of people with incurable cancer believed that their physician would initiate the conversation about palliative care. They believed that physicians usually know better what is medically feasible and what care is needed for them (Chapter 4). Some reported feeling unable to assess their own health condition as a barrier to starting the conversation about palliative care with their physician (Chapter 5). Some people with cancer might expect their physician to take the initiative at the appropriate time[70] and might entrust their physician in taking care-decisions[69]. Practice showed that professional carers usually guide the palliative care conversations[71]. These findings illustrate that patients' positive attitudes towards starting a conversation about palliative care are not yet standard attitudes and that patient empowerment as defined by the European Patients Forum[69] is not yet well-established and well-embedded in palliative care research and policies. This contrasts with the increasing interest in patient empowerment in high-quality care[72,73]. The currently existing culture of physicians having higher medical authority in clinical decision-making needs to be changed[74]. Professional carers should consider the patients' experiential knowledge as complementary to their own knowledge[75,76].

Is patient-empowerment in timely communication about palliative care an overall wish among people with cancer?

About a third of the participants in the survey study had started the conversation or had the intention to do so (Chapter 5). Most participants could imagine themselves doing so in case of specific circumstances (Chapters 4-5). However, empowering people with cancer in starting the conversation about palliative care with their physician themselves might not necessarily be in line with their current wishes and care goals. People with cancer want information about palliative care well before the terminal phase of their disease[77], but not all of them want to be empowered to ask about palliative care themselves. Some do not wish to have an active role in their own care and will always prefer their physician to take decisions. For example, older patients with a lower level of education may be less willing to challenge their physician's authority[78]. Our results also showed that some patients were not interested in palliative care, now or in the future (Chapters 4 and 5). Interventions aimed at increasing patient empowerment in palliative care initiation (cfr. Chapter 6) should stress the voluntary process and avoid pressure[79]. Such interventions should help patients in determining their degree of patient empowerment and help them with identifying their care needs and deciding whether these needs can be met with palliative care or not.

Feasibility of increasing patient empowerment in specific groups

We can question whether it is feasible to empower people with incurable cancer in taking the initiative in starting a conversation about palliative care with the physician. Currently, a scarce number of (empirical) studies focused on patient empowerment in people with chronic, life-threatening diseases. Those studies[80] compared to studies that focused on factors related to patient empowerment among patients with non-chronic diseases[81,82], indicated that patient empowerment is not related to chronic conditions. However, some patient groups might be more difficult to reach or experience lack of ability (e.g. due to the terminal phase of the disease[83], low health literacy[84,85]) to be empowered. We suggest that intervention materials should be adjusted accordingly and think that greater efforts to increase patient empowerment is needed in these patient groups[83,86] Patient empowerment should be discussed and negotiated with every patient, according to his/her own particular situation[86].

Opportunities to increase patient empowerment in communication about palliative care

The findings in Chapters 4 and 5 illustrate the facilitating factors for starting the conversation about palliative care with the physician by people with cancer. These findings therefore show opportunities to increase patient empowerment (see below). Evidence showed that targeting factors such as attitudes and self-efficacy can lead to a higher degree of patient empowerment in people with an advanced disease[83]. However, efforts to increase patient empowerment should not be limited to the patient level. Patient empowerment could also be approached by the family carer, professional carer and health care system[87].

8.4.3 Barriers and opportunities for timely communication about palliative care among people with incurable cancer

This dissertation has shown important barriers and hence opportunities for timely communication about palliative care and the initiation of palliative care at the patients' level (Chapters 3-4). Multiple psychological – in particular attitudinal- and perceived socio-environmental factors were found to be related to starting a conversation about palliative care with the physician in people with incurable cancer. Previous barriers and opportunities identified at patients' level[88–91] were limited to the awareness and understanding of the prognosis and knowledge about palliative care. Patients mostly overestimated their prognosis and or minimized their disease[95,96].

Psychological factors

Next to psychological factors such as awareness, knowledge and perceived behavioral control (Chapters 4 and 5), attitudinal factors were most strongly associated with starting a conversation about palliative care in people with incurable cancer (Chapter 5). This emphasizes the need for the application and implementation of adequate theoretical strategies such as arguments and persuasive communication[6] to change patients' attitudes towards palliative care conversations (e.g. towards perceiving more benefits than disadvantages; finding solutions for barriers) and patient empowerment (*see paragraph 8.5.1 - clinical implications*)[58]. A negative attitude towards palliative care, i.e. palliative care being equated with terminal care and death, is internationally found to be an important barrier in the communication about palliative care and the initiation of palliative care amongst all people involved in the care for people with cancer[89,92,96,97] as well as among the general public[93]. The belief that palliative and curative care cannot be provided simultaneously is in contrast with the prevailing paradigm that palliative care can be provided concordantly with all other disease-modifying treatments[98,99]. This negative attitude towards palliative care might be explained by the current practice of late initiation of palliative care[100,101] and might be related to lack of knowledge about palliative care and understanding of the benefits of timely communication about it[102].

Should palliative care be renamed?

This raises the question whether palliative care should be renamed or not or whether particularly the attitude towards palliative care should be targeted. Behavioral interventions that inform and educate people about palliative care—including patient-centred care and a planned approach— might change preconceptions and might result in destigmatisation of the term palliative care in patients, family carers and professional carers. When developing our intervention aimed at helping people with cancer in starting the conversation about palliative care (Chapter 6), it was chosen not to use the term palliative care in the logo, slogan or on the title pages. For example, the flyer starts with concepts such as 'customized care' and 'standard oncology care' and is then carefully followed by an introduction of the term 'palliative care'. This to prevent the intervention material from scaring off patients and to make clear that it can be interesting and useful for everyone with cancer (attitude). According to important stakeholders, it was found to be important to give people with cancer the free choice in 'how to' start the conversation about palliative care with their treating physician. It was decided together with these stakeholders to define the behavior of starting a conversation about palliative care with the physician as people with incurable cancer using the words palliative care (either verbally or by showing palliative care documentation) or alternative words that cannot be interpret very differently (e.g. comfort care) in a conversation with the treating physician. However, it is an ongoing discussion whether particularly attitudes towards palliative care and knowledge about it need to be changed or whether palliative should be renamed and other terms such as supportive and anticipatory care should be used[103–106]. Future research should examine to what extent patients receive the care they need and wished for when using the term palliative care compared to an alternative term.

Perceived socio-environmental factors

Next to psychological factors, this dissertation showed that perceived socio-environmental factors related to physicians and family carers were important in determining whether or not people with cancer start a palliative care conversation with their physician (Chapters 4 and 5). The most important factors were the perceived attitudes towards the patient starting the conversation about palliative care with the physician: do they find this behavior important, relevant, not too soon? These findings corroborate previous studies of various health behaviors showing the importance of the social norm[107]. Physicians play an important role in discussions about (palliative) care and timely initiation of palliative care[108,109] and family carers have the potential to play an important role[110–112]. To get insight into the socio-environmental factors, we only relied on the patients' perceptions and did not ask about these factors among physicians and family carers themselves. Patients who negatively scored the items related their own attitudes, may also have negatively scored the items related to the perceived attitudes in people around them (e.g. striving for consistency across scales). Consequently, rater bias might have occurred[113]. Looking at studies from physicians' perspective, physicians recognized the importance of their own attitude towards palliative care in the communication with patients[114], but reported rather negative attitudes towards palliative care[115–118]. Physicians experience lack of knowledge and skills about palliative care and its possibilities[119,120] and low perceived behavioral control[1,37]. They should be educated to provide information and be trained for applying a patient-centered approach[121], for stimulating patients in starting a conversation about palliative care and for reacting appropriately. In the qualitative study exploring family carers' factors related to palliative care behaviors that contribute to timely initiation of palliative care (chapter 7) and other studies[92,94], attitudes towards palliative care were identified as influential factors as well.

From a rather health service towards a system-approach?

Besides patient factors, other factors at the professional carers' level[77,122,123], family carers' level[88,89,92] or community level[93,124] are determining timely initiation of palliative care (*see Introduction, paragraph 2.5*). The behavioral intervention (Chapter 6) involves the physician as environmental agent and aims to support them in reacting appropriately to people with cancer starting a conversation about palliative care with him/her. The intervention targets the perceived social norm among family carers by stimulating people with cancer to communicate about palliative care with the family carer in order to get to know their opinion. However, the intervention did not involve family carers as environmental agent. Not targeting and changing family carers' behavior may cause only a small change in the perceived social norm in family carers. However, the preliminary model developed in Chapter 7 can form the basis to develop an intervention component aimed at family carers as well.

This dissertation may contribute to the shift from using a health service and professional carer approach to a system-based approach in achieving patient-centred care and improving timely initiation of palliative care[99]. To improve timely initiation of palliative care, there is an (ongoing) need for behavioral change in physicians but also for behavioral change in patients, family carers, general public, volunteers etc. The latter emphasizes the importance of the upcoming compassionate communities[125,126]. These are communities investing in education of the public (e.g. local volunteer forces, schools) about death and dying, loss and grief, advance directives and palliative care to get them ready to support palliative care[127].

8.4.4 What is timely in timely communication about palliative care and timely initiation of palliative care?

Shift from a prognostic-based approach to a needs-based approach

The quantitative survey study showed that the minority, who had a life expectancy of less than 5 years and who were not receiving specialised palliative care yet, had a conversation about palliative care already or had the intention to start a conversation about palliative care with their physician in the next 6 months (Chapter 5). This is in line with previous literature showing that people confronted with serious illness often avoid or postpone communication about palliative care[77,89]. However, findings of this dissertation showed that most people with incurable cancer, even those who had no intention at all, could imagine themselves starting a conversation about palliative care once and could identify reasons for (e.g. if the cancer has metastasized) or benefits (e.g. feeling of having more control about their care) of doing so (Chapters 4 and 5). Based on these findings, following questions arose: is late communication always bad? Is timely communication always good? What is timely communication about palliative care in people with incurable cancer? What is timely initiation of palliative care in people with cancer? In current literature about the timing of palliative care, rather mixed results are found. Some studies stated that palliative care can be beneficial if death will likely occur within 6 or 12 months[128]. Others suggested that palliative care should be initiated from the moment the cancer is in an advanced stage or no longer curable[100,129].

It has been suggested for a long time, for example by WHO and previous literature about patient-centred care[130], that communication about palliative care and initiation of palliative care should be based on patients' wishes and needs[130] rather than on the prognosis and the stage of the cancer. Patients develop palliative care needs well before the terminal phase of their disease[131,132]. In addition, they are not always aware of these earlier palliative care wishes and needs (e.g. the wish to be informed about palliative care, need for psychological support)[77]. Strong evidence shows that earlier communication about palliative care is beneficial and that earlier integration of palliative care in the regular care reduces the likelihood of receiving aggressive treatment and of depression at the end of life. Furthermore, earlier initiation of palliative care improves the survival time and quality of life in patients[100,133–135] and improves burden and quality of life for family carers[100,133,134,136]. This dissertation highlights the importance to shift from a prognostic-based approach towards a needs-based approach in palliative care, as it showed that timely communication about palliative care and timely initiation of palliative care is still too often dominated by the prognostic approach. The qualitative findings (Chapter 4) revealed that people with cancer who were already receiving palliative care wanted to have received palliative care much earlier and that family carers (Chapter 6) experienced rather late initiation of palliative care to meet their own and their beloved ones' palliative care needs.

8.4.5 External validity: what do our findings mean for other context and populations?

Some methodological choices within this dissertation (Chapters 4, 5 and 7) might have affected external validity. The settings of recruitment were limited to one or two hospitals and one palliative care network resulting in rather small sample sizes. There might have been variation in different hospital wards (Chapter 5), but there was controlled for cancer type and this was not related to intending to start or starting a conversation about palliative care. Other studies in end-of-life care research are also often limited in sample size and settings[137]. Because of these reasons, the conclusions drawn about the factors may not apply to people with cancer in other care settings or geographic locations. Furthermore, informing potential participants about the study topic being palliative care may have led to selection bias[138]. Because of the prevailing negative attitude towards palliative care, participants interviewed were possibly more willing to think and talk about palliative care. People with cancer without any interest in participating in palliative care studies could possibly have identified other behavioral factors. However, the interviewed group was sufficiently varied in terms of attitude towards palliative care (communication). We tried to minimize selection bias by asking the professional carers, i.e. our intermediaries, to inform all potentially eligible participants about the study and to not use the term palliative care. The researchers only started talking about palliative care and explicitly using the term during the information and data-collection processes. This approach provided more time and opportunities to clearly frame the study subject. Potential participants still dropped out during these processes, but the drop-out rate might have been lower. However, we have to keep in mind that potential participants have to be well-informed considering the ethical principles in palliative care research[139].

Finally all studies were in Dutch, i.e. the native language of the researchers involved in these studies. This resulted in participant groups with mainly people born in Flanders, Belgium and only limited number of people born in other regions and countries. The factors related to starting a conversation about palliative care with the physician in people with incurable cancer and overarching behaviors in family carers might not be generalizable towards participants of other ethnicities and cultures. Ethnicity and culture has an impact on illness beliefs, health care preferences and behaviors[140]. Evidence also showed that ethnicity and culture had an impact on palliative care and communication perceptions[141,142]. Patients from other ethnicities and cultures protected themselves even more from topics related to end-of-life care and may not felt allowed to be empowered and autonomous in taking end-of-life care decisions (e.g. Korean culture)[57,143]. However, considering the external validity, it is important to mention that our purpose was to theoretically generalize about associated factors rather than statistical generalization towards populations. But we do recognize that efforts are needed to explore how people with cancer and family carers from other ethnicities could be stimulated to start a conversation about palliative care as well (cfr. Chapter 6). Because some factors related to palliative care and communication about palliative care might differ across countries (e.g. palliative care policy, practice and culture[144]), we believe that the factors added to the palliative care behavioral model developed aimed at people with cancer (Chapters 4 and 5) and the behavioral model developed aimed at family carers (Chapter 7) can be theoretically generalized in countries with a similarly developed health care context where palliative care is accessible to everybody and family carers play an important role in the (palliative) care for the patient[110–112]. Previous international literature in countries with a similarly developed health care context showed comparable knowledge about palliative care and attitudes towards palliative care in people with advanced illness[89,92]. However, the behavioral model developed aimed at family carers (Chapter 7) needs to be further elaborated and tested.

Furthermore, perceptions of palliative care and communication about palliative care might vary based on types of life-threatening illness (cfr. other illness trajectories[145]), but evidence is lacking[146]. Some illness trajectories go along with different needs and priorities or make it more difficult to plan care in advance. For example, patients with COPD mainly seem to have lack of awareness of the severity of COPD and the palliative care possibilities to improve their situation[147,148]. We suggest that the importance of some patient' factors may be slightly different, but that targeting a combination of psychological and perceived socio-environmental factors may increase empowerment across life-threatening illnesses. However, it is clear from literature that improvement of timely communication about palliative care and timely initiation of palliative care is important and highly needed among other populations as well. Palliative care is more lately initiated, i.e. closer to death, in people with non-cancer diseases compared to people with cancer[149].

8.5 Implications for practice, policy and research

8.5.1 Recommendations for practice

Patient-physician communication

This dissertation and other studies[70,71] showed that patient and family carer empowerment is not well-established in palliative care practice yet. Therefore, we suggest that clinicians (physicians, nurses, physiotherapists etc.) pay more attention to the active roles of patients and family carers in communicating about palliative care and initiating palliative care. This dissertation shows that patients and family carers assign an important role to physicians in communication about palliative care and initiation of palliative care and in helping patients and family carers to be actively involved. This confirmed previous findings[108,109]. Therefore, we suggest that physicians take their responsibilities. We think it is important that physicians recognize them as partners in care and make efforts to understand which role the patients and their families want to play and are capable to/of[150]. If wished for, physicians can play an important role in stimulating people with cancer in taking initiative in communication about palliative care. They can do so by providing positive, correct and clear information about timely communication about palliative care and timely initiation of palliative care and by highlighting the importance, relevance and benefits of it. For example, they can inform patients that timely communication about palliative care can enhance patient-centered care and their active involvement in decision making and inform them about the disadvantages of waiting until it is urgent[151]. This dissertation suggests that physicians explain to people with cancer that palliative care can be initiated at any stage of the disease, it is not only for people who are dying, focusses on other needs than those related to the tumor or cancer, can be provided along with curative care, a conversation about palliative care should not necessarily lead to the initiation of palliative care, the initiation of palliative care is not irreversible etc. Physicians can also help people with cancer to identify their barriers for starting a conversation about palliative care and how to overcome them, for example, by providing prepared lists of simple questions such as how are you now or what do you want to do in the coming weeks/months?[152]. Physicians can also help patients to take the initiative in communication about palliative care by showing their positive attitude towards palliative care and openness to talk about it. Physicians should guide their (palliative) care conversations and decisions based on the patients' wishes and needs instead of based on the diagnosis and prognosis.

Family carer-physician communication

Furthermore, our findings emphasize the need to pay more attention to family carer-physician communication by providing positive, correct and clear information about palliative care (possibilities) and its importance, relevance and benefits for the patient. Physicians should highlight the benefits of timely communication for family carers as well (e.g. less care burden)[153]. A positive attitude towards palliative care and timely communication about palliative care among family carers might stimulate the patient in taking initiative in communication about palliative care with the physician.

Participation to tailored interventions aimed at patient empowerment and timely initiation of palliative care

Physicians report to experience lack of knowledge of palliative care (communication) and skills for a good communication[37,119,120]. This dissertation suggests a higher participation to tailored educational programs aimed at patient empowerment and communication about palliative care to improve their knowledge and skills[154]. Once our theory-based behavioral intervention (Chapter 6) is fully tested, physicians can promote the patient materials and use the physician materials (e.g. participate to the online training, make use of the conversation card).

8.5.2 Recommendations for policy

Globally, cancer is the second leading cause of death[155]. Its incidence and the number of people with cancer in need of palliative care are expected to increase in the coming decades[155,156]. To date, palliative care is initiated late or not at all[100,133,149]. Late or no initiation of palliative care can lead to suboptimal care in the final months or weeks of life[89], but also to unnecessary health care utilization and costs. Timely initiation of palliative care can improve patient outcomes and family carers outcomes[100,133–135], and reduce unnecessary health care utilization and costs[157,158].

Timely palliative care should be recognized as a health care priority and should be included at policy level. Policy can advocate to raise awareness of the importance of a higher degree of patient empowerment, earlier communication about palliative care and initiation of palliative care. They can also advocate to change attitudes. It is important to focus on all people involved: professional carers, patients, family carers and the broader community. For example, the beneficial effects of timely initiation of palliative care[100,133–135] can be widely disseminated (e.g. via facts and figures). Policy can also facilitate the development, implementation and evaluation of quality indicator tools including indicators[159] for the degree of patient empowerment and communication about palliative care. We suggest that policy uses a system-based approach to reach all people involved and supports the development and promotion of public awareness campaigns to inform the broader community about palliative care (communication) (e.g. media campaigns, compassionate communities). Furthermore, policy can advocate to educate professional carers about palliative care communication and initiation. Both basic and continuing education are needed to increase their knowledge and skills. We advocate for palliative care (communication) being integrated into the mandatory education for undergraduate professionals and the continuing professional development of professional carers. Finally, policy should invest in providing adequate resources (expertise, infrastructure, funding).

8.5.3 Recommendations for future research

Using a health promotion approach in palliative care research instead of a pathogenesis approach

Evidence in other health care domains showed the relevance of using behavioral theories[15,46], but limited number of palliative care studies already have used behavioral theories. However, those palliative care studies that used behavioral theories showed these were relevant to better understand and change palliative care behaviors. More empirical evidence is needed to determine what theories are most suitable and what key palliative care behaviors and factors are. We suggest to use a health promotion approach and behavioral theories more often to better understand and explain (palliative care) behaviors in people confronted with serious illness (e.g. people with non-cancer diseases). Those studies that used behavioral theories failed to report about it in detail. We recommend that palliative care researchers (e.g. health promotors) who are about to use behavioral theories report in detail about how they used behavioral theories and disseminate their study findings (e.g. what behavioral theory was used; what behavior and factors were targeted). Our methodological paper (Chapter 3) can be used as guideline. If possible, longitudinal designs are recommended, to provide better evidence, i.e. to claim causations[23] and to gain insight into the intention-behavior gap[25,26].

Using a system-based approach to improve timely communication about palliative care and timely initiation of palliative care

To date, palliative care research is mainly dominated by the health service or professional carer perspective[160]. We suggest that improvement of patient empowerment and timely initiation of palliative care need to be approached by all people involved[99]. Next to professional carers' level, better understanding and changing of palliative care behaviors is needed at patient level, family carer level and community level. Special attention may be needed to obtain behavioral change in more vulnerable and hard-to-reach groups such as people at their end of life, people with lower health literacy or other ethnic groups.

Implementation and evaluation of our theory-based behavioral intervention developed (Chapter 6)

This dissertation suggests that people with cancer are likely to start the conversation about palliative care with their physician, if they are sufficiently supported. Based on the palliative care model developed (Chapter 4) and quantified (Chapter 5), we have developed a highly-promising theory-based behavioral intervention (Chapter 6). By combining Intervention Mapping (IMP), i.e. using behavioral theories, and a participatory approach, prototypes of materials are now available that align well with the needs and interests of both people with cancer and physicians. Implementation and evaluation of this intervention is needed to examine if these intervention materials effectively lead to change in the target behaviors and factors and can improve patient empowerment, patient-physician communication about palliative care, patient-centred care, timely initiation of palliative care and the quality of life of patients and their families. Interventions based on behavioral theories are effective in changing population-level behavior in various contexts, but more evidence on how to implement theory-based palliative care interventions and more empirical data is needed[16]. For future research, it may also be interesting and relevant to involve family carers as environmental agent and to develop an intervention component aimed at family carer' behavior change. The behavioral model developed, including family carers' behaviors and factors that may contribute to timely initiation of palliative care (Chapter 6) can form the basis to develop this intervention component.

8.6 Conclusions

A health promotion and behavioral theory lens is highly suitable in better understanding palliative care behaviors of patients and family carers confronted with serious illness. We suggest that theory-based behavioral interventions aimed at stimulating patients and family carers in performing behaviors that may contribute to earlier initiation of palliative care target both psychological and perceived socio-environmental behavioral factors.

Our study findings showed that a limited group of people with cancer had started a conversation about palliative care with their physician yet or intended to do so. Attitudinal factors were the most important factors that hindered or helped them in starting the palliative care conversation. Next to attitudinal factors, the perceived social norm in their partner, family, friends and the physician was associated with starting a conversation about palliative care with the physician or intending to do so. As next to barriers multiple facilitating factors were identified and associated with starting a conversation about palliative care, our study findings create opportunities to empower and support patients in starting the conversation about palliative care. Therefore, we developed a behavioral intervention targeting these psychological and perceived socio-environmental factors. This intervention aims to help people with cancer to start a conversation about palliative care with the physician. As physicians are the conversation partner and physicians' behaviors and factors play an important role in stimulating people with cancer to start the conversation about palliative care, we chose to involve them as environmental agent. This intervention also aims to support physicians to react appropriately to people with cancer starting a conversation with them. This intervention that was developed together with the end-users, has high potential to improve patient empowerment and patient-physician communication about palliative care. Additionally, it may lead to more timely initiation of palliative care and improve quality of life for both patients and family carers. Therefore, implementing and evaluating this theory-based behavioral intervention will be our next step.

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Summary

Background

Cancer is the second leading cause of death, with nearly 10 million deaths globally (2020). About 19.3 million new cancer cases occurred in 2020. In Belgium, cancer accounted for 28% of all deaths (2018) and 83 267 new cancer cases occurred in 2020. Considering their illness trajectory, people with cancer mostly maintain comfort and functioning for a substantial period of time, followed by a short period of health status decline and usually a clear terminal phase. They generally receive oncology care, which mainly focuses on cancer-directed therapy and aims to cure the cancer, improve symptom burden, reduce medical complications related to cancer or prolong life. They might experience high symptom burden and develop palliative care needs such as physical (e.g. pain), psychological (e.g. emotional support on fear or depression), social (e.g. social support in daily living activities such as domestic work or transport) or spiritual needs (e.g. dignity) well before the terminal phase of the disease. Family carers may also develop palliative care needs. Timely communication about palliative care creates opportunities to hear the patient and their families, to discuss (upcoming) needs and wishes and to plan the care of the patient. Palliative care is considered a crucial part of integrated and patient-centred health care and should be integrated early in the curative care. Timely initiation of palliative care lead to better outcomes such as quality of care and quality of life for both the patient and their families. Despite the beneficial effects of timely initiation of palliative care, palliative care is often initiated too late. An important reason for late initiation of palliative care, is that first discussions about palliative care are frequently avoided or postponed by the physician, patient and their families. Late initiation of palliative care may result in suboptimal care in the final months and weeks of life.

Efforts have been made to increase the proportion of people with cancer for whom palliative care is timely initiated. However, palliative care research (and practice) is mainly dominated by the paradigm of pathogenesis. Furthermore, palliative care research (and practice) is mainly approached as health professionals guiding care discussions and making care decisions. Insufficient attention is paid to the pertinent role that patients themselves and family carers can play in the timely initiation of palliative care. Patients have unique abilities to communicate their preferences, (unmet) care needs and to be actively involved in the initiation of palliative care. However, most of the patients still expect their professional carer, whom they trust, to take initiative in the initiation of palliative care if needed. They do not experience sufficient support to become equal partners in care. These findings from previous research illustrate how patient empowerment is still not well-established in palliative care policies and practices. Nevertheless, a higher degree of patient and family empowerment can result in increased patient satisfaction and better health.

A health promotion approach is frequently used in other health care domains to better understand and change health behaviors and result in better health outcomes. Health promotion is a possible approach to empower patients and family carers in actively taking up their role in the initiation of palliative care actively. A health promotion approach can focus on the pertinent role that their behavior and its related factors can play. Using a health promotion approach and behavioral theories such as the Theory of Planned Behavior in palliative care research can help to better understand palliative care behaviors in order to develop effective and sustainable interventions aimed at improving these behaviors.

Research objectives

By using behavioral theories, this dissertation aimed to better understand and explain palliative care behaviors of people with cancer and family carers confronted with serious disease. This dissertation had three main objectives. The first objective was to assess the end-of-life care studies that have used behavioral theories (*Chapter 2*) and to describe how behavioral theories can be used in the domain of end-of-life care research (*Chapter 3*). The second objective was to better understand and explain starting a conversation about palliative care with the physician by people with incurable cancer from both the home care and hospital setting (*Chapters 4-5*) and to develop a behavioral intervention aimed at patient behavior change *(Chapter 6).* The third objective was to explore family carers' behavior and its factors contributing to the initiation of palliative care from the perspective of family carers (*Chapter 7*).

Methodology

The abovementioned objectives were addressed through different study designs including a systematic review, three qualitative studies, a cross-sectional survey study and a methodological descriptive study.

A systematic review was performed to gain insight into the number of end-of-life care and palliative care studies that have used behavioral theories and what behavioral theories were most commonly used (*Chapter 2*). *Chapter 3* described how behavioral theories were used to gain insight into the patient behavior of starting a conversation about palliative care with the physician step-by-step. A qualitative interview study (*Chapter 4*) was conducted to identify the behavioral factors related to the behavior of starting a conversation about palliative with the physician or having the intention to do so in people with incurable cancer. The interview guide was based on the Theory of Planned Behavior

(*Appendix 1*). A quantitative cross-sectional survey design (*Chapter 5*) was used to examine what behavioral factors identified in Chapter 4 were quantitatively associated with the behavior of starting a conversation about palliative care with the physician or having the intention to do so. A patient questionnaire assessing the psychological and perceived environmental factors related to palliative care and the behavior of starting a conversation about palliative care with the physician was developed. The questionnaire development was based on existing questionnaires from other health behavior domains and the findings from the previous qualitative study. This questionnaire (*Appendices 3 and 4*) was cognitively tested and face validated. In addition, a theory-based behavioral intervention that aims to help people with cancer in starting the conversation about palliative care with the physician, and to support physicians in reacting appropriately, was developed. This intervention was based on the study findings described in *Chapters 4 and 5* and was developed by using a participatory approach (*Chapter 6*). Qualitative interviews (*Chapter 7*) were used to identify family carers' behaviors and its factors that contribute to the initiation of palliative care for people confronted with serious illness. The interview guide was developed also based on the Theory of Planned Behavior (*Appendix 6*).

Main findings

Behavioral theories are scarcely (fully) used in end-of-life care and palliative care research, but evidence prove their relevance (*Chapter 2*)

In a systematic review of literature published until June 2017, we found 31 studies on palliative or end-of-life care related themes that had used behavioral theories, 27 used quantitative designs -of which four (quasi-)randomized controlled trials- and four used qualitative designs. Most were published after 1990. In total, 13 different behavioral theories were identified. More than half of the studies used the Theory of Planned Behavior (n=9), the Theory of Reasoned Action (n=4) or the Transtheoretical Model (n=8). Three studies combined two theories. In only 9 of the 31 studies, the behavioral theory was fully used and explored, operationalised and/or measured all main constructs. In terms of populations, most of these studies focused on the general public (n=14) and health care professional carers (n=12). Only a limited number of the studies focused on behaviors of people confronted with serious illness, i.e. patients (n=4*) or family carers (n=2*). In terms of topics, most (16 of the 31) studies focused on behavioral outcomes related to advance care planning. The studies included showed that using behavioral theories – particularly the Theory of Planned Behavior, the Theory of Reasoned Action and the Transtheoretical Model - were relevant in better understanding and changing end-of-life care behaviors and its factors.

**One study focused on both patients and family carers.*

A step-by-step approach that can be followed to use behavioral theories in palliative care research *(Chapter 3)*

In this chapter we described how we followed a step-wise approach on how behavioral theories in palliative care research can be used, by using our case example of starting a conversation about palliative care with the physician in people with incurable cancer. We selected the Theory of Planned Behavior (step 1). Through qualitative interviews we found that this theory was applicable to the target behavior, but needed extending (step 2). Our final questionnaire developed to quantitatively test the palliative care behavioral model for starting a conversation about palliative care with the physician in people with cancer included 131 items (step 3). The last and fourth step showed that in particular attitudinal factors were associated with starting a conversation about palliative care with the physician in people with incurable cancer (step 4).

Behavioral factors related to starting a conversation about palliative care with a professional carer in people with incurable cancer (*Chapter 4*)

Using a qualitative semi-structured face to face interview study with 25 people with incurable cancer we explored which factors hindered or facilitated the starting of a conversation about palliative care with a professional carer. The Theory of Planned Behavior was used as a deductive framework while allowing room for inductive identification of other factors not included in this theory. Identified psychological factors that hindered or facilitated the starting of a conversation about palliative with the physician or the intention to do so included awareness (e.g. about their illness being life-threatening), knowledge (e.g. about palliative care and its possibilities), attitude (e.g. towards palliative care, perceived benefits and advantages related to starting a conversation about palliative care) and perceived behavioral control (e.g. self-confidence). Identified perceived socio-environmental factors included perceived subjective norm (e.g. perceived attitude towards palliative care in people around them) and perceived social influence (e.g. relationship with the professional carer). Next to these modifiable factors, a series of non-modifiable factors were identified: for example, character traits and past experiences with palliative care. This qualitative study resulted in a preliminary palliative care behavioral model, which helps to better understand and explain why people with incurable cancer do or do not start a conversation about palliative care with a professional carer.

Most important psychological and perceived socio-environmental factors associated with starting a conversation about palliative care with the physician in people with incurable cancer (*Chapter 5*)

The palliative care behavioral model developed in Chapter 4 was then quantified into a cross-sectional interview survey among 80 people with different types of incurable cancer. This survey study showed that both psychological and perceived socio-environmental factors were moderately to strongly associated with starting a conversation about palliative care with the physician in people with incurable cancer. The patients' attitude towards the behavior was the most important factor associated with starting the palliative care conversation or intending to do so, followed by perceived barriers, perceived benefits, perceived attitude towards the behavior in the physician and family or friends and perceived disadvantages. People holding a positive attitude towards this behavior (OR 4.74; 95%CI 2.35-9.54), perceiving more benefits of it (OR 2.60; 95%CI 1.37-4.96) and perceiving a positive attitude towards the behavior in family/friends (OR 2.07; 95%CI 1.26-3.41) and the physician (OR 2.19; 95%CI 1.39-3.45) were more likely to starting the palliative care conversation or intending to do so; people perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI 0.15-0.63) were less likely to starting the palliative care conversation or intending to do so. These factors together explained 64% of the variance and should therefore be the focus of future interventions to change patients' behavior.

A theory-based behavioral intervention aimed at patient behavior change (*Chapter 6*)

A behavioral intervention aimed at helping people with incurable cancer to start a conversation about palliative care with their physician themselves and at supporting physicians in reacting appropriately was developed together with the end-users. This resulted in the My care my voice intervention, including following materials:

- People with cancer: a short introduction movie, poster, flyer, theme pen and website
- Physicians: a poster, online training and conversation card.

This study is still ongoing.

Family carers' behaviors and its factors perceived by family carers as contributing to the initiation of palliative care (*Chapter 7*)

A qualitative semi-structured face-to-face interview study with 16 family carers of deceased persons who used palliative care explored what behaviors of family carers might influence the initiation of palliative care and what factors might be related to these behaviors. One of the key overarching behaviors reported by the family carer was communicating about palliative care and its possibilities with the seriously ill person, other family members and professional carers. This was a recurrent behavior in each interview. Another key overarching behavior reported was related to seeking information and helping the seriously ill person process the information from professional carers. Organizing and coordinating care was also reported as a key overarching behavior. Again, the Theory of Planned Behavior was used as a deductive framework while allowing room for inductive identification of other determinants not included in this theory. Reported behavioral factors facilitating and hindering these behaviors included awareness (e.g. of poor health of the seriously ill person), knowledge (e.g. about palliative care and its possibilities), attitudes (e.g. negative attitude towards palliative care), perceived behavioral control (e.g. feeling unable to perform the behaviors), anticipated regret and moral duty (e.g. wanting to exhaust all treatment before giving up) and social influences (e.g., important others' opinions about palliative care). This study resulted in a preliminary model behavioral model including the factors related to family carers' behaviors perceived as contributing to the initiation of palliative care for the seriously ill people such as communicative behaviors. This model helps to better understand why family carers do or do not display these family carers' behaviors.

Discussion of the main findings

Why palliative care researchers should use a health promotion approach and behavioral theories and what to watch out for

Throughout this dissertation *(Chapter 3-6*), a health promotion approach and behavioral theories were innovatively used to better understand palliative care behaviors of patients and family carers confronted with serious illness. We identified modifiable factors determining palliative care behaviors of patients and family carers that contribute to timely initiation of palliative care. There is sufficient evidence in other health care domains showing that targeting these factors (e.g. *Chapter 6*) may successfully lead to change in these factors and thus behavioral change. As a result, this may lead to improvement of patient empowerment and patients' initiative in palliative care communication, patient-centred care, timely initiation of palliative care and improved quality of life for both patients and their families.

Despite the potential benefits of using behavioral theories, some challenges occurred when using these theories to better understand and explain palliative care behaviors. A first challenge was to select a theory, seeing a wide range of different theories exist and empirical evidence is lacking concerning which theories are most appropriate in palliative care research. However behavioral theories are by nature abstract and not content- or topic-specific. We suggest to choose a theory based on study purpose and population. Second, there was lack of experience and expertise in using behavioral theories in the domain of palliative care. No clear examples or guidelines were available. The detailed description of how we used behavioral theories in better understanding a specific palliative care behavior (*Chapter 3*) may address this need. Third, participants experienced difficulty to think hypothetically and to imagine themselves talking about palliative care (if they would do so or not, or why). They often perceived that palliative care was a long way off and something that would happen in the future. Furthermore, question items related to a rather complex and abstract behavior made this imagination process even more challenging. This third challenge can be partially tackled by using face to face interviews and providing more information and by stimulating participants' hypothetical thinking with 'if… then' scenarios. Fourth, there is lack of empirical knowledge about what key palliative care behaviors and factors are. Future research is needed in this domain.

In conclusion, this dissertation illustrated that the challenges of using behavioral theories to gain better understanding of factors related to palliative care behaviors do not outweigh the added value.

Importance of studying timely communication of palliative care from a patients' perspective

Next to the professional carers' perspective, the main focus in most research, this dissertation showed that it is important to gain insight into the perspectives of patients themselves and their families to have a full understanding of communication about palliative care and to improve timely initiation of palliative care.

The qualitative interviews revealed that a small group of people with incurable cancer was convinced that their physician would initiate the conversation about palliative care (*Chapter 4*). Some reported feeling unable to assess their own health condition as a barrier to starting the conversation about palliative care with their physician (*Chapter 5*). People with cancer might expect their physician to take the initiative at the appropriate time. Others might entrust their physician in taking care-decisions. Practice also showed that professional carers usually guide the palliative care conversations. These findings illustrate that patients' positive attitudes towards starting a conversation about palliative care are not yet standard attitudes and that patient empowerment is not yet well-established and well-embedded in palliative care research and policies. There is a need for a shift in patients' thinking concerning how to receive patient-centred care and in professional carers' thinking about how to deliver quality care and improve quality of life.

This dissertation suggested that there is a need for increasing patient empowerment to ensure that they receive patient-centred care, i.e. care according to their wishes, needs and preferences. Furthermore, this dissertation showed opportunities for empowering patients in communication about palliative care, seeing it identified its factors that hindered or facilitated them in doing so. Targeting both patient' factors and physician' factors might increase patient empowerment and stimulate people with cancer in starting the conversation about palliative care with their physician. The behavioral intervention developed (*Chapter 6*) aims to address this need.

Barriers and opportunities for timely communication about palliative care among people with incurable cancer

Psychological factors

This dissertation showed the importance of multiple psychological and perceived socio-environmental factors related to the performance of palliative care behaviors in people confronted with serious illness, i.e. people with cancer (*Chapters 4&5*) and family carers (*Chapter 7*). Attitudinal factors were highly reported as influential in both people with cancer and family carers (*Chapters 4&7*). Attitudinal factors were most strongly associated with starting a conversation about palliative care with the physician (*Chapter 5*). This emphasizes the need for the application and implementation of adequate theoretical strategies such as arguments and persuasive communication to change patients' attitudes towards palliative care conversations (e.g. towards perceiving more benefits than disadvantages; finding solutions for barriers) and increasing patient empowerment. A negative attitude towards palliative care, i.e. palliative care being equated with terminal care and death, is internationally found to be an important factor determining communication about palliative care and the initiation of palliative care amongst all people involved. We suggest that informing and educating people about palliative care—including patient-centred care and a planned approach— might change preconceptions and might result in destigmatisation of the term palliative care.

Perceived socio-environmental factors

Next to psychological factors, this dissertation showed that perceived socio-environmental factors related physicians and family carers were important in determining whether or not a conversation about palliative care would be started with the physician in people with cancer (*Chapters 4&5*). The most important factors were the perceived attitudes towards the patient starting the conversation about palliative care with the physician: do they find this behavior important, relevant, not to soon? These findings emphasize the importance of shared responsibility in timely communication about palliative care and initiation of palliative care, and the (ongoing) need for behavioral change in all people involved (patients, family carers, physicians and other professional carers, volunteers…).

The theory-based behavioral intervention developed (*Chapter 6*) involved physicians as the environmental agent. Next to helping people with cancer in starting a conversation about palliative care with their physician through targeting its behavioral factors, this intervention aims to support physicians in reacting appropriately to people with cancer starting a conversation with him/her. In future, we can involve family carers as the environmental agent and develop an intervention component aimed at behavioral change in family carers as well.

Recommendations for practice, policy and future research

Practice

Patient-physician communication:

- pay more attention to the roles of patients and family carers in communicating about palliative care and initiating palliative care
- play an important role in stimulating people with cancer in taking initiative in communication about palliative care by providing positive, correct and clear information about timely communication about palliative care and timely initiation of palliative care and highlighting the importance, relevance and benefits of it; by helping people with cancer to identify their barriers for starting a conversation about palliative care and how to overcome them; by showing their positive attitude towards palliative care and openness to talk about
- guide their (palliative) care conversations and decisions based on the patients’ wishes and needs instead of based on the diagnosis and prognosis.

Family carer-physician communication:

- provide positive, correct and clear information about palliative care (possibilities) (its importance, relevance, benefits…).

Participating in tailored interventions aimed at patient empowerment and timely palliative care

Policy

Recognize timely palliative care as a health care priority and include it at policy level:

- advocate to raise awareness of the importance of a higher degree of patient empowerment, timelier communication about palliative care and initiation of palliative care and to change attitudes
- use a community-based approach (e.g. media campaigns, compassionate communities)
- advocate to educate professional carers communication about palliative care and palliative care
- invest in providing adequate resources (expertise, infrastructure, funding).

Research

Using a health promotion approach in palliative care research instead of a pathogenesis approach

Using a system-approach to improve timely communication about palliative care and timely initiation of palliative care

Implementation and evaluation of our theory-based behavioral intervention developed (*Chapter 6*)

Samenvatting

Situering

Kanker is de tweede belangrijkste doodsoorzaak, met bijna 10 miljoen doden wereldwijd (2020). In 2020 waren er ongeveer 19,3 miljoen nieuwe gevallen van kanker. In België was kanker verantwoordelijk voor 28% van alle sterfgevallen (2018) en waren er 83 267 nieuwe gevallen van kanker (2020). Personen met kanker behouden hun comfort en functioneren gedurende een aanzienlijke periode, gevolgd door een korte periode van achteruitgang van de gezondheidstoestand en meestal een duidelijke terminale fase. Ze krijgen over het algemeen standaard oncologische zorg, die zich voornamelijk richt op kankergerichte therapie en gericht is op het genezen van de kanker, het verbeteren van de symptoomlast, het verminderen van medische complicaties die verband houden met kanker of het verlengen van het leven. Personen met kanker kunnen een hoge symptoomlast ervaren en palliatieve zorgnoden, zoals fysieke (bijv. pijn), psychologische (bijv. emotionele ondersteuning bij angst of depressie), sociale (bijv. sociale ondersteuning bij dagelijkse activiteiten zoals huishoudelijk werk of vervoer) of spirituele behoeften (bijv. waardigheid) ontwikkelen ruim voor de terminale fase van de ziekte. Ook mantelzorgers kunnen palliatieve zorgnoden ontwikkelen. Tijdige communicatie over palliatieve zorg biedt de mogelijkheid om naar de patiënt en de familie te luisteren, (toekomstige) noden en wensten te bespreken en de zorg te plannen. Palliatieve zorg wordt beschouwd als een cruciaal onderdeel van geïntegreerde en patiëntgerichte gezondheidszorg en wordt best zo vroeg mogelijk in het zorgtraject geïntegreerd. Tijdige initiatie van palliatieve zorg leidt tot betere gezondheidsuitkomsten zoals meer kwaliteitsvolle zorg en een hogere levenskwaliteit voor zowel de patiënt als de families. Ondanks deze gunstige effecten van tijdige initiatie van palliatieve zorg, wordt deze veeleer te laat geïnitieerd. Een belangrijke reden voor het laattijdig initiëren van palliatieve zorg, is dat de eerste gesprekken hierover vermeden of uitgesteld worden door zowel de arts, de patiënt als de familie. Laattijdige initiatie van palliatieve zorg kan leiden tot suboptimale zorg in de laatste maanden en weken van het leven.

Er worden heel wat inspanningen geleverd om het aandeel personen met kanker voor wie palliatieve zorg tijdig wordt geïniteerd, te vergroten. Echter heerst binnen onderzoek naar palliatieve zorg en de palliatieve zorg praktijk vooral de overtuiging dat professionele zorgverleners de gesprekken over zorg initiëren en vervolgens de zorgbeslissingen nemen. Er is onvoldoende aandacht voor de relevante rol die patiënten en hun mantelzorgers kunnen spelen bij het tijdig initiëren van palliatieve zorg. Patiënten beschikken over unieke mogelijkheden om te communiceren over hun voorkeuren, (onvervulde) zorgnoden en om actief betrokken te zijn bij de initiatie van palliatieve zorg. De meeste patiënten verwachten echter dat hun professionele verzorger, die men vertrouwt, indien nodig het initiatief neemt om palliatieve zorg te initiëren. Patiënten ervaren onvoldoende ondersteuning om gelijkwaardige partners in de zorg te worden. Deze bevindingen tonen aan dat *patient empowerment* op heden nog niet voldoende ingeburgerd is. Nochtans kan een hogere mate van empowerment van patiënten en mantelzorgers resulteren in een hogere zorgtevredenheid en een betere gezondheid.

Gezondheidsbevordering is een benadering die vaak gebruikt wordt in andere gezondheidszorgdomeinen om gezondheidsgedrag beter te begrijpen en te veranderen. Er is voldoende evidentie dat dit in betere gezondheidsuitkomsten resulteert. Gezondheidsbevordering is een mogelijke benadering om patiënten en mantelzorgers in staat te stellen om hun rol bij het initiëren van palliatieve zorg actief in te vullen. Onderzoek vanuit deze benadering richt zich op de relevante rol die hun gedrag en daaraan gerelateerde factoren kunnen spelen. Het gebruik van gedragstheorieën zoals de *Theory of Planned Behavior* (het beredeneerd gedragsmodel) in onderzoek naar palliatieve zorg kan helpen om palliatieve zorg gedragingen beter te begrijpen en om effectieve en duurzame interventies te ontwikkelen die zich richten op het stimuleren van deze gedragingen.

Onderzoeksdoelen

Dit proefschrift heeft gedragstheorieën gebruikt om palliative zorg gedragingen van patiënten en mantelzorgers beter te begrijpen en te verklaren. Het proefschrift had drie hoofdonderzoeksdoelen. Het eerste onderzoeksdoel was het in kaart brengen van studies in levenseindezorg onderzoek die gebruik gemaakt hebben van gedragstheorieën (*hoofdstuk 2*) en om te beschrijven hoe gedragstheorieën kunnen gebruikt worden in onderzoek naar levenseindezorg en palliatieve zorg (*hoofdstuk 3*). Het tweede onderzoeksdoel richtte zich op het beter begrijpen en uitleggen van één specifiek palliatief zorggedrag, namelijk het starten van een gesprek over palliatieve zorg met de arts vanuit het perspectief van personen met een ongeneeslijke kanker die zowel in de thuiszorg als de ziekenhuissetting verblijven (*hoofdstukken 4-5*). Hierbij was het doel tevens om een gedragsinterventie te ontwikkelen die zich richt op gedragsverandering bij personen met ongeneeslijke kanker (*hoofdstuk 6*). Het derde onderzoeksdoel beoogde om gedragingen van mantelzorgers en de onderliggende gedragsfactoren die bijdragen aan het opstarten van palliatieve zorg te identificeren vanuit het perspectief van mantelzorgers (*hoofdstuk 7*).

Methodologie

De bovengenoemde onderzoeksdoelen werden bereikt door middel van verschillende onderzoeksdesigns, waaronder een systematische review, drie kwalitatieve studies, een cross-sectioneel kwantitatief onderzoek en een methodologisch beschrijvende studie.

Er werd een systematische review uitgevoerd om inzicht te krijgen in het aantal studies in levenseinde zorg en palliatieve zorg onderzoek waarin gedragstheorieën gebruikt werden en welke gedragstheorieën het meest werden gebruikt (*hoofdstuk 2*). In *hoofdstuk 3* werd stap voor stap beschreven hoe gedragstheorieën werden gebruikt om inzicht te krijgen in het gedrag waarbij personen met kanker zelf een gesprek starten over palliatieve zorg met de arts. Er werd een kwalitatief interviewonderzoek uitgevoerd bij personen met een ongeneeslijke kanker om de gedragsfactoren gerelateerd aan het starten van een gesprek over palliatieve met de arts of de intentie om dit in de nabije toekomst te doen, te identificeren (*hoofdstuk 4*). De interviewleidraad was gebaseerd op de Theory of Planned Behavior (*bijlage 1*). Door middel van een kwantitatieve cross-sectionele studie werd onderzocht welke van de geïdentificeerde gedragsfactoren uit het voorgaand kwalitatief interviewonderzoek kwantitatief geassocieerd waren met het starten van een gesprek over palliatieve zorg met de arts of de intentie om dit in de nabije toekomst te doen. Op basis van bestaande vragenlijsten uit andere gezondheidsgedragsdomeinen en de bevindingen uit het voorgaande kwalitatief onderzoek werd een patiëntenvragenlijst ontwikkeld (*bijlagen 3 en 4*). Deze vragenlijst werd getest door middel van cognitieve interviewing en het nagaan van de indruksvaliditeit (*face validity*). Met behulp van deze vragenlijst konden die psychologische en gepericipieerde sociale omgevingsfactoren met betrekking tot palliatieve zorg en het gedrag om een gesprek te starten over palliatieve zorg met de arts bevraagd worden (*hoofdstuk 5*). Verder werd op basis van de onderzoeksbevindingen beschreven in *hoofdstukken 4 en 5* een op theorie gebaseerde gedragsinterventie ontwikkeld die beoogt om personen met kanker te helpen om een gesprek over palliatieve zorg met de arts te starten en om artsen te ondersteunen om hier adequaat op te reageren. Voor deze interventie-ontwikkeling werd gebruik van het Intervention Mapping Protocol en werd een participatieve benadering toegepast (*hoofdstuk 6*). Kwalitatieve interviews werden gebruikt om het gedrag van mantelzorgers en de onderliggende gedragsfactoren die bijdragen aan het starten van palliatieve zorg voor personen die geconfronteerd worden met een levensbedreigende aandoening, te identificeren (*hoofdstuk 7*). De interviewleidraad werd eveneens ontwikkeld op basis van de Theory of Planned Behavior (*bijlage 5*).

Samenvatting van de belangrijke bevindingen

Gedragstheorieën worden in onderzoek naar levenseindezorg en palliative zorg nauwelijks (volledig) gebruikt, maar evidentie bewijst hun relevantie (*hoofdstuk 2*)

Uit de systematische review bleek dat tot vóór juni 2017 in 31 studies – 27 kwantitatieve studies, waarvan vier (quasi-)gerandomiseerde gecontroleerde studies, en vier kwalitatieve studies – in onderzoek naar levenseindezorg en palliatieve zorg gedragstheorieën werden gebruikt. De meeste studies werden gepubliceerd na 1990. In totaal werden 13 verschillende gedragstheorieën geïdentificeerd. De Theory of Planned Behavior (n=9), de Theory of Reasoned Action (n=4) en het Transtheoretical Model (n=8) waren de meest gebruikte gedragstheorieën. Drie studies combineerden twee theorieën. In 9 van de 31 studies werd de gedragstheorie volledig gebruikt, wat wilt zeggen dat alle gedragsdeterminanten geoperationaliseerd en/of gemeten werden. Wat de doelgroepen betreft, waren de meeste studies gericht op gedrag van de algemene bevolking (n=14) en professionele zorgverleners zoals artsen en verpleegkundigen (n=11). Slechts een beperkt aantal studies richtte zich op het gedrag van personen die met een ernstige aandoening worden geconfronteerd, namelijk patiënten (n=4*) en mantelzorgers (n=2*). Gekeken naar de gedragsuitkomsten, waren zestien van de 31 studies gericht op vroegtijdige zorgplanning. Echter kan uit deze review geconcludeerd worden dat het gebruik van gedragstheorieën – voornamelijk de Theory of Planned Behavior, de Theory of Reasoned Action en het Transtheoretical Model – relevant is om levenseindezorg gedragingen beter te begrijpen en te veranderen.

*één studie richtte zich op zowel patiënten als mantelzorgers

Een stapsgewijze methode die kan worden toegepast om gedragstheorieën te gebruiken in onderzoek naar palliatieve zorg (*hoofdstuk 3*)

We hebben beschreven hoe wij op een stapsgewijze manier gedragstheorieën gebruikt hebben in onderzoek naar palliatieve zorg. We illustreerden dit aan de hand van ons eigen voorbeeld, waarbij we gedragstheorieën gebruikten om een concreet gedrag, namelijk starten van een gesprek over palliatieve zorg met de arts door personen met een ongeneeslijke kanker, beter te begrijpen. In de eerste stap werd de Theory of Planned Behavior gekozen. In de tweede stap werd deze theorie getest in kwalitatieve interviews met de doelgroep. Deze stap toonde aan dat deze theorie geschikt was om het palliatieve zorg gedrag beter te begrijpen, maar moest worden uitgebreid met andere factoren. De derde stap resulteerde in een finale vragenlijst om de factoren in het palliatieve zorggedragsmodel voor het starten van een gesprek over palliatieve zorg met de arts kwantitatief te testen. Deze vragenlijst bestond uit 131 items. De laatste en vierde stap lieten zien dat voornamelijk attitudefactoren geassocieerd zijn met het starten van een gesprek over palliatieve zorg met de arts door mensen met ongeneeslijke kanker.

Gedragsfactoren gerelateerd aan het starten van een gesprek over palliatieve zorg met een professionele zorgverlener bij mensen met ongeneeslijke kanker (*hoofdstuk 4*)

Door middel van semi-gestructureerde face-to-face interviews met 25 personen met een ongeneeslijke kanker werden factoren die het starten van een gesprek over palliatieve zorg met een professionele zorgverlener faciliteren en belemmeren geïdentificeerd. De Theory of Planned Behavior werd gebruikt als een deductief theoretisch kader, maar met de mogelijheid om op inductive wijze factoren van andere gedragstheorieën te identificeren. De volgende psychologische factoren werden geïdentificeerd: bewustzijn (bv. dat hun ziekte levensbedreigend is), kennis (bv. over palliatieve zorg en de mogelijkheden daarvan), houding (bv. houding ten opzichte van palliatieve zorg, gepercipieerde voor- en nadelen gerelateerd aan het starten van een gesprek over palliatieve zorg) en waargenomen gedragscontrole (bv. zelfvertrouwen). De volgende waargenomen sociale omgevingsfactoren werden geïdentificeerd: waargenomen social norm (bv. waargenomen houding ten opzichte van palliatieve zorg bij belangrijke mensen uit hun omgeving) en waargenomen sociale invloed (bv. relatie met de professionele zorgverlener). Naast deze veranderbare factoren werden de volgende niet-veranderbare factoren geïdentificeerd: karaktereigenschappen en vroegere ervaringen met palliatieve zorg. Dit kwalitatieve onderzoek resulteerde in een preliminair gedragsmodel dat helpt om beter te begrijpen en uit te leggen waarom personen met een ongeneeslijke kanker wel of niet een gesprek starten over palliatieve zorg met een professionele hulpverlener.

Belangrijkste psychologische en waargenomen sociale omgevingsfactoren geassocieerd met het starten van een gesprek over palliatieve zorg met de arts door mensen met ongeneeslijke kanker (*hoofdstuk 5*)

Het palliatieve gedragsmodel dat ontwikkeld werd in bovenstaande kwalitatieve studie (hoofdstuk 4) werd kwantitatief getest in een cross-sectionele studie gebaseerd op face-to-face interviews met 80 personen met een ongeneeslijke kanker. Deze studie toonde aan dat zowel psychologische als gepericipieerde sociale omgevingsfactoren matig tot sterk geassocieerd waren met het starten van een gesprek over palliatieve zorg met de arts. Attitudes ten opzichte van het doelgedrag, d.w.z. algemene houding, gepercipieerde voordelen, gepercipieerde nadelen en gepercipieerde barrières, en de subjectieve norm ten opzichte van het doelgedrag waren de belangrijkste factoren geassocieerd met starten van een gesprek over palliatieve zorg met de arts of hier de intentie toe hebben. Mensen die een positievere houding hadden ten opzichte van dit gedrag (OR 4.74; 95%CI 2.35-9.54), er meer voordelen aan verbonden (OR 2.60; 95%CI 1.37-4.96) en een positievere houding ten opzichte van het gedrag waarnamen bij familie/vrienden (OR 2.07; 95%CI 1.26-3.41) en de arts(OR 2.19; 95%CI 1.39-3.45), waren meer waarschijnlijk; mensen die meer nadelen (OR 0.53; 95%CI 0.32-0.87) en barrières (OR 0.31; 95% CI 0.15-0.63) percipieerden waren minder snel geneigd om het gedrag te stellen of de intentie ertoe te hebben. Deze factoren samen verklaarden 64% van de variantie in het doelgedrag van de patiënt en zouden daarom de focus moeten zijn van toekomstige interventies om het gedrag van patiënten te kunnen veranderen.

Een op theorie gebaseerde gedragsinterventie gericht op gedragsverandering van patiënten (*hoofdstuk 6*)

Er werd samen met de eindgebruikers de gedragsinterventie, ‘Mijn zorg mijn stem’, ontwikkeld. Deze interventie beoogt om mensen met ongeneeslijke kanker te helpen bij het zelf starten van een gesprek over palliatieve zorg met de arts en om artsen te ondersteunen bij het gepast reageren hierop. De Mijn zorg mijn stem interventie bevat de volgende materialen:

- Mensen met kanker: een korte introductiefilm, poster, folder, themapen en website
- Artsen: een poster, online training en gesprekskaart.

De materialen worden op dit moment (mei 2022) getest op aanvaardbaarheid.

Gedragingen van mantelzorgers en de onderliggende factoren die door mantelzorgers worden gepercipieerd als belangrijk voor het starten van palliatieve zorg (*hoofdstuk 7*)

Door middel van interviews met 16 mantelzorgers van overleden personen die palliatieve zorg ontvingen, werden de belangrijkste overkoepelende gedragingen van mantelzorgers en daaraan gerelateerde factoren geïdentificeerd die werden gepercipieerd als belangrijk voor de initiatie van palliatieve zorg. Een van de belangrijkste overkoepelende gedragingen die werd gerapporteerd, was het communiceren over palliatieve zorg en de mogelijkheden ervan met de patiënt, andere familieleden en professionele zorgverleners. Dit gedrag kwam in elk interview terug naar boven. Een ander belangrijk overkoepelend gedrag dat werd gerapporteerd, had betrekking op het zoeken naar informatie en het helpen van de ernstig zieke persoon bij het verwerken van verkregen informatie door professionele zorgverleners. Het organiseren en coördineren van zorg werd ook als een belangrijk overkoepelend gedrag gerapporteerd. Gerapporteerde gedragsfactoren die deze gedragingen faciliteren en/of belemmeren, waren onder meer bewustzijn (bijv. van een slechte gezondheid van de ernstig zieke persoon), kennis (bijv. over palliatieve zorg en de mogelijkheden daarvan), attitudes (bijv. negatieve houding ten opzichte van palliatieve zorg), waargenomen gedragscontrole (bijv. selfvertrouwen om het gedrag uit te voeren) verwachte spijt en morele plicht (bijv. alle curatieve behandelingen willen uitproberen vooraleer over te gaan naar palliatieve zorg) en gepercipieerde sociale invloed (bijv. de mening van belangrijke anderen over palliatieve zorg). Dit kwalitatieve onderzoek resulteerde in een voorlopig gedragsmodel dat helpt om beter te begrijpen waarom mantelzorgers deze overkoepelende gedragingen wel of niet vertonen.

Bespreking van de belangrijkste bevindingen

Waarom moeten onderzoekers in de palliatieve zorg een gezondheidsbevording benadering en gedragstheorieën gebruiken en wat zijn mogelijke valkuilen?

In dit proefschrift (*hoofdstukken 3-7*) werden een gezondheidsbevordering benadering en gedragstheorieën gebruikt om palliatieve zorggedragingen van patiënten en mantelzorgers die met een ernstige ziekte worden geconfronteerd beter te begrijpen. Hierdoor hebben we zicht op welke veranderbare gedragsfactoren een rol spelen bij het stellen van palliatieve zorg gedragingen die kunnen bijdragen aan de tijdige initiatie van palliatieve zorg. Er is voldoende evidentie in andere gezondheidszorgdomeinen dat interventies gericht op deze factoren (bijv. *hoofdstuk 6*) kunnen leiden tot effectieve en succesvolle gedragsverandering. Dit kan bijkomstig resulteren in een verbetering van de *patient empowerment* en de initiatiefname van de patiënt in palliatieve zorg communicatie, patiëntgerichte zorg, tijdige initiatie van palliatieve zorg en levenskwaliteit van zowel patiënten als hun families.

Ondanks de meerwaarde, bracht het gebruik van gedragstheorieën om palliatieve zorg gedragingen beter te begrijpen ook enkele uitdagingen met zich mee. Allereerst was het niet makkelijk om een gedragstheorie te selecteren, aangezien er een breed scala aan verschillende theorieën bestaat en empirisch bewijs ontbreekt over welke theorieën het meest geschikt zijn in palliatieve zorg onderzoek. Gedragstheorieën zijn echter van nature abstract en niet inhoudelijk of onderwerpspecifiek. We stellen daarom voor om een theorie te kiezen op basis van het onderzoeksdoel en de doelpopulatie. Ten tweede bestond er een gebrek aan ervaring en expertise in het gebruik van gedragstheorieën binnen het domein van de palliatieve zorg. Er waren geen duidelijke voorbeelden of richtlijnen beschikbaar. De gedetailleerde beschrijving van hoe wij gedragstheorieën hebben gebruikt om een specifiek palliatief zorggedrag beter te begrijpen (*hoofdstuk 3*) kan mogelijks aan deze nood tegemoetkomen. Ten derde ervoeren de deelnemers dat het moeilijk was om hypothetisch te denken en om zich voor te stellen dat ze over palliatieve zorg zouden praten (of ze dat zouden doen of niet, en waarom). Ze beschouwden palliatieve zorg vaak als iets dat nog ver weg was en iets dat ze pas zouden kunnen nodig hebben in de toekomst. Bovendien werden er vragen gesteld over een eerder complex en abstract gedrag. Dit maakte het voor de deelnemers nog moeilijker om zich deze gedragingen in te beelden. Deze derde uitdaging kan gedeeltelijk worden aangepakt door gebruik te maken van persoonlijke interviews en meer informatie te geven en door het hypothetische denken van deelnemers te stimuleren met 'als... dan'-scenario's. Ten vierde is er een gebrek aan empirische kennis over wat de belangrijkste palliatieve zorggedragingen en -factoren zijn. Toekomstig onderzoek is nodig om dit verder uit te zoeken.

Op basis van dit proefschrift, kunnen we concluderen dat de uitdagingen bij het gebruik van gedragstheorieën in palliatieve zorg onderzoek niet opwegen ten opzichte van de toegevoegde waarde.

Het belang om tijdige communicatie van palliatieve zorg vanuit het perspectief van de patiënt te bekijken en aan te pakken

Naast het perspectief van de professionele zorgverlener, dat in de meeste onderzoeken centraal staat, toonde dit proefschrift aan dat het belangrijk is om inzicht te krijgen in de perspectieven van de patiënten zelf en de mantelzorgers. Dit om een volledig begrip te hebben van communicatie over palliatieve zorg en om tijdige initiatie van palliatieve zorg te verbeteren.

Uit de kwalitatieve interviews bleek dat een kleine groep mensen met ongeneeslijke kanker ervan overtuigd was dat hun arts het gesprek over palliatieve zorg zou aangaan (*hoofdstuk 4*). Sommigen gaven aan niet in staat te zijn hun eigen gezondheidstoestand in te schatten, wat geïdentificeerd werd als een barrière om het gesprek over palliatieve zorg met hun arts te beginnen (*hoofdstuk 5*). Mogelijk verwachten mensen met kanker dat hun arts initiatief neemt op het gepaste moment. Anderen vertrouwen hun arts dusdanig, opdat hij/zij alle zorgbeslissingen mag nemen. Uit de praktijk bleek ook dat professionele zorgverleners de palliatieve zorggesprekken meestal initiëren. Deze bevindingen illustreren dat de positieve houding van patiënten ten aanzien van het starten van een gesprek over palliatieve zorg nog geen standaard houding is en dat *patient empowerment* nog niet goed ingeburgerd en ingebed is in onderzoek naar palliatieve zorg en het palliatieve zorg beleid. Patiënten dienen meer overtuigd te worden van hun rol in het ontvangen van patiëntgerichte zorg. Daarnaast, dienen professionele zorgverleners aan te nemen dat *patient empowerment* een belangrijke rol speelt in het aanbieden van kwaliteitsvolle zorg en het verbeteren van de levenskwaliteit. Er is behoefte aan een verschuiving in het denken van patiënten over het ontvangen van patiëntgerichte zorg en in het denken van professionele zorgverleners over het leveren van kwaliteitszorg en het verbeteren van de kwaliteit van leven.

Dit proefschrift suggereert dat er behoefte is aan meer *patient empowerment* om ervoor te zorgen dat personen met kanker patiëntgerichte zorg ontvangen, d.w.z. zorg volgens hun wensen, behoeften en voorkeuren. Bovendien toont dit proefschrift aan waar kansen liggen om *patient empowerment* te verhogen in de communicatie over palliatieve zorg. Dit proefschrift identificeerde de factoren die personen met kanker belemmeren en helpen bij het starten van een gesprek over palliatieve zorg met de arts. Door zowel patiëntfactoren als artsenfactoren aan te pakken, kan de patientempowerment positief evolueren en kunnen mensen met kanker gestimuleerd worden om het gesprek over palliatieve zorg met hun arts aan te gaan. De ontwikkelde gedragsinterventie (*hoofdstuk 6*) beoogt hieraan tegemoet te komen.

Barrières en facilitatoren voor tijdige communicatie over palliatieve zorg bij mensen met ongeneeslijke kanker

Dit proefschrift toonde aan dat meerdere psychologische en gepercipieerde sociale omgevingsfactoren bepalend zijn voor het stellen van palliatieve zorg gedragingen door patiënten (*hoofdstukken 4 en 5*) en mantelzorgers (*hoofdstuk 7*) die worden geconfronteerd met een ernstige ziekte.

Psychologische factoren

Het belang van attitude-factoren werd sterk benadrukt bij zowel personen met kanker als bij mantelzorgers (*hoofdstukken 4 en 7*). Bijgevolg waren attitude-factoren het sterkst geassocieerd met het starten van een gesprek over palliatieve zorg met de arts (*hoofdstuk 5*). Dit benadrukt dat er nood is aan de toepassing en implementatie van adequate theoretische strategieën zoals 'argumenten' en 'overtuigende communicatie' om de houding van patiënten ten opzichte van gesprekken over palliatieve zorg te veranderen (bijvoorbeeld om er meer voordelen dan nadelen aan te verbinden; door manieren te vinden om om te gaan met barrières) en de *patient empowerment* te verbeteren. Een negatieve houding ten opzichte van palliatieve zorg, dat wil bijvoorbeeld zeggen dat palliatieve zorg gelijkgesteld wordt aan terminale zorg en de dood, wordt internationaal en door alle betrokkenen beschouwd als een belangrijke factor die bepalend is voor de communicatie over palliatieve zorg en het initiëren ervan. We suggereren dat het informeren en opleiden van mensen over palliatieve zorg - inclusief patiëntgerichte zorg en een geplande aanpak - vooroordelen zou kunnen veranderen en zou kunnen leiden tot destigmatisering van de term palliatieve zorg.

Waargenomen socio-omgevingsfactoren

Naast de psychologische factoren, toonde dit proefschrift aan dat ervaren socio-omgevingsfactoren gerelateerd aan artsen en mantelzorgers bepalend waren voor het starten van een gesprek over palliatieve zorg met de arts door personen met kanker (*hoofdstukken 4 en 5*). De waargenomen attitude ten opzichte van de patiënt die het gesprek over palliatieve zorg met de arts begon bleek het belangrijkste: vinden artsen of mantelzorgers dit gedrag belangrijk, relevant, niet te vroeg? Deze bevindingen benadrukken het belang van de gedeelde verantwoordelijkheid in tijdige communicatie over palliatieve zorg en het tijdig initiëren ervan alsook het belang van de (voortdurende) nood aan gedragsverandering bij alle betrokkenen (patiënten, mantelzorgers, artsen en andere professionele zorgverleners, vrijwilligers…).

In de theorie gebaseerde gedragsinterventie (*hoofdstuk 6*) die ontwikkeld werd, wordt de arts betrokken als omgevingsactor. Het doel van deze interventie is tweeledig. Enerzijds beoogt het om personen met kanker te helpen om een gesprek te starten over palliatieve zorg met hun arts. Anderzijds beoogt deze interventie om artsen te ondersteunen bij het gepast reageren op personen met kanker die een gesprek starten over palliatieve zorg. Naar toekomstig onderzoek toe, is het een idee om mantelzorgers ook te betrekken als omgevingsactor en een interventiecomponent te ontwikkelen gericht op gedragsverandering bij mantelzorgers.

Aanbevelingen voor praktijk, beleid en toekomstig onderzoek

Praktijk

Patiënt-arts communicatie:
- meer aandacht besteden aan potentiële rol van patiënten en mantelzorgers in de communicatie over palliatieve zorg en het initiëren van palliatieve zorg
- verantwoordelijkheid nemen bij het stimuleren van personen met kanker om initiatief te nemen in communicatie over palliatieve zorg door positieve, correcte en duidelijke informatie te geven over tijdig communiceren over palliatieve zorg en tijdig initiëren van palliatieve zorg en het belang, de relevantie en de voordelen ervan te benadrukken; door mensen met kanker te helpen bij het

identificeren van hun barrières om een gesprek over palliatieve zorg aan te gaan en hoe deze te overwinnen; door hun eigen positieve houding ten opzichte van palliatieve zorg duidelijk te maken en aan te geven aan de patiënt dat men openstaat om over zo een thema's te praten
- (palliatieve) zorggesprekken en beslissingen initiëren op basis van de wensen en noden van de patiënt in plaats van op basis van de diagnose en prognose.

Mantelzorger-arts communicatie:
- positieve, correcte en duidelijke informatie geven over palliatieve zorg (mogelijkheden) (belang, relevantie, voordelen…).

Deelname aan interventies gericht op *patient empowerment* en tijdige initiatie van palliatieve zorg.

Beleid

Tijdige palliatieve zorg erkennen als zorgprioriteit en dit meenemen op beleidsniveau:
- pleiten voor een hogere bewustwording van het belang van *patient empowerment*, tijdigere communicatie over palliatieve zorg en het tijdig initiëren van palliatieve zorg en om attitudes te veranderen
- een gemeenschapsgerichte benadering toepassen (bijv. mediacampagnes, meelevende gemeenschappen)
- pleiten voor opleiden van professionele zorgverleners over palliatieve zorg en communicatie over palliatieve zorg
- investeren in voorziening van voldoende middelen (expertise, infrastructuur, financiering).

Toekomstig onderzoek

Een gezondheidsbevorderende benadering gebruiken in onderzoek naar palliatieve zorg in plaats van een pathogenesebenadering

Een systeem- of gemeenschapsgerichte benadering gebruiken om tijdige communicatie over palliatieve zorg en tijdige initiatie van palliatieve zorg te verbeteren

Implementatie en evaluatie van de op theorie gebaseerde gedragsinterventie die wij ontwikkeld hebben (*hoofdstuk 6*).

APPENDICES

Appendix 1

TERMS USED IN SEARCH STRATEGIES

Appendix 1

Terms used in MEDLINE search strategy

1 (“Care”[TIAB] OR “caring”[TIAB] OR “Therapy”[TIAB] OR “Therapies”[TIAB] OR “Nursing”[TIAB] OR “Treatment”[TIAB] OR “Treatments”[TIAB] OR “Surgery”[TIAB] OR “Surgeries”[TIAB] OR “disease”[TIAB] OR “ill”[TIAB] OR “illness”[TIAB])

2 (“End-of-life”[TIAB] OR “EoL”[TIAB] OR “palliative”[TIAB] OR “terminal”[TIAB] OR “terminally”[TIAB] OR “comfort”[TIAB] OR “hospice”[TIAB] OR “respite”[TIAB] OR “life’s end”[TIAB] OR “last year of life”[TIAB] OR “LYOL”[TIAB] OR “life-threatening”[TIAB] OR “refusal”[TIAB] OR “withholding”[TIAB] OR “withdrawing”[TIAB] OR “withdrawal”[TIAB] OR “incurable”[TIAB] OR “progressive patient”[TIAB])

3 (“palliative care"[MeSH Terms] OR “hospice and palliative care nursing”[MeSH Terms] OR "terminal care"[MeSH Terms] OR “EoLC”[TIAB] OR “terminally ill”[MeSH Terms] OR “progressive patient care”[MESH Terms] OR “respite care”[MeSH Terms] OR "advance care planning"[MeSH Terms] OR “advance care planning”[TIAB] OR "advance directives"[MeSH Terms] OR “advance directive”[TIAB] OR “advance directives”[TIAB] OR “ulysses contract”[TIAB] OR “ulysses contracts”[TIAB] OR “living wills”[MeSH Terms] OR “living will”[TIAB] OR “living wills”[TIAB] OR “resuscitation orders”[MeSH Terms] OR “resuscitation orders”[TIAB] OR “withholding treatment”[MeSH Terms] OR “euthanasia”[MeSH Terms] OR “euthanasia”[TIAB] OR “sedation”[TIAB] OR “suicide, assisted”[MeSH] OR “assisted dying”[TIAB] OR “assisted suicide”[TIAB] OR “assisted death”[TIAB])

4 (”behavior change”[TIAB] OR “behaviour change”[TIAB] OR ”behavioral change”[TIAB] OR “behavioural change”[TIAB] OR “behavior-oriented”[TIAB] OR “behaviour-oriented”[TIAB] OR “behavioral-oriented”[TIAB] OR “behavioural-oriented”[TIAB] OR "goal directed behavior"[TIAB] OR "goal directed behaviour"[TIAB] OR "automatic behavior"[TIAB] OR "automatic behaviour"[TIAB] OR "impulsive behavior"[TIAB] OR "impulsive behaviour"[TIAB] OR “stigma”[TIAB] OR “discrimination”[TIAB] OR “information-motivation-behavioral skills”[TIAB] OR ”behavior change”[TW] OR “behaviour change”[TW] OR ”behavioral change”[TW] OR “behavioural change”[TW] OR “behavior-oriented”[TW] OR “behaviour-oriented”[TW] OR “behavioral-oriented”[TW] OR “behavioural-oriented”[TW] OR "goal directed behavior"[TW] OR "goal directed behaviour"[TW] OR "automatic behavior"[TW] OR "automatic behaviour"[TW] OR "impulsive behavior"[TW] OR "impulsive behaviour"[TW] OR “stigma”[TW] OR “discrimination”[TW] OR “information-motivation-behavioral skills”[TW])

5, (“model”[TIAB] OR “models”[TIAB] OR “theory”[TIAB] OR “theories”[TIAB] OR “model”[TW] OR “models”[TW] OR “theory”[TW] OR “theories”[TW])

6, “(“Learning theory”[TIAB] OR “learning theories”[TIAB] OR “bandura’s theory”[TIAB] OR “bandura’s model”[TIAB] OR “social cognitive theory”[TIAB] OR “social cognitive theories”[TIAB] OR “social cognitive model”[TIAB] OR “social cognitive models”[TIAB] OR “social cognition theory”[TIAB] OR "social cognition model"[TIAB] OR “social cognition theories”[TIAB] OR “social cognition models”[TIAB] OR “classical conditioning”[TIAB] OR “operant conditioning”[TIAB] OR “operant learning”[TIAB] OR “information processing theory”[TIAB] OR “information processing theories”[TIAB] OR “semantic network theory”[TIAB] OR “mental model theory”[TIAB] OR "elaboration likelihood model”[TIAB] OR "health belief model"[TIAB] OR "protection motivation theory"[TIAB] OR “extended parallel process model”[TIAB] OR "theory of reasoned action"[TIAB] OR “reasoned action theory”[TIAB] OR “theory planned behavior”[TIAB] OR “theory of planned behavior”[TIAB] OR “theory of planned behaviour”[TIAB] OR “planned behavior theory”[TIAB] OR “planned behaviour theory”[TIAB] OR “integrated behavioral model”[TIAB] OR “integrated behavioural model”[TIAB] OR “goal setting theory”[TIAB] OR "dual system model"[TIAB] OR "reflective impulsive model"[TIAB] OR "transtheoretical model"[TIAB] OR "stages of change model"[TIAB] OR "precaution adoption process model"[TIAB] OR "risk communication model"[TIAB] OR "attribution theory"[TIAB] OR "relapse prevention theory"[TIAB] OR “self-regulation theory”[TIAB] OR “self-regulation model”[TIAB] OR “self determination theory”[TIAB] OR "diffusion of innovation theory"[TIAB] OR “innovation diffusion theory”[TIAB] OR “self-efficacy theory”[TIAB] OR “self-efficacy theories”[TIAB] OR "ase model"[TIAB] OR “Learning theory”[TW] OR “learning theories”[TW] OR “bandura’s theory”[TW] OR “bandura’s model”[TW] OR “social cognitive theory”[TW] OR “social cognitive theories”[TW] OR “social cognitive model”[TW] OR “social cognitive models”[TW] OR “social cognition theory”[TW] OR "social cognition model"[TW] OR “social cognition theories”[TW] OR “social cognition models”[TW] OR “classical conditioning”[TW] OR “operant conditioning”[TW] OR “operant learning”[TW] OR “information processing theory”[TW] OR “information processing theories”[TW] OR “semantic network theory”[TW] OR “mental model theory”[TW] OR "elaboration likelihood model”[TW] OR "health belief model"[TW] OR "protection motivation theory"[TW] OR “extended parallel process model”[TW] OR "theory of reasoned action"[TW] OR “reasoned action theory”[TW] OR “theory planned behavior”[TW] OR “theory of planned behavior”[TW] OR “theory of planned behaviour”[TW] OR “planned behavior theory”[TW] OR “planned behaviour theory”[TW] OR “integrated behavioral model”[TW] OR “integrated behavioural model”[TW] OR “goal setting theory”[TW] OR "dual system model"[TW] OR "reflective impulsive model"[TW] OR "transtheoretical model"[TW] OR "stages of change model"[TW] OR "precaution adoption process model"[TW] OR "risk communication model"[TW] OR "attribution theory"[TW] OR "relapse prevention theory"[TW] OR “self-regulation theory”[TW] OR “self-regulation model”[TW] OR “self determination theory”[TW] OR "diffusion of innovation theory"[TW] OR “innovation diffusion theory”[TW] OR “self-efficacy theory”[TW] OR “self-efficacy theories”[TW] OR "ase model"[TW]

7, (“ecological model”[TIAB] OR “ecological models”[TIAB] OR “ecological theory”[TIAB] OR “ecological theories”[TIAB] OR "social support theory"[TIAB] OR “social network theory”[TIAB] OR “social norm theory”[TIAB] OR “ecological model”[TW] OR “ecological models”[TW] OR “ecological theory”[TW] OR “ecological theories”[TW] OR "social support theory"[TW] OR “social network theory”[TW] OR “social norm theory”[TW])

8. =1 AND 2
9. =8 OR 3
10. =4 AND 5
11. =10 OR 6 OR 7
12. =9 AND 11

Terms used in PsychINFO search strategy

1 (Care.tw OR caring.tw OR therapy.tw OR therapies.tw OR nursing.tw OR treatment.tw OR treatments.tw OR surgery.tw OR surgeries.tw OR disease.tw OR ill.tw OR illness.tw)

2 (end-of-life.tw OR eol.tw OR palliative.tw OR terminal.tw OR terminally.tw OR comfort.tw OR hospice.tw OR respite.tw OR last year of life.tw OR LYOL.tw OR life-threatening.tw OR refusal.tw OR withholding.tw OR withdrawing.tw OR withdrawal.tw OR incurable.tw OR progressive patient.tw)

3 (exp palliative care/ OR exp respite care/ OR exp euthanasia/ OR eolc.tw OR advance care planning.tw OR advance directive.tw OR advance directives.tw OR ulysses contract.tw OR living will.tw OR living wills.tw OR resuscitation orders.tw OR euthanasia.tw OR sedation.tw OR assisted dying.tw OR assisted suicide.tw OR assisted death.tw)

4 (*behaviour change/ OR behavior change.tw OR behavioral change.tw OR behaviour change.tw OR behavioural change.tw OR behavior change.tw OR behavioral change.tw OR behaviour change.tw OR behavioural change .tw OR behavior-oriented.tw OR behaviour oriented.tw OR behavioral-oriented.tw OR behavioural oriented.tw OR goal directed behavior.tw OR goal directed behaviour.tw OR automatic behavior.tw OR automatic behaviour.tw OR impulsive behavior.tw OR impulsive behaviour.tw OR information-motivation-behavioral skills.tw OR information-motivation-behavioural skills.tw)

5 (model.tw OR models.tw OR theory.tw OR theories.tw)

6 (exp planned behavior/ OR exp learning theory/ OR learning theory.tw OR learning theories.tw OR social cognitive theory.tw OR social cognitive theories.tw OR social cognitive model.tw OR social cognitive models.tw OR social cognition theory.tw OR social cognition model.tw OR social cognition theories.tw OR social cognition models.tw OR classical conditioning.tw OR operant conditioning.tw OR operant learning.tw OR information processing theory.tw OR information processing theories.tw OR semantic network theory.tw OR mental model theory.tw OR elaboration likelihood model.tw OR health belief model.tw OR protection motivation theory.tw OR extended parallel process model.tw OR theory of reasoned action.tw OR reasoned action theory.tw OR theory planned behavior.tw OR theory planned behaviour.tw OR theory of planned behavior.tw OR theory of planned behaviour.tw OR planned behavior theory.tw OR planned behaviour theory.tw OR integrated behavioral model.tw OR integrated behavioural model.tw OR goal setting theory.tw OR dual system model.tw OR reflective impulsive model.tw OR transtheoretical model.tw OR stages of change model.tw OR precaution adoption process model.tw OR risk communication model.tw OR attribution theory.tw OR relapse prevention theory.tw OR self-regulation theory.tw OR self-regulation model.tw OR self determination theory.tw OR diffusion of innovation theory.mp OR innovation diffusion theory.tw OR self-efficacy theory.tw OR self-efficacy theories.tw OR ase model.tw)

7, (Ecological model.tw OR ecological models.tw OR ecological theory.tw OR ecological theories.tw OR social support theory.tw OR social network theory.mp OR social norm theory.tw)

8. =1 AND 2
9. =8 OR 3
10. =4 AND 5
11. =10 OR 6 OR 7
12. =9 AND 11

Terms used in EMBASE search strategy

1 (‘Care’:ab,ti OR ‘caring’:ab,ti OR ‘therapy’:ab,ti OR ‘therapies’:ab,ti OR ‘nursing’:ab,ti OR ‘treatment’:ab,ti OR ‘treatments’:ab,ti OR ‘surgery’:ab,ti OR ‘surgeries’:ab,ti OR ‘disease’:ab,ti OR ‘ill’:ab,ti OR ‘illness’:ab,ti)

2 (‘end-of-life’:ab,ti OR ‘EoL’:ab,ti OR ‘palliative’:ab,ti OR ‘terminal’:ab,ti OR ‘terminally’:ab,ti OR ‘comfort’:ab,ti OR ‘hospice’:ab,ti OR ‘respite’:ab,ti OR 'life end':ab,ti OR 'lifes end':ab,ti OR ‘last year of life’:ab,ti OR ‘LYOL’:ab,ti OR ‘life-threatening’:ab,ti OR ‘refusal”:ab,ti OR ‘withholding’:ab,ti OR ‘withdrawing’:ab,ti OR ‘withdrawal’:ab,ti OR ‘incurable’:ab,ti OR ‘progressive patient’:ab,ti)

3 (‘Terminal care’/exp OR ‘terminally ill patient’/exp OR ‘palliative therapy’/exp OR ‘palliative nursing’/exp OR ‘hospice nursing’/exp OR ‘progressive patient care’/exp OR ‘respite care’/exp OR ‘living will’/exp OR ‘treatment withdrawal’/exp OR ‘sedation’/exp OR ‘deep sedation’/exp OR ‘Eolc’:ab,ti OR ‘advance care planning’:ab,ti OR ‘advance directive’:ab,ti OR ‘advance directives’:ab,ti OR ‘ulysses contract’:ab,ti OR ‘living will’:ab,ti OR ‘living wills’:ab,ti OR ‘resuscitation orders’:ab,ti OR ‘euthanasia’:ab,ti OR ‘sedation’:ab,ti OR ‘assisted dying’:ab,ti OR ‘assisted suicide’:ab,ti OR ‘assisted death’:ab,ti)

4 (‘Behavior change’ OR ‘behaviour change’ OR ‘behavioral change’ OR ‘behavioural change’ OR ‘behavior-oriented’ OR ‘behaviour-oriented’ OR ‘behavioral-oriented’ OR ‘behavioural-oriented’ OR ‘goal directed behavior’ OR ‘goal directed behaviour’ OR ‘automatic behavior’ OR ‘automatic behaviour’ OR ‘impulsive behavior’ OR ‘impulsive behaviour’ OR ‘stigma’ OR ‘discrimination’ OR ‘information-motivation-behavioral skills’ OR ‘information-motivation-behavioural skills’)

5, (‘model’ OR ‘models’ OR ‘theory’ OR ‘theories’)

6, (‘Social cognitive theory’/exp OR ‘social learning theory’/exp OR ‘health belief model’/exp OR ‘theory of planned behavior’/exp OR ‘theory of reasoned action’/exp OR ‘self regulation model’/exp OR ‘learning theory’ OR ‘learning theories’ OR ‘bandura/s theory’ OR ‘bandura/s model’ OR ‘social cognitive theory’ OR ‘social cognitive theories’ OR ‘social cognitive model’ OR ‘social cognitive models’ OR ‘social cognition model’ OR ‘social cognition models’ OR ‘social cognition theory’ OR ‘social cognition theories’ OR ‘classical conditioning’ OR ‘operant conditioning’ OR ‘operant learning’ OR ‘information processing theory’ OR ‘information processing theories’ OR ‘semantic network theory’ OR ‘mental model theory’ OR ‘elaboration likelihood model’ OR ‘health belief model’ OR ‘protection motivation theory’ OR ‘extended parallel model’ OR ‘theory of reasoned action’ OR ‘reasoned action theory’ OR ‘theory planned behavior’ OR ‘theory planned behaviour’ OR ‘theory of planned behavior’ OR ‘theory of planned behaviour’ OR ‘planned behavior theory’ OR ‘planned behaviour theory’ OR ‘ajzen-fishbein theory’ OR ‘integrated behavioral model’ OR ‘integrated behavioural model’ OR ‘goal setting theory’ OR ‘dual system model’ OR ‘reflective impulsive model’ OR ‘transtheoretical model’ OR ‘stages of change model’ OR ‘precaution adoption process model’ OR ‘risk communication model’ OR ‘attribution theory’ OR ‘relapse prevention theory’ OR ‘self-regulation theory’ OR ‘theory of self regulation’ OR ‘self regulation model’ OR ‘self determination theory’ OR ‘diffusion of innovation theory’ OR ‘innovation diffusion theory’ OR ‘self-efficacy theory’ OR ‘self-efficacy theories’ OR ‘theory of self-efficacy’ OR ‘model of self-efficacy’)
7, (‘Ecological model’ OR ‘ecological models’ OR ‘ecological theory’ OR ‘ecological theories’ OR ‘social support theory’ OR ‘social network theory’ OR ‘social norm theory’)
8. =1 AND 2
9. =8 OR 3
10. =4 AND 5
11. =10 OR 6 OR 7
12. =9 AND 11

Terms used in Web of Science search strategy

1 TS=("care" OR "caring" OR "therapy" OR "therapies" OR "nursing" OR "treatment" OR "treatments" OR "surgery" OR "surgeries" OR "disease" OR "ill" OR "illness")
2 TS=("end-of-life" OR "eol" OR "palliative" OR "terminal" OR "terminally" OR "comfort" OR "hospice" OR "respite" OR “refusal” OR "life's end" OR "last year of life" OR "lyol" OR "life-threatening" OR "withholding" OR "withdrawing" OR “withdrawal” OR "incurable" OR “progressive patient”)
3 TS=(“EoLC” OR “advance care planning” OR "advance directive” OR “advance directives” OR “ulysses contract” OR “ulysses contract” OR “living will” OR “living wills” OR “resuscitation orders” OR “euthanasia” OR “sedation” OR “assisted dying” OR “assisted suicide” OR “assisted death”)
4 TS=(”behavior change” OR “behaviour change” OR “behavioral change” OR “behavioural change” OR “behavior-oriented” OR “behaviour-oriented” OR “behavioral-oriented” OR “behavioural-oriented” OR "goal directed behavior" OR "goal directed behaviour" OR "automatic behavior" OR "automatic behaviour" OR "impulsive behavior" OR "impulsive behaviour" OR “stigma” OR “discrimination” OR “information-motivation-behavioral skills” OR “information-motivation-behavioural skills”)
5, TS=(“model” OR “models” OR “theory” OR “theories”)
6, TS=(“Learning theory” OR “learning theories” OR “bandura’s theory” OR “bandura’s model” OR “social cognitive theory” OR “social cognitive theories” OR “social cognitive model” OR “social cognitive models” OR "social cognition model" OR “social cognition models” OR “social cognition theory” OR “social cognition theories” OR “classical conditioning” OR “operant conditioning” OR “operant learning” OR “information processing theory” OR “information processing theories” OR “semantic network theory” OR “mental model theory” OR "elaboration likelihood model” OR "health belief model" OR "protection motivation theory” OR “extended parallel process model” OR "theory of reasoned action" OR “reasoned action theory” OR “theory planned behavior” OR “theory planned behaviour” OR “theory of planned behavior” OR “theory of planned behaviour” OR “planned behavior theory” OR “planned behaviour theory” OR “integrated behavioral model” OR “integrated behavioural model” OR “goal setting theory” OR "dual system model" OR "reflective impulsive model" OR "transtheoretical model" OR "stages of change model" OR "precaution adoption process model" OR "risk communication model" OR "attribution theory" OR "relapse prevention theory" OR “self-regulation theory” OR “self-regulation model” OR “self determination theory” OR "diffusion of innovation theory" OR “innovation diffusion theory” OR “self-efficacy theory” OR “self-efficacy theories” OR "ase model")
7, TS=(“ecological model” OR “ecological models” OR “ecological theory” OR “ecological theories” OR "social support theory" OR “social network theory” OR “social norm theory”)
8. =1 AND 2
9. =8 OR 3
10. =4 AND 5
11. =10 OR 6 OR 7
12. =9 AND 11

Terms used in CINAHL search strategy

1 (TI “care” OR AB “care” OR TI “caring” OR AB “caring OR TI “therapy” OR AB “therapy" OR TI “therapies” OR AB “therapies” OR TI “nursing” OR AB “nursing” OR TI “treatment*” OR AB “treatment*” OR TI “surgery” OR AB “surgery” OR TI “sugeries” OR AB “sugeries” OR TI “disease” OR AB “disease” OR TI “ill” OR AB “ill” OR TI “illness” OR AB “illness”)

2 (TI “end-of-life OR AB “end-of-life” OR TI “EoL” OR AB “EoL” OR TI “palliative” OR AB “palliative” OR TI “terminal” OR AB “terminal” OR TI “terminally” OR AB “terminally” OR TI “comfort” OR AB “comfort” OR TI “hospice OR AB “hospice” OR TI “respite” OR AB “respite” OR TI “refusal” OR AB “refusal” OR TI “life’s end” OR AB “life’s end” OR TI “last year of life” OR AB “last year of life” OR TI “LYOL” OR AB “LYOL” OR TI “life-threatening” OR AB “life-threatening” OR TI “withholding” OR AB “withholding” OR TI “withdrawing” OR AB “withdrawing” OR TI “withdrawal” OR AB “withdrawal” OR TI “incurable” OR AB “incurable” OR TI “progressive patient” OR AB “progressive patient”)

3 (MH "Palliative Care" OR MH "Hospice and Palliative Nursing" OR MH "Terminal Care+" OR MH "Hospice Care" OR MH “Terminall Ill Patients+” OR MH “Progressive Patient Care” OR MH “Respite Care” OR MH “life support care+” OR MH “advance care planning” OR MH “Advance Directives+” OR MH “Living Wills” OR MH “Euthanasia+” OR MH "Resuscitation Orders" OR MH "Suicide, Assisted" OR MH “Sedation” OR TI “Eolc” OR AB “Eolc” OR TI “advance care planning” OR AB “advance care planning” OR TI “advance directive*” OR AB “advance directive*” OR TI “ulysses contract*” OR AB “ulysses contract*” OR TI “living will*” OR AB “living will*” OR TI “resuscitation orders” or AB “resuscitation orders” OR TI “euthanasia” OR AB “euthanasia” OR TI “sedation” OR AB “sedation” OR TI “assisted dying” OR AB “assisted dying” OR TI “assisted suicide” OR AB “assisted suicide” OR TI “assisted death” OR AB “assisted death” OR TI “resuscitation orders” OR AB “resuscitation orders”)

4 (TX “behavior change” OR TX “behaviour change” OR TX “behavioral change” OR TX “behavioural change” OR TX “behavior-oriented” OR TX “behaviour-oriented” OR TX “behavioral-oriented” OR TX “behavioural-oriented” OR TX “goal directed behavior” OR TX “goal directed behaviour” OR TX “automatic behavior” OR TX “automatic behaviour” OR TX “impulsive behavior” OR TX “impulsive behaviour” OR TX “stigma” OR TX “discrimination” OR TX “information-motivation-behavioral skills” OR TX “information-motivation-behavioural skills”)

5, (TX “model*” OR TX “theory” OR TX “theories)

6, (MH “social learning theory+” OR MH “learning theory” OR MH “Transtheoretical Stages of Change Model" OR MH "Ajzen-Fishbein Theory of Reasoned Action" OR MH "Ajzen's Theory of Planned Behavior" OR TX “Learning theory OR TX “learning theories) OR TX “bandura’s theory” OR TX “bandura’s model” OR TX “social cognitive theory” OR TX “social cognitive model+” OR TX “social cognitive theories” OR TX “social cognition model+” OR TX “social cognition theories” OR TX “classical conditioning” OR TX “operant conditioning” OR TX “operant learning” OR TX “information processing theory” OR TX “information processing theories” OR TX “semantic network theory” OR TX “mental model theory” OR TX “elaboration likelihood model” OR TX “health belief model” OR TX “protection motivation theory” OR TX “extended parallel process model” OR TX “theory of reasoned action” OR TX “reasoned action theory” OR TX “theory planned behavior” OR TX “theory planned behaviour” OR TX “theory of planned behavior” OR TX “theory of planned behaviour” OR TX “planned behavior theory” OR TX “planned behaviour theory” OR TX “integrated behavioral model” OR TX “integrated behavioural model” OR TX “goal setting theory” OR TX “dual system model” OR TX “reflective impulsive model” OR TX “transtheoretical model” OR TX “stages of change model” OR TX “transtheoretical stages of change model” OR TX “precaution adoption process model” OR TX “risk communication model” OR TX “attribution theory” OR TX “relapse prevention theory” OR TX “self-regulation theory” OR TX “self-regulation model” OR TX “self determination theory” OR TX “diffusion of innovation theory” OR TX “innovation diffusion theory” OR TX “self-efficacy theory” OR TX “self-efficacy theories” OR TX “ase model”)

7, (TX “ecological model*” OR TX “ecological theory” OR TX “ecological theories” OR TX "social support theory" OR TX “social network theory” OR TX “social norm theory”)

8. =1 AND 2
9. =8 OR 3
10. =4 AND 5
11. =10 OR 6 OR 7
12. =9 AND 11

Appendix 2

TOPIC INTERVIEW GUIDE STUDY PEOPLE WITH CANCER

Question type	**Question***	**Prompts**
Transition	- What does palliative care[a] mean to you/what might palliative care mean to you? - When should palliative care be initiated? - Who should initiate palliative care?	
Key	- *No palliative care (yet):* have you already thought of talking to someone about palliative care? - *Already palliative care:* before receiving palliative care, did you think of talking to someone about palliative care? - *If yes:* with which professional carer? What did you discuss? Did you start the conversation yourself? What helped and what hindered you when starting a conversation about palliative care with a professional carer? - *If no:* how come? What would help and what would hinder you when starting a conversation about palliative care with a professional carer?	Prompts related to the concepts of the Theory of Planned Behavior (depending on the content of the interview): - What were/would be the advantages/disadvantages of starting a conversation about palliative care with a professional carer? (attitude) - What did/would people in your environment think about palliative care initiation? (social norm) - What did/would people in your environment expect if you were about to start a conversation about palliative care with your professional carer? (social norm) - How confident were you/would you be about starting a conversation about palliative care with your professional carer (perceived behavioral control) Etc…

[a] The interviewer **introduced palliative care as** care that can be provided in addition to oncological care. Oncological care focuses on physical complaints related to the cancer/tumor. The interviewer gave **a definition of palliative care** prior to the first questions related to palliative care. Palliative care was defined as physical, psychological, social and spiritual care for people with a life-threatening illness; which can be introduced early in the disease trajectory; which is not only for people who are about to die in the near future; which depends on the wishes and needs of a patient; and it was explicitly stated that it was not necessarily applicable to the participant.

Appendix 3

QUESTIONNAIRE FOR PEOPLE WITH CANCER

(ORIGINAL, DUTCH VERSION)

Appendix 3

(Identificatienummer participant, in te vullen door interviewer)

Communicatie tussen personen met kanker en hun arts

A) Onderzoeksgegevens

(gegevens voor interviewer, in te vullen door interviewer)

Initialen interviewer: ……..
Datum: …….. / ……. / ……..
Startuur: … : …
Einduur: … : ….

B) Instructies voor de INTERVIEWER

- Vul de vragenlijst **altijd zelf** in.
- Geef bij elke vraag de **juiste antwoordkaart** (waarop de antwoordcategorieën in een vergroot lettertype worden weergegeven)
- Lees bij elke vraag de bijhorende **verduidelijkingen** (‘LEES’).
- De *instructies voor de interviewer* zijn enkel van toepassing **voor u**zelf en worden niet luidop gelezen. Deze instructies zijn heel belangrijk om op te volgen.
- Gelieve slechts **1 antwoord** aan te duiden (indien meerdere antwoorden mogelijk zijn, zal dit bij de vraag vermeld staan).
- PAPIER: Indien er een antwoord voluit geschreven moet worden, gelieve dit in **drukletters** te doen. Bij andere vragen moet u het bolletje inkleuren. Indien de deelnemer een **antwoord wil veranderen**, het huidig antwoord doorkrassen (+’fout’ neerschrijven) en het juiste antwoord opnieuw inkleuren.
- Geef de **beschrijving van palliatieve zorg** pas NA de kennisvragen tav palliatieve zorg
- Geef de **beschrijving van palliatieve zorg** volledig en steeds op dezelfde manier
- Vanaf de vragen met betrekking tot de determinanten (DEEL II, pagina 15), neem de gepaste versie (A, B, C, D) met de **juiste werkwoordtijd** die afhankelijk is van de ervaring met gespecialiseerde palliatieve zorg en het gestelde gedrag en de intentie.
- (!) Indien u opmerkt dat het voor de deelnemer erg moeilijk is om de vragen te beantwoorden (problemen met het abstracte gedrag, het hypothetisch denken), dient u de vragenlijst niet verder af te nemen. U kan overschakelen naar een semi-gestructureerd kwalitatief interview (zie interviewguide ‘De visie van mensen met een kankerdiagnose op communicatie in de zorg’).

C) Instructies door de interviewer te geven aan de DEELNEMER

- Benadrukken dat de antwoorden **vertrouwelijk** worden verwerkt.
  Men kan nooit weten van wie de antwoorden komen.
  De informatie wordt niet doorgegeven **aan de arts** en deze studie zal op geen enkele manier een invloed hebben op de relatie tussen de deelnemer en de arts.
- Uitleggen hoe het interview zal verlopen. De vragenlijst staat op de computer. De vragen worden voorgelezen. Aan de deelnemer wordt gevraagd om deze vragen mondeling te beantwoorden. Indien vragen vaste antwoordcategorieën hebben, dan wordt een gepaste **antwoordkaart** gegeven (*instructies interviewer: toon een willekeurige antwoordkaart ter illustratie*).
- Benadrukken dat er met uitzondering van de kennisvragen **GEEN juist of foute antwoorden** zijn.
- Bij vragen mag de deelnemer **steeds onderbreken** om deze te stellen.
- Op elk moment kan de deelnemer aangeven dat men even **wenst te pauzeren, op een ander moment wenst verder te doen of wenst te stoppen**.

DEEL I

1) GEZONDHEID EN ZIEKTE

LEES*:* We zijn geïnteresseerd in uw gezondheidstoestand en uw kankerdiagnose.
Instructies interviewer: ***GEEN ANTWOORDKAART***

1.1) Wanneer heeft u voor de eerste keer gehoord dat u kanker heeft?

…………… (maand) /……………… (jaar)

1.2) Welk type kanker heeft u?

Instructies interviewer: het antwoord van de participant zo volledig mogelijk neerschrijven (bv. longkanker, sclc).

(Vul in):……

1.3) Heeft u op dit moment uitzaaiingen?

Instructies interviewer: met uitzaaiingen bedoelen we dat er ook kankercellen aanwezig zijn op andere plaatsen in het lichaam dan op de plaats van de primaire kanker.
Instructies interviewer: indien participant zegt dat men het niet weet, dan 'neen' aanduiden.

O Ja *(ga verder naar vraag 1.4 en 1.5)*

O Neen *(ga onmiddellijk verder naar vraag 1.6)*

Indien ja bij 1.3) - 1.4) Waar bevinden de uitzaaiingen zich?

(Vul in):……………………………………………………………………………………………………

Indien ja bij 1.3) - 1.5) Hoe lang heeft u al uitzaaiingen?

O Minder dan een maand
O Meer dan een maand, minder dan een half jaar
O Tussen een half jaar en een jaar
O Tussen een jaar en twee jaar
O Tussen twee jaar en vijf jaar
O Langer dan vijf jaar

1.6) Krijgt u op dit moment therapieën/behandelingen om u te helpen genezen?

O Ja, (*vul in welke therapieën/behandelingen*)………………………………………

O Neen

O Weet ik niet

1.7) Krijgt u op dit moment therapieën/behandelingen om u te helpen om langer te leven?

O Ja, (*vul in welke therapieën/behandelingen*)……………………………………..

O Neen

O Weet ik niet

1.8) Krijgt u op dit moment therapieën/behandelingen om u beter te doen voelen?

O Ja, (*vul in welke therapieën/behandelingen*)……………………………………..

O Neen

O Weet ik niet

LEES*:* We willen ook graag meer weten over de manier waarop u naar uw ziekte kijkt, denkend aan de afgelopen maand.

Instructies interviewer: GROENE ANTWOORDKAART
Instructies interviewer item 1.8: indien de participant om verduidelijking vraagt, het antwoord steeds breed houden. Het gaat om alle klachten/ongemakken/problemen (zowel fysieke, als mentale, als sociale) die een effect kunnen hebben op de kwaliteit van leven.

	Helemaal geen	Een beetje	Matig	Redelijk veel	Zeer veel
1.9) Hoe sterk ervaart u klachten/ongemakken/problemen door uw ziekte?	O	O	O	O	O
1.10) Hoeveel zorgen maakt u zich over uw ziekte?	O	O	O	O	O
1.11) Hoeveel invloed heeft uw ziekte op uw dagelijks leven?	O	O	O	O	O
1.12) Hoeveel invloed heeft de ziekte op uw humeur/stemming?	O	O	O	O	O

2) ALGEMENE COMMUNICATIE

LEES: De volgende vragen gaan over uw communicatie met uw arts, en uw ervaring daarmee.
*Instructies interviewer: **GEEN ANTWOORDKAART***

2.1) Wie is uw behandelende arts? (*Meerdere antwoorden zijn mogelijk)*

O Huisarts
O Oncoloog (medisch oncoloog, oncologisch chirurg, radiotherapeut-oncoloog…)
O Een andere specialist (longarts, gynaecoloog, hematoloog…)
O Andere: …………………………………………………………………………………………
2.2) Met welke arts zou u het meeste praten over het maken van keuzes omtrent uw zorg?
(Vul in):…………………………………………………………………………………………

LEES: In elk van de volgende vragen waarin naar uw arts verwezen wordt, gaat het over uw behandelende arts(en) die u zonet heeft aangeduid, namelijk *[herhaal bovenstaand antw.]***.**

LEES: Er volgen enkele stellingen. Het is de bedoeling dat u aangeeft in welke mate u akkoord gaat met elke stelling.

Instructies interviewer: 'niet van toepassing (NVT)' wordt niet weergegeven op de antwoordkaart van de participant en wordt enkel uitzonderlijk aangeduid. Enkelvoud of meervoud van 'arts' en het werkwoord gebruiken afhankelijk van het aantal opgesomde artsen bij vraag 2.1.
Instructies interviewer: ***BLAUWE ANTWOORDKAART***

	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord	NVT
2.3) Mijn arts(en) heeft/hebben me duidelijk uitgelegd wat de ziekte betekent	O	O	O	O	O	O
2.4) Mijn arts(en) heeft/hebben me de mogelijke behandeling duidelijk uitgelegd	O	O	O	O	O	O
2.5) Ik heb voldoende mogelijkheden om vragen te stellen aan mijn arts(en)	O	O	O	O	O	O
2.6) Mijn arts(en) moedig(t)(en) mij aan om mijn mening te geven	O	O	O	O	O	O
2.7) Ik vind het gemakkelijk om vragen te stellen aan mijn arts(en)	O	O	O	O	O	O

3) PALLIATIEVE ZORG

Kennis over palliatieve zorgmogelijkheden

LEES: De vragen gingen tot nu toe over uw zorg die gericht is op uw kankerdiagnose en over communicatie met uw arts. Een soort zorg niet enkel gericht op uw tumor of kanker, kan 'palliatieve zorg' zijn. Palliatieve zorg is mogelijks nog niet van toepassing voor u, maar wij willen uw mening en idee hierover vragen. Met de eerstvolgende vragen willen wij nagaan wat uw kennis over palliatieve zorg is.

Instructies interviewer: Stellen als een ja-nee vraag. De participant krijgt ***GEEN ANTWOORDKAART****. Indien de participant denkt dat hij het weet, maar niet zeker is, dan antwoordoptie 'ik denk dat ik het weet' aanduiden.*

	Neen, ik weet het niet	Ik denk dat ik het weet	Ja, ik weet het zeker
3.1) Weet u dat palliatieve zorg bestaat?	O	O	O
3.2) Weet u wat palliatieve zorg is?	O	O	O
3.3) Weet u wanneer u palliatieve zorg kan krijgen?	O	O	O

<u>Instructies interviewer:</u> Enkel indien drie maal 'neen' bij 3.1), 3.2) en 3.3), onmiddellijk naar de beschrijving van palliatieve zorg (en dus bij vragen 3.4-3.14 'NVT' aanduiden).

<u>LEES</u>: Er volgen nu enkele uitspraken over palliatieve zorg. Geef aan in welke mate <u>u</u> denkt dat onderstaande uitspraken juist zijn.

Instructies interviewer: GELE ANTWOORDKAART

	Zeker niet juist	Waarschijnlijk niet juist	Waarschijnlijk juist	Zeker juist	NVT
3.4) Palliatieve zorg kan de pijn verlichten	O	O	O	O	O
3.5) Palliatieve zorg is bedoeld om de dood te bespoedigen	O	O	O	O	O
3.6) Palliatieve zorg richt zich ook op de eventuele psychologische problemen	O	O	O	O	O
3.7) Palliatieve zorg wil de dood uitstellen	O	O	O	O	O
3.8) Palliatieve zorg richt zich ook op de eventuele spirituele of existentiële problemen	O	O	O	O	O
3.9) Palliatieve zorg biedt ondersteuning aan de patiënt	O	O	O	O	O
3.10) Palliatieve zorg biedt ondersteuning aan de familie/mantelzorger van de patiënt	O	O	O	O	O
3.11) Palliatieve zorg is gelijk aan terminale zorg	O	O	O	O	O
3.12) Palliatieve zorg is gelijk aan het einde, de dood					
3.13) Palliatieve zorg wil de kwaliteit van leven verhogen	O	O	O	O	O
3.14) Palliatieve zorg is enkel voor bedlegerigen	O	O	O	O	O
	Zeker niet juist	Waarschijnlijk niet juist	Waarschijnlijk juist	Zeker juist	NVT
3.15) Palliatieve zorg kost veel geld voor de patiënt	O	O	O	O	O

Instructies interviewer: de gegeven antwoorden op items 3.4-3.15 <u>niet</u> overlopen

Instructies interviewer: beschrijving palliatieve zorg <u>altijd</u> en <u>op dezelfde manier</u> toelichten (voorlezen + zelf laten lezen); KAART BESCHRIJVING PALLIATIEVE ZORG

<u>LEES</u>: Er zijn heel wat misvattingen over palliatieve zorg. <u>Palliatieve zorg</u> wil de levenskwaliteit verbeteren, zowel voor een persoon die eenlevensbedreigende ziekte heeft als voor de familie van

die persoon. De pijn onder controle houden en aandacht geven aan de lichamelijke, psychologische, sociale en geestelijke noden staan centraal. Palliatieve zorg kan op elk moment van het ziekteproces verleend worden. Het is dus niet enkel voor mensen die op korte termijn kunnen overlijden. Palliatieve zorg pakt ook de problemen aan los van de tumor- of kankerbehandeling. Het kan worden opgestart vanaf dat iemand noden heeft die door de standaardzorg niet opgelost kunnen worden.

Uw ervaring met palliatieve zorg

3.16) Krijgt u palliatieve zorg van een van de volgende gespecialiseerde palliatieve zorgteams: een Palliatieve Thuiszorgequipe; het Palliatief Dagcentrum; een Palliatief Support Team of de Palliatieve Eenheid binnen het ziekenhuis (dit wil zeggen dat u palliatieve zorg ontvangt van een gezondheidszorgverlener, bv. een arts of een verpleegkundige, die gespecialiseerd is in palliatieve zorg)? *Instructies interviewer: vanaf men één keer contact heeft gehad met iemand van een gespecialiseerd palliatief zorgteam, kunnen we dat beschouwen als een 'ja'.* ***GEEN ANTWOORDKAART***

O Ja *(ga verder naar 3.17)*

O Neen *(ga onmiddelijk verder naar 3.18)*

Indien ja bij 3.16 - 3.17) Van wie/waar krijgt u deze gespecialiseerde palliatieve zorg? *(Meerdere antwoorden mogelijk)*
Instructies interviewer: ***ORANJE ANTWOORDKAART***

O Palliatieve thuiszorg (Multidisciplinaire BegeleidingsEquipe)

O Palliatief dagcentrum

O Palliatief Support Team in het ziekenhuis

O Palliatieve eenheid in het ziekenhuis

O Andere (*vul in*):……………………………………………………………………………………

Houding ten opzichte van palliatieve zorg

LEES: Geef aan in welke mate u akkoord gaat met onderstaande stellingen over palliatieve zorg.
Instructies interviewer: ***BLAUWE ANTWOORDKAART***
Instructies interviewer: *3.19) kwaliteit van leven = op dit moment vind ik palliatieve zorg belangrijk om te kunnen behouden waar ik veel belang aan hecht.*

Op dit moment…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
3.18) …ben ik geïnteresseerd in palliatieve zorg	O	O	O	O	O
3.19) …vind ik palliatieve zorg belangrijk om de kwaliteit van mijn leven te verbeteren	O	O	O	O	O
3.20) …vind ik palliatieve zorg nodig voor mij	O	O	O	O	O

3.21) …bezorgt het woord palliatieve zorg mij stress of angst	O	O	O	O	O
3.22) …vind ik het te vroeg om over palliatieve zorg na te denken	O	O	O	O	O
3.23) …maakt denken over palliatieve zorg maakt mij neerslachtig of depressief	O	O	O	O	O

Houding van uw omgeving ten opzichte van palliatieve zorg

LEES: We willen weten hoe u denkt dat uw nabije omgeving (uw partner, familie en/of vrienden) tegenover palliatieve zorg staat.

Instructies interviewer: ***BRUINE ANTWOORDKAART***

Instructies interviewer: 'Ik weet het niet' wordt niet weergegeven op de antwoordkaart van de participant en wordt enkel aangeduid als men het écht niet weet. De antwoordoptie 'NVT' wordt evenmin weergegeven op de antwoordkaart en wordt enkel aangeduid als de participant aangeeft geen partner, familie of vrienden rondom zich te hebben.

Hoeveel van de belangrijke mensen in uw omgeving (partner, familie en vrienden) vinden op dit moment…	Niemand	Enkelen	De helft	De meesten	Iedereen	Ik weet het niet	NVT
3.24) …palliatieve zorg te vroeg voor u	O	O	O	O	O	O	O
3.25) …palliatieve zorg nodig voor u	O	O	O	O	O	O	O
3.26) …palliatieve zorg in het algemeen belangrijk	O	O	O	O	O	O	O
Hoeveel van de belangrijke mensen in uw omgeving (partner, familie en vrienden) vinden op dit moment…	Niemand	Enkelen	De helft	De meesten	Iedereen	Ik weet het niet	NVT
3.27) …dat palliatieve zorg uw eigen keuze is	O	O	O	O	O	O	O

LEES: Ook willen we weten hoe u denkt dat uw arts tegenover palliatieve zorg staat. Het gaat hier om uw de arts die u eerder in het interview beschouwde als de arts met wie u het meeste zou praten over het maken van keuzes omtrent uw zorg.

Instructies interviewer: 'ik weet het niet' is een antwoordoptie, maar wordt niet weergegeven op de antwoordkaart van de participant. Enkel aanduiden indien de participant het écht niet weet.

Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Mijn arts vindt op dit moment…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder akkoord	Helemaal akkoord	Ik weet het niet
3.28) … palliatieve zorg in het algemeen belangrijk	O	O	O	O	O	O
3.39) … palliatieve zorg nodig voor mij	O	O	O	O	O	O
3.30) … palliatieve zorg niet aan de orde voor mij	O	O	O	O	O	O
3.31)… dat palliatieve zorg mijn eigen keuze is	O	O	O	O	O	O

4) GESPREKKEN OVER PALLIATIEVE ZORG

LEES: We gaan verder met enkele vragen over uw ervaring met en uw kijk op gesprekken over het thema palliatieve zorg.

Instructies interviewer: de participant kan telkens antwoorden met 'ja' of 'neen; ***GEEN ANTWOORDKAART.***

	Ja	Neen
4.1) Heeft u reeds een gesprek gehad over palliatieve zorg voor uzelf?	O	O
Instructies interviewer: indien ja, ga verder naar vraag 4.2) en 4.3); indien nee ga onmiddellijk naar vraag 4.4) of 4.7)		
Indien ja bij 4.1) - 4.2) Met wie heeft u reeds een gesprek gehad over palliatieve zorg voor uzelf? *(meerdere antwoorden mogelijk)*		
- Huisarts		
- Oncoloog	O	
- Een andere specialist	O	
- Verpleegkundige	O	
- Verpleegkundige consulent/specialist	O	
- Psycholoog	O	
	O	
- Andere (*vul in*)	…………………..	
	Ja	Neen
4.3) Heeft u dit gesprek over palliatieve zorg zelf gestart?	O	O
Instructies interviewer: indien zelf een gesprek over palliatieve zorg gestart met huisarts, oncoloog of een andere specialist, ga onmiddelijk verder naar DEEL II; in elk ander geval (bv. indien zelf een gesprek over palliatieve zorg gestart maar niet met een huisarts, oncoloog of andere specialist of indien een gesprek over palliatieve zorg gehad met een huisarts, oncoloog, andere specialist, maar dit gesprek niet zelf gestart) ga naar vraag 4.4):		

4.4) Welke arts vindt u het meest geschikt om zelf een gesprek over palliatieve zorg tegen te starten? O Huisarts O Oncoloog O Een andere specialist (longarts, gynaecoloog, hematoloog…)		
Instructies interviewer: - *Indien nog geen gespecialiseerde pz: 4.5) – 4.7)* *(!) Het gaat over de intentie op de dag van het interview* - *Indien reeds gespecialiseerde pz: 4.8)*		
Voor de participanten die nog geen palliatieve zorg krijgen ('neen' op vraag 3.15)		
	Ja	Neen
4.5) Ik ben van plan om binnenkort (komende maand) zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O
Instructies interviewer: indien ja bij 4.5) ga onmiddellijk naar DEEL II		
4.6) Ik ben van plan om op termijn (binnen het komende half jaar) zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O
Instructies interviewer: indien ja bij 4.6) ga onmiddellijk naar DEEL II		
4.7) Ik ben niet van plan om binnen het komende half jaar zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O
Instructies interviewer: indien ja bij 4.7) ga onmiddellijk naar DEEL II		
Voor de participanten die reeds palliatieve zorg krijgen ('ja' op vraag 3.15)		
	Ja	Neen
4.8) Achteraf gezien zou ik voorafgaand aan de opstart van palliatieve zorg wel zelf een gesprek over palliatieve zorg met mijn arts gestart hebben	O	O

DEEL II

(!) Instructies interviewer: afhankelijk van het gestelde gedrag en het al dan niet krijgen van gespecialiseerde palliatieve zorg, de juiste versie erbij nemen (versies verschillen in werkwoordtijden)

Men krijgt nog geen gespecialiseerde palliatieve zorg

- *Als ze nog niet zelf een gesprek over palliatieve zorg gestart hebben met de arts en het niet van plan zijn: voorwaardelijke tijd (**versie A**)*
- *Als ze nog niet zelf een gesprek over palliatieve zorg gestart hebben met de arts en het van plan zijn: tegenwoordige/toekomstige tijd (**versie B**)*
- *Als ze al zelf een gesprek over palliatieve zorg gestart hebben met de arts: verleden tijd (**versie C**)*

Men krijgt wel al gespecialiseerde palliatieve zorg

- *Gesprek over palliatieve zorg met de arts niet zelf gestart: verleden, (voorwaardelijke) tijd (**versie D**)*
- *Gesprek over palliatieve zorg met de arts zelf gestart: verleden tijd (**versie C**)*

DEEL II – VERSIE A

(identificatienummer participant, in te vullen door interviewer)

LEES: Ik heb begrepen dat u niet van plan bent om zelf een gesprek over palliatieve zorg te starten met uw arts. Hierna volgt er nog een hele reeks vragen over dat u zelf een gesprek over palliatieve zorg zou kunnen starten met uw arts. Wij willen namelijk weten hoe u tegenover dit gedrag staat en dus te weten komen waarom u niet meteen zelf een gesprek over palliatieve zorg zou starten met uw arts. Het gaat telkens om de arts die u als het meest geschikt beschouwt om zelf een gesprek over palliatieve zorg tegen te starten (zie antwoord op de vraag 4.4).
(!) Instructies interviewer: indien de participant duidelijk aangeeft dat men niet dieper op dit gedrag wenst in te gaan, dan uitleggen dat je graag zou weten waarom. Hierbij enkel de items 5.1-5.6; 5.13-5.19 en 5.31-5.35 bevragen.

5) DETERMINANTEN VAN HET ZELF STARTEN VAN EEN GESPREK OVER PALLIATIEVE ZORG MET DE ARTS

Kennis

5.1) Was u er voor dit interview van op de hoogte dat u als patiënt zelf een gesprek over palliatieve zorg met uw arts kan starten?
*Instructies interviewer: aanmoedigen om 'ja' of 'neen' te antwoorden, **GEEN ANTWOORDKAART.***

Neen	Ja
○	○

Houding ten opzichte van het zelf starten van een gesprek over palliatieve zorg met uw arts

LEES: Geef aan in welke mate u akkoord gaat met de volgende stellingen die peilen naar uw houding ten opzichte van het zelf starten van een gesprek over palliatieve zorg met uw arts.

*Instructies interviewer: **BLAUWE ANTWOORDKAART***

Ik vind zelf een gesprek over palliatieve zorg starten met mijn arts op dit moment…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
5.2) …belangrijk	○	○	○	○	○
5.3) …nodig voor mij	○	○	○	○	○
5.4) …nog te vroeg voor mij	○	○	○	○	○
5.5) …mijn eigen keuze	○	○	○	○	○
5.6) …de verantwoordelijkheid van mijn arts	○	○	○	○	○

LEES: Er zijn veel redenen waarom iemand WEL of NIET zelf een gesprek over palliatieve zorg met zijn/haar arts zou starten. Geef aan in welke mate u akkoord bent met de volgende stellingen.
*Instructies interviewer: **BLAUWE ANTWOORDKAART***
Instructies interviewer: relatie met gedrag herhaaldelijk benadrukken

Een factor die ervoor zou kunnen zorgen dat ik **WEL** zelf een gesprek over palliatieve zorg met mijn arts start, zou zijn…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
5.7)…dat ik mijn diagnose aanvaard heb	○	○	○	○	○
5.8) …dat ik mij slechter voel dan nu	○	○	○	○	○
5.9) …dat mijn levenskwaliteit vermindert	○	○	○	○	○
5.10)…dat geen behandeling nog effectief blijkt voor mij					
5.11)…dat iemand uit mijn omgeving al palliatieve zorg krijgt of kreeg	○	○	○	○	○
5.12)…dat de woorden ‘palliatieve zorg’ al eerder worden aangehaald bv. door één van de professionele zorgverleners	○	○	○	○	○
5.13) …dat ik al eens een gesprek over palliatieve zorg start/gestart heb met partner, een verpleegkundige…	○	○	○	○	○
Een reden voor mij om **NIET** zelf een gesprek over palliatieve zorg met mijn arts te starten, is	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
5.14) …dat ik mij goed voel	○	○	○	○	○
5.15)…dat ik niet durf	○	○	○	○	○
5.16)…dat ik liever met iemand anders dan mijn arts een gesprek over palliatieve zorg start	○	○	○	○	○
5.17) …dat ik palliatieve zorg associeer met terminale zorg	○	○	○	○	○
5.18) …dat ik niet geïnteresseerd ben in palliatieve zorg	○	○	○	○	○
5.19) …dat ik mijn medische toestand niet kan inschatten	○	○	○	○	○

LEES: In welke mate gaat u akkoord met onderstaande stellingen over de mogelijke voordelen van zelf een gesprek starten over palliatieve zorg met uw arts.

Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Een voordeel van zelf een gesprek starten over palliatieve zorg met mijn arts zou voor mij kunnen zijn…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
5.20)…dat ik mijn zorgwensen kan uitdrukken	O	O	O	O	O
5.21) … dat ik informatie krijg over bv. mijn ziekte, mogelijke behandeling…	O	O	O	O	O
5.22) …dat ik informatie krijg over palliatieve zorg	O	O	O	O	O
5.23) …dat ik emotionele/psychologische ondersteuning krijg	O	O	O	O	O
5.24)…dat ik mij opgelucht voel	O	O	O	O	O
5.25)…dat ik mij gerustgesteld voel	O	O	O	O	O
5.26)…dat palliatieve zorg wordt opgestart	O	O	O	O	O
5.27)…dat ik met palliatieve zorg een comfortabeler leven kan leiden	O	O	O	O	O
5.28)…dat ik het gevoel heb meer controle te hebben over mijn zorg					
5.29) …dat mijn naaste omgeving (bv. partner, kinderen) ontlast wordt	O	O	O	O	O
5.30) …dat mijn arts er niet onverwacht zelf over kan beginnen	O	O	O	O	O
5.31) …dat ik de visie van mijn arts op palliatieve zorg kan weten	O	O	O	O	O

LEES: In welke mate gaat u akkoord met onderstaande stellingen over de mogelijke nadelen van zelf een gesprek starten over palliatieve zorg met uw arts.
Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Een nadeel van zelf een gesprek starten over palliatieve zorg met mijn arts zou voor mij kunnen zijn…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
5.32) …dat ik door het gesprek stress en angst zou voelen	O	O	O	O	O
5.33)…dat ik mij door het gesprek verdrietig zou voelen	O	O	O	O	O
5.34) …dat ik zou opgeven	O	O	O	O	O
5.35) …dat ik mijn arts zou belasten terwijl het nog niet nodig is	O	O	O	O	O
5.36) …dat ik dan zou vooruit lopen op de zaken	O	O	O	O	O

Eigen-effectiviteit

LEES: De volgende stelling gaat over het zelfvertrouwen om zelf een gesprek te starten over palliatieve zorg met uw arts. Geef aan in welke mate u akkoord gaat.
*Instructies interviewer: **BLAUWE ANTWOORDKAART***

5.37) Ik zou er vertrouwen in hebben dat ik in staat ben om zelf een gesprek over palliatieve zorg met mijn arts te starten

Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord
O	O	O	O	O

Sociale norm en sociale invloed

LEES: We willen ook graag weten in welke mate belangrijke personen in uw omgeving (bv. uw partner, kinderen, vrienden, uw arts…) een rol spelen in het niet van plan zijn om zelf een gesprek over palliatieve zorg met uw arts te starten.

LEES: De eerstvolgende vragen gaan over de houding van uw dichtste familie en vrienden over het feit dat u zelf een gesprek over palliatieve zorg met uw arts zou starten.
*Instructies interviewer: **BRUINE ANTWOORDKAART***
Instructies interviewer: De antwoordoptie 'NVT' wordt niet weergegeven op de antwoordkaart en wordt enkel aangeduid als de participant aangeeft geen partner, familie of vrienden rondom zich te hebben.

Hoeveel van de belangrijke mensen in uw omgeving (denk hierbij aan partner, familie en vrienden) zouden op dit moment…	Niemand	Enkelen	De helft	De meesten	Iedereen	Ik weet het niet	NVT
5.38) … het belangrijk vinden dat u zelf een gesprek over palliatieve zorg start met uw arts	O	O	O	O	O	O	O
5.39) … het nodig vinden dat u zelf een gesprek over palliatieve zorg start met uw arts	O	O	O	O	O	O	O

Hoeveel van de belangrijke mensen in uw omgeving (denk hierbij aan partner, familie en vrienden) zouden op dit moment…	Niemand	Enkelen	De helft	De meesten	Iedereen	Ik weet het niet	NVT
5.40) … het te vroeg vinden dat u zelf een gesprek over palliatieve zorg start met uw arts	O	O	O	O	O	O	O
5.41) … vinden dat het uw keuze is of u al dan niet zelf een gesprek over palliatieve zorg start met uw arts	O	O	O	O	O	O	O

<u>LEES:</u> Ook willen wij weten welke houding <u>uw arts</u> heeft over dat u <u>zelf</u> een gesprek over <u>palliatieve zorg</u> zou starten met hem/haar.

Instructies interviewer: 'ik weet het niet' is een antwoordoptie, maar wordt niet weergegeven op de antwoordkaart van de participant. Enkel aanduiden indien de participant het echt niet weet.

Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Mijn arts…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord	Ik weet het niet
5.42) … zou het belangrijk vinden dat ik zelf een gesprek over palliatieve zorg start met hem/haar	O	O	O	O	O	O
5.43) … zou het nodig vinden dat ik zelf een gesprek over palliatieve zorg start met hem/haar	O	O	O	O	O	O
5.44) … zou het te vroeg vinden dat ik zelf een gesprek over palliatieve zorg start met hem/haar	O	O	O	O	O	O

<u>LEES:</u> Geef aan in welke mate u akkoord gaat met de volgende stellingen.

Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Instructies interviewer: De antwoordoptie 'NVT' wordt niet weergegeven op de antwoordkaart en wordt enkel aangeduid als de participant aangeeft geen partner, familie of vrienden/lotgenoten rondom zich te hebben.

Instructies interviewer: items 5.51 en 5.52) Lotgenoten = andere mensen die ook kanker hebben en dus een gelijkaardige ziekte-ervaring hebben.

	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord	NVT
5.45) Ik vind het belangrijk om te doen wat mijn partner/familie/vrienden van mij verwachten mbt het zelf starten van een gesprek over palliatieve zorg met mijn arts	O	O	O	O	O	O
5.46) Mijn partner/familie/vrienden zouden mij aanmoedigen om zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O	O	O	O	O
5.47) Mijn partner/familie/vrienden zouden mij tegenhouden om zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O	O	O	O	O
5.48) Ik vind het belangrijk om te doen wat mijn arts… van mij verwacht	O	O	O	O	O	
5.49) Mijn arts zou mij aanmoedigen om zelf een gesprek over palliatieve zorg te starten met hem/haar	O	O	O	O	O	
5.50) Mijn arts zou mij tegenhouden om zelf een gesprek over palliatieve zorg te starten met hem/haar	O	O	O	O	O	
5.51) Lotgenoten zouden mij aanmoedigen om zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O	O	O	O	NVT O
5.52) Lotgenoten zouden mij tegenhouden om zelf een gesprek over palliatieve zorg te starten met mijn arts	O	O	O	O	O	NVT O

LEES: Geef aan in welke mate onderstaande stellingen u zouden helpen om zelf een gesprek over palliatieve zorg met uw arts te starten.

Instructies interviewer: ***BLAUWE ANTWOORDKAART***

Instructies interviewer: De antwoordoptie 'NVT' wordt niet weergegeven op de antwoordkaart en wordt enkel aangeduid als de participant aangeeft geen partner, familie of vrienden rondom zich te hebben

Instructies interviewer: item 5.63) Lotgenoten = andere mensen die ook kanker hebben en dus een gelijkaardige ziekte-ervaring hebben.

Een factor die ervoor zou kunnen zorgen dat ik zelf een gesprek over palliatieve zorg start met mijn arts, zou zijn…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord	NVT
5.53) …dat mijn familie mij steunt	O	O	O	O	O	O
5.54) …dat mijn familie meegaat tijdens gesprek	O	O	O	O	O	O
5.55) …dat ik vertrouwen heb in mijn arts	O	O	O	O	O	
5.56) …dat ik een sterke band heb met mijn arts	O	O	O	O	O	
5.57) …dat mijn arts mij kent (mijn ingesteldheid, hoe ik met problemen omga, mijn achtergrond…)	O	O	O	O	O	
5.58) …dat mijn arts medelevend is	O	O	O	O	O	
5.59) …dat mijn arts correct en eerlijk is	O	O	O	O	O	
5.60) …dat mijn arts tijd maakt of heeft voor mij	O	O	O	O	O	
Een factor die ervoor zou kunnen zorgen dat ik zelf een gesprek over palliatieve zorg start met mijn arts, zou zijn…	Helemaal niet akkoord	Eerder niet akkoord	Noch niet akkoord, noch akkoord	Eerder wel akkoord	Helemaal akkoord	
5.61) …dat mijn arts open staat voor het palliatieve zorg thema	O	O	O	O	O	
5.62) …dat mijn arts ervaring heeft met palliatieve zorg	O	O	O	O	O	
5.63) …dat mijn lotgeno(t)ot(en) mij steunen	O	O	O	O	O	

LEES: Ook willen wij weten wat lotgenoten doen. Het is mogelijk dat u dit niet zeker weet. Wij zijn benieuwd naar wat u denkt.

*Instructies interviewer: **RODE ANTWOORDKAART***

Instructies interviewer: Lotgenoten = andere mensen die ook kanker hebben en dus een gelijkaardige ziekte-ervaring hebben.

5.64) Denk je dat over het algemeen andere personen met kanker of lotgenoten zelf het gesprek over palliatieve zorg met hun arts starten?

Ik weet zeker dat ze dit NIET doen	Ik denk dat ze dit NIET doen	Ik twijfel of ze dit doen	Ik denk dat ze dit WEL doen	Ik weet zeker dat ze dit WEL doen
O	O	O	O	O

6) ALGEMENE INFORMATIE

Instructies interviewer: indien de participant te vermoeid oogt, kan dit eventueel ingevuld worden met de hulp van de partner of een ander familielid. ***GEEN ANTWOORDKAARTEN, met uitzondering van vraag 6.5.***

LEES: Enkele algemene, informatieve vragen… Deze gegevens zijn van belang als achtergrondinformatie over u en uw huidige situatie.

6.1) Wat is uw geslacht?

O Man

O Vrouw

O X

6.2) Wat is uw leeftijd?

……….. jaar

6.3) Wat is uw moedertaal *(1 antwoord)*

O Nederlands

O Frans

O Duits

O Engels

O Andere: ……………………………………………………………………………………

6.4) In welk land bent u en zijn uw ouders geboren? *(1 antwoord per kolom)*

	uzelf	moeder	vader
België	O	O	O
Frankrijk	O	O	O
Nederland	O	O	O
Duitsland	O	O	O
Italië	O	O	O
Spanje	O	O	O
Portugal	O	O	O
Polen	O	O	O
Turkije	O	O	O
Marokko	O	O	O
Ander land: ……………………….	O	O	O
Ik weet het niet/niet gekend	O	O	O

6.5) In welke mate is uw geloof of levensbeschouwing bepalend voor uw zorgkeuzes?

Instructies interviewer: iemand zijn levensbeschouwing zegt iets over hoe men tegen het leven aan kijkt, wat de waarde ervan is en hoe het geleefd moet worden. ***PAARSE ANTWOORDKAART.***

Helemaal niet	Nauwelijks	In redelijke mate	In hoge mate	In zeer hoge mate
O	O	O	O	O

6.6) Wat is het **hoogste diploma** of de hoogste graad die u **behaald** heeft?

O Lager onderwijs of geen diploma

O Lager secundair onderwijs of secundair onderwijs van de 1ste of 2de graad

O Hoger secundair onderwijs of secundair onderwijs van de 3e graad

O Post-secundair niet hoger-onderwijs (bv. een zevende jaar)

O Hoger onderwijs, niet-universitair

O Universitair onderwijs

6.7) Bent/was u werkzaam in de sector gezondheidszorg?

O Ja

O Neen

6.8) Wat is uw huidige leefsituatie? *(meerdere antwoorden mogelijk)*

O Alleen wonend

O Samenwonend met ouders, echtgeno(o)t(e)/partner, kinderen…

O Wonend in een zorginstelling

O Andere: ……………………………………………………………………………………………

6.9) Heeft u één of meerdere (plus)kinderen?

O Ja

O Neen

Vragen of opmerkingen

Heeft u naar aanleiding van de vragenlijst nog vragen of opmerkingen?

……

……

……

……

LEES: U bent aan het einde van de vragenlijst toegekomen! Hartelijk BEDANKT voor uw deelname aan ons onderzoek

Appendix 4

QUESTIONNAIRE FOR PEOPLE WITH CANCER

(ENGLISH VERSION, translated without backtranslation)

(Participant identification number)

Communication between people with cancer and their physician

A) Research data

(Data for the researcher, to be completed by the interviewer)

Initials of the researcher: ……..
Date: …….. / ……. / ……..
Start time: … : ….
End time: … : ….

B) INSTRUCTIONS FOR THE INTERVIEWER

- Always fill in the survey **yourself**.
- Give the appropriate **reply card** with each question
- Read all sentences for **clarification** (‘READ’)
- The *instructions for the interviewer* only apply **to you** and do not have to be read out loud. These instructions are important to follow up.
- Please only indicate **1 answer** (if more answer are allowed, this will be mentioned)
- PAPER VERSION: if an open question has to be answered, please write the answer down in capital letters. In answering the other questions, a circle has to be colored in. If the participant wants to change a previous answer, cross out the previous answer (+ identify as ‘fault’) and color in the new answer.
- Give **the description of palliative care** AFTER the questions about palliative care knowledge
- Always give **the description of palliative care** completely and in the same way.
- Before starting the **second part** of the survey (part II, page 15), determine on the basis of the participants’ experience with specialized palliative care and their intention or behavior displayed which version and **verb tense** (A, B, C, D) is appropriate.
- (!) If you notice that it is very difficult for the participant to answer the questions (problems with the abstract behavior, with hypothetical thinking) than stop asking questions. You can switch to an open conversation guided by a semi-structured interview schedule.

C) INSTRUCTIONS THAT THE INTERVIEWER SHOULD GIVE TO THE PARTICIPANT

- Emphasize that the **data processing** is **anonymous**.

  It is not possible to know who gave which answers.

  The information will never be reported to the physician and this study will have no influence on the relationship between the participant and the physician.
- Explain **how the interview will proceed**. The survey is on the computer. The questions will be read out. The interviewer will ask the participant to answer these questions verbally. If questions have to be answered with the help of a **reply card**, the appropriate reply card will be given (Instructions for interviewer: illustrate a random reply card).
- Emphasize that there are **NO right or wrong answers**, except for the knowledge questions.
- If the participant has questions during the interview, he/she **can always interrupt** to ask the questions.
- The participant can ask at any time for a **break**, ask to **continue another day** or to **stop**.

PART I

1) HEALTH AND ILLNESS

READ: ***We are interested in your health status and your cancer diagnosis.***
Instructions for interviewer: ***NO REPLY CARD***

1.1) When did you first hear you had cancer?

…………… (month) /……………… (year)

1.2) What type of cancer do you have?

Instructions for interviewer: write down the participant's answer as fully as possible (e.g. lung cancer, sclc).

(Fill in):…………………………………………………………………………………………………

1.3) Do you have metastasis at the moment?

Instructions for interviewer: Metastasis means that there are cancer cells present at other places in the body than the location of the primary cancer.
Instructions for interviewer: if the participant indicates they don't know, check 'No'

O Yes *(go to question 1.4 and 1.5)*

O No *(go to question 1.6)*

If 'Yes' is checked for question 1.3) - 1.4) Where are the metastases located?

(Fill in):…………………………………………………………………………………………………

If 'Yes' is checked for question 1.3) - 1.5) How long have you had metastases?

O Less than a month
O More than a month, less than half a year
O Between half a year and a year
O Between a year and two years
O Between two years and five years
O Longer than five years

1.6) At this moment, are you receiving therapies/treatment to help you get cured?

O Yes, (*Fill in what therapies/treatments*)………………………………………

O No

O I don't know

1.7) At this moment, are you receiving therapies/treatment to help you live longer?

O Yes, (*Fill in what therapies/treatments*)……………………………………..

O No

O I don’t know

1.8) At this moment, are you receiving therapies/treatment to make you feel better?

O Yes, (*Fill in what therapies/treatments*)……………………………………..

O No

O I don’t know

READ*:* We would like to know more about the way you look at your illness, especially in the last month.

Instructions for interviewer: GREEN REPLY CARD
Instructions for interviewer item 1.9: if the participant asks for clarification, always give the broad meaning. We are interested in all complaints/discomforts/problems (physical, mental and social) that could have an effect on the quality of life.

	Not at all	A little	Moderate	Quite a lot	A lot
1.9) How strongly do you experience complaints/discomforts/problems because of your illness?	O	O	O	O	O
1.10) How much do you worry about your illness?	O	O	O	O	O
1.11) How much does your illness influence your daily life?	O	O	O	O	O
1.12) How much does your illness influence your mood/state of mind?	O	O	O	O	O

2) GENERAL COMMUNICATION

READ: The following questions are about communication with your physician, and your experience with communicating.
Instructions for interviewer: ***NO REPLY CARD***

2.1) Who is your treating physician? (*Multiple answers possible)*

O Family doctor/general practitioner
O Oncologist (medical oncologist, cancer surgeon, radiotherapist-oncologist …)
O Another specialist (pneumonologist, gynaecologist, hematologist…)
O Other: …………………………………………………………………………………………

2.2) With which physician would you talk the most about making choices concerning your care?
(Fill in):……………………………………………………………………………………………

READ: In each of the following statements where your physician is mentioned, we mean the treating physician who you just mentioned, who is *[repeat aforementioned response to question 2.1]***.**
READ: We will present you with a few statements. We would like you to indicate to what extent you agree with each statement.
Instructions for interviewer: 'non applicable (NA)' is not shown on the participant's reply card and is only checked as an exception. Use the singular or plural form of 'physician' and the verb, depending on the number of physicians mentioned in question 2.1.
Instructions for interviewer: ***BLUE REPLY CARD***

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	NA
2.3) My physician(s) has/have clearly explained to me what my illness means.	O	O	O	O	O	O
2.4) My physician(s) has/have clearly explained the possible treatment to me.	O	O	O	O	O	O
2.5) I have enough opportunities to ask my physician(s) questions.	O	O	O	O	O	O
2.6) My physician(s) encourage(s) me to express my opinion.	O	O	O	O	O	O
2.7) I find it easy to ask my physician(s) questions.	O	O	O	O	O	O

3) PALLIATIVE CARE

Knowledge about palliative care options

READ: The previous questions were about the care related to your cancer diagnosis and about communication with your physician(s). One type of care that is not solely focused on your tumor or cancer, is 'palliative care'. It's possible that palliative care isn't applicable to your situation yet, but we would still like to know your opinions and ideas about it. The following questions explore your knowledge about palliative care.

Instructions for interviewer: Ask these questions in a yes-or-no format. The participant gets ***NO REPLY CARD****. If the participant report they know it, but aren't sure, check the 'I think I know'-box.*

	No, I don't know	I think I know	Yes, I know for sure
3.1) Are you aware of the existence of palliative care?	○	○	○
3.2) Do you know what palliative care is?	○	○	○
3.3) Do you know when you can get palliative care?	○	○	○

Instructions for interviewer: Only if the three 'No, I don't know'-boxes are checked for questions 3.1), 3.2) and 3.3), skip questions 3.4-3.15) by checking 'NA' and go to the description of palliative care.

READ: The following statements are about palliative care. Please indicate to what extent you think each statement is correct.

Instructions for interviewer: YELLOW REPLY CARD

	Certainly not correct	Probably not correct	Probably correct	Certainly correct	NA
3.4) Palliative care can provide relief from pain.	○	○	○	○	○
3.5) Palliative care intends to hasten death.	○	○	○	○	○
3.6) Palliative care also addresses possible psychological problems.	○	○	○	○	○
3.7) Palliative care intends to postpone death.	○	○	○	○	○
3.8) Palliative care also addresses possible spiritual or existential problems.	○	○	○	○	○
3.9) Palliative care offers support to the patient.	○	○	○	○	○

	Certainly not correct	Probably not correct	Probably correct	Certainly correct	NA
3.10) Palliative care offers support to the patient's family/caregiver.	O	O	O	O	O
3.11) Palliative care equals end-of-life care.	O	O	O	O	O
3.12) Palliative care equals the end, death.	O	O	O	O	O
3.13) Palliative care aims to enhance the quality of life.	O	O	O	O	O
3.14) Palliative care is only for the bedridden.	O	O	O	O	O
3.15) Palliative care costs the patient a lot of money.	O	O	O	O	O

Instructions for interviewer: do not go over the responses given to questions 3.4-3.15
Instructions for interviewer: Always describe palliative care the same way (read aloud + let participant read themselves); CARD DESCRIPTION PALLIATIVE CARE

READ: There are a lot of misconceptions about palliative care. Palliative care aims to enhance the quality of life, both for someone who has a life-threatening illness and for their families. Central aspects of palliative care include controlling the pain and giving attention to physical, psychological, social and spiritual needs. Palliative care can be given at any point during the course of the illness. This means it is not only for people who might die in the near future. Palliative care also tackles problems that are not directly related to the treatment of the tumor or the cancer. It can be initiated from the moment someone has needs that can't be met with standard care.

Your experience with palliative care

3.16) Are you receiving palliative care from one of the following specialised palliative care teams: a 'Palliative Home Care Team'; the 'Palliative Day Centre'; a 'Palliative Support Team' or the Palliative Unit within a hospital (this means that you receive palliative care from a health care professional, e.g. a physician or a medical nurse, specialized in palliative care)?
*Instructions for interviewer: as soon as the participant has had contact once with anyone from a specialised palliative care team, check 'Yes'. **NO REPLY CARD***

O Yes *(go to question 3.17)*

O No *(go to question 3.18)*

If ‘Yes’ is checked for question 3.16) - 3.17) Who is providing this specialist palliative care? *(Multiple answers possible)*
Instructions for interviewer: ***ORANGE REPLY CARD***

O Palliative care at home (Multidisciplinary Guidance Team)

O Palliative Day Centre

O Palliative Support Team in the hospital

O Palliative Unit in the hospital

O Other (*fill in*):………………………………………………………………………………………

Attitude towards palliative care

READ: Please indicate to what extent you agree with the following statements about palliative care.
Instructions for interviewer: ***BLUE REPLY CARD***
Instructions for interviewer: *3.19) quality of life = at this moment I feel palliative care is important to keep the things in life that are important to me.*

At this moment…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3.18) …I am interested in palliative care	O	O	O	O	O
3.19) …I feel palliative care is important to enhance my quality of life	O	O	O	O	O
3.20) …I think palliative care is necessary for me	O	O	O	O	O
3.21) …the words ‘palliative care’ give me stress or anxiety	O	O	O	O	O
3.22) …It is too early to think about palliative care	O	O	O	O	O
3.23) …thinking about palliative care makes me feel low or depressed	O	O	O	O	O

Attitude of the people around you towards palliative care

READ: We would like to know what you think the attitude of the people around you (your partner, family and/or friends) is towards palliative care.

Instructions for interviewer: ***BROWN REPLY CARD***

Instructions for interviewer: 'I don't know' is not shown on the participant's reply card and is only checked if the participant really doesn't know. The response 'NA' (non applicable) also isn't shown on the reply card and is only checked if the participant indicates they don't have a partner, family or friends.

How many of the important people around you (partner, family and friends) think at this moment…	None of them	Some of them	Half of them	Most of them	All of them	I don't know	NA
3.24) …that it is too soon for you to have palliative care	○	○	○	○	○	○	○
3.25) …that palliative care is necessary for you	○	○	○	○	○	○	○
3.26) …that palliative care in general is important	○	○	○	○	○	○	○
3.27) …that palliative care is your own choice	○	○	○	○	○	○	○

READ: We would also like to know what you think the attitude of your physician towards palliative care is. With 'your physician', we mean the physician you mentioned previously in this interview with whom you would talk the most about care choices.

Instructions for interviewer: 'I don't know' is a valid response, but is not shown on the participant's reply card. Check this box only if the participant really doesn't know.

Instructions for interviewer: ***BLUE REPLY CARD***

At this moment, my physician thinks…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	I don't know
3.28) …that palliative care in general is important	○	○	○	○	○	○
3.39) …that palliative care is necessary for me	○	○	○	○	○	○
3.30) … that it is too soon for me to have palliative care	○	○	○	○	○	○
3.31) …that palliative care is my own choice	○	○	○	○	○	○

4) CONVERSATIONS ABOUT PALLIATIVE CARE

READ: We will continue with a few questions about your experience with and your view on conversations about the theme palliative care.

Instructions for interviewer: the participant can answer with 'yes' or 'no'; ***NO REPLY CARD.***

	Yes	No
4.1) Have you ever had a conversation about palliative care for yourself?	○	○
Instructions for interviewer: if 'yes', go to question 4.2) and 4.3); if 'no', go to question 4.4) or 4.7)		
If 'yes' is checked for question 4.1) - 4.2) Who did you have a conversation with about palliative care for yourself? *(multiple answers possible)*		
- Family doctor/general practitioner	○	
- Oncologist	○	
- Another specialist	○	
- Nurse	○	
- Nurse consultant/specialist	○	
- Psychologist	○	
- Other (*fill in*)	………………….	
	Yes	No
4.3) If you had this conversation with a physician (family doctor, oncologist, another specialist), did you start this conversation yourself?	○	○
Instructions for interviewer: if the conversation about palliative care with the family doctor/general practitioner, oncologist or another specialist was started by the participant themselves, go directly to PART II; in any other case (e.g. the participant started a conversation about palliative care themselves, but not with a family doctor/general practitioner, oncologist or another specialist or if the participant has had a conversation with a family doctor/general practitioner, oncologist or another specialist but they didn't start this conversation themselves), go to question 4.4)		
4.4) Which physician do you deem most appropriate to start a conversation about palliative care with? ○ Family doctor/general practitioner ○ Oncologist ○ Another specialist (pneumonologist, gynaecologist, hematologist…)		
Instructions for interviewer: - *If the participant doesn't receive any specialist palliative care: go to questions 4.5) – 4.7)* *(!) The intention on the day of the interview is what's most important* - *If the participant already receives specialist palliative care: go to question 4.8)*		
Questions for participants who don't receive any specialist palliative care yet ('no' is checked for question 3.16)		

	Yes	No
4.5) I'm planning to start a conversation about palliative care with my physician soon (within the month)	○	○
Instructions for interviewer: if 'yes' is checked for question 4.5), go directly to PART II		
4.6) I'm planning to start a conversation about palliative care with my physician in the longer run (within half a year)	○	○
Instructions for interviewer: if 'yes' is checked for question 4.6), go directly to PART II		
4.7) I'm not planning to start a conversation about palliative care with my physician within half a year	○	○
Instructions for interviewer: if 'yes' is checked for question 4.7), go directly to PART II		
Questions for participant who already receive specialist palliative care ('yes' is checked for question 3.16)		
	Yes	No
4.8) Looking back to before I received palliative care, I would have started a conversation myself about it with my physician	○	○

PART II

(!) Instructions for interviewer: dependent on the (intentional) behavior displayed and whether or not the participant is receiving specialized palliative care, take the appropriate second half of this survey (versions are different due to verb tense)

The participant is not (yet) receiving specialized palliative care

- *If they have not yet started a conversation about palliative care with the physician and they are not planning it: verb tense: conditional (**version A**)*
- *If they have not yet started a conversation about palliative care with the physician but they are planning it: verb tense: present/future (**version B**)*
- *If they have started a conversation about palliative care with the physician: past tense (**version C**)*

The participant is receiving specialized palliative care

- *They did not start a conversation about palliative care with the physician: past (conditional) tense (**version D**)*
- *They did start a conversation about palliative care with the physician: past tense (**version C**)*

PART II – VERSION A

(Participant identification number, to be completed by the interviewer)

READ: I understand that you are not planning on starting a conversation about palliative care with your physician. The following questions are about the fact that you could start a conversation about palliative care with your physician. We will ask these questions because we would like to know what your attitude is towards this behavior and to know why you wouldn't start a conversation about palliative care with your physician yourself. When we mention your physician, we always mean the physician you deem most appropriate to have this kind of conversation with (see response to question 4.4).

(!) Instructions for interviewer: if the participant clearly indicates they don't want to elaborate on this behavior, explain that you would like to know why. In this case, only ask questions 5.1-5.6; 5.13-5.19 and 5.31-5.35.

5) FACTORS OF STARTING A CONVERSATION ABOUT PALLIATIVE CARE WITH YOUR PHYSICIAN YOURSELF

Knowledge

5.1) Prior to this interview, were you aware that as a patient you could start a conversation about palliative care with your physician yourself?

*Instructions for interviewer: encourage participant to give yes or no answers, **NO REPLY CARD.***

No	Yes
O	O

Attitude towards starting a conversation about palliative care with your physician yourself

READ: Please indicate to what extent you agree with the following statements about your attitude towards starting a conversation about palliative care with your physician yourself.

*Instructions for interviewer: **BLUE REPLY CARD***

At this moment, I think starting a conversation about palliative care with my physician myself…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5.2) …is important	O	O	O	O	O
5.3) …is relevant to me	O	O	O	O	O
5.4) …is too soon for me	O	O	O	O	O
5.5) …is my own choice	O	O	O	O	O
5.6) …is the responsibility of my physician	O	O	O	O	O

READ: There are a lot of reasons why someone WOULD or WOULD NOT start a conversation about palliative care with their physician themselves. Please indicate to what extent you agree with the following statements.

*Instructions for interviewer: **BLUE REPLY CARD***

Instructions for interviewer: repeatedly emphasize the relation with the behavior

A factor that could **ENCOURAGE** me to start a conversation about palliative care with my physician myself, would be…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5.7)…that I accepted my diagnosis	O	O	O	O	O
5.8) …if I felt worse than I do now	O	O	O	O	O
5.9) …if my quality of life decreased	O	O	O	O	O
5.10)…if no treatment was effective for me any longer					
5.11)…if someone around me had already received/was receiving palliative care	O	O	O	O	O
5.12)…if the words 'palliative care' had been mentioned before, e.g. by one of the health care professionals	O	O	O	O	O
5.13) …if I had already started a conversation about palliative care with a partner, nurse etc.	O	O	O	O	O
A reason for me to **NOT** start a conversation about palliative care with my physician myself, is…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agee
5.14) …that I feel good	O	O	O	O	O
5.15)…that I'm afraid to do so	O	O	O	O	O
5.16)…that I'd rather start a conversation about palliative care with someone other than my physician	O	O	O	O	O
5.17) …that I associate palliative care with end-of-life care	O	O	O	O	O
5.18) …that I'm not interested in palliative care	O	O	O	O	O
5.19) …that I can't assess my medical health status	O	O	O	O	O

READ: Please indicate to what extent you agree with the following statements concerning the possible advantages of starting a conversation about palliative care with your physician yourself.
Instructions for interviewer: ***BLUE REPLY CARD***

An advantage for me of starting a conversation about palliative care with my physician myself would be…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5.20)…that I can express my care wishes	○	○	○	○	○
5.21) … that I could get information about e.g. my illness, possible treatment etc.	○	○	○	○	○
5.22) …that I could get information about palliative care	○	○	○	○	○
5.23) …that I could get emotional/psychological support	○	○	○	○	○
5.24)…that I would feel relieved	○	○	○	○	○
5.25)…that I would feel reassured	○	○	○	○	○
5.26)…that palliative care would be initiated	○	○	○	○	○
5.27)…that I could lead a more comfortable life with palliative care	○	○	○	○	○
5.28)…that I would feel like I had more control over my care					
5.29) …that it would relieve the burden on the people around me (e.g. partner, children)	○	○	○	○	○
5.30) …that my physician wouldn’t bring it up unexpectedly	○	○	○	○	○
5.31) …that I would find out my physician’s opinion about palliative care	○	○	○	○	○

READ: Please indicate to what extent you agree with the following statements concerning the possible disadvantages of starting a conversation about palliative care with your physician yourself.
*Instructions for interviewer: **BLUE REPLY CARD***

A disadvantage for me of starting a conversation about palliative care with my physician myself would be…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
5.32) …that I would feel stressed and anxious because of the conversation	O	O	O	O	O
5.33)…that I would feel sad because of the conversation	O	O	O	O	O
5.34) …that I would give up	O	O	O	O	O
5.35) …that I would burden my physician when it's not necessary yet	O	O	O	O	O
5.36) …that I would get ahead of myself	O	O	O	O	O

Self-efficacy

READ: The following statement is about the self-confidence you feel about starting a conversation about palliative care with your physician yourself. Please indicate to what extent you agree with this statement.
*Instructions for interviewer: **BLUE REPLY CARD***

5.37) I am confident that I would be able to start a conversation about palliative care with my physician myself.

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
O	O	O	O	O

Social norm and social influence

READ: We would also like to know to what extent important people around you (e.g. your partner, children, friends, your physician…) play a role in your choice not to plan to start a conversation about palliative care with your physician yourself.

READ: The following questions are about your closest family and friends' attitude to the fact that you would start a conversation about palliative care with your physician yourself.
*Instructions for interviewer: **BROWN REPLY CARD***
Instructions interviewer: The response NA is not shown on the participant's reply card and is only checked if the participant indicates they don't have a partner, family or friends.

At this moment, how many of the important people around you (partner, family and friends) would…	None of them	Some of them	Half of them	Most of them	All of them	I don't know	NA
5.38) …find it important for you to start a conversation about palliative care with your physician yourself?	O	O	O	O	O	O	O
5.39) …find it relevant for you to start a conversation about palliative care with your physician yourself?	O	O	O	O	O	O	O
5.40) …find it too soon for you to start a conversation about palliative care with your physician yourself?	O	O	O	O	O	O	O
5.41) …think that it's your own choice whether or not you start a conversation about palliative care with your physician yourself?	O	O	O	O	O	O	O

READ: We would also like to know your physician's attitude towards you starting a conversation about palliative care with them yourself.

Instructions for interviewer: 'I don't know' is a valid response, but is not shown on the participant's reply card. Check this box only if the participant really doesn't know.

Instructions for interviewer: ***BLAUWE ANTWOORDKAART***

My physician…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	I don't know
5.42) …would find it important for me to start a conversation about palliative care with him/her myself	O	O	O	O	O	O
5.43) …would find it relevant for me to start a conversation about palliative care with him/her myself	O	O	O	O	O	O
5.44) …would find it too soon for me to start a conversation about palliative care with him/her myself	O	O	O	O	O	O

READ: Please indicate to what extent you agree with the following statements.

Instructions for interviewer: ***BLUE REPLY CARD***

Instructions for interviewer: The response NA is not shown on the participant's reply card and is only checked if the participant indicates they don't have a partner, family or friends.

Instructions for interviewer: questions 5.51 and 5.52) Fellow sufferers = other people that also have cancer and have a similar experience with illness.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	NA
5.45) I find it important to do what my partner/family/friends expect of me concerning starting a conversation about palliative care with my physician myself	O	O	O	O	O	O
5.46) My partner/family/friends would encourage me to start a conversation about palliative care with my physician myself	O	O	O	O	O	O
5.47) My partner/family/friends would stop me from starting a conversation about palliative care with my physician myself	O	O	O	O	O	O
5.48) I find it important to do what my physician expects of me	O	O	O	O	O	
5.49) My physician would encourage me to start a conversation about palliative care with them myself	O	O	O	O	O	
5.50) My physician would stop me from starting a conversation about palliative care with them myself	O	O	O	O	O	

5.51) Fellow sufferers would encourage me to start a conversation about palliative care with my physician myself	O	O	O	O	O	NA O
5.52) Fellow sufferers would stop me from starting a conversation about palliative care with my physician myself	O	O	O	O	O	NA O

READ: Please indicate to what extent the following statements would help you to start a conversation about palliative care with your physician yourself.

Instructions for interviewer: ***BLUE REPLY CARD***

Instructions for interviewer: The response NA is not shown on the participant's reply card and is only checked if the participant indicates they don't have a partner, family or friends.

Instructions for interviewer: question 5.63) Fellow sufferers = other people that also have cancer and have a similar experience with illness.

A factor that could encourage me to start a conversation about palliative care with my physician myself, would be…	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	NA
5.53) …support from my family	O	O	O	O	O	O
5.54) …that my family would come with me during this conversation	O	O	O	O	O	O
5.55) …that I trust my physician	O	O	O	O	O	
5.56) …that I have a strong connection with my physician	O	O	O	O	O	
5.57) …that my physician knows me (my attitudes, how I cope with problems, my background etc.)	O	O	O	O	O	
5.58) …that my physician is empathetic	O	O	O	O	O	
5.59) …that my physician is appropriate and honest	O	O	O	O	O	
5.60) …that my physician makes or has time for me	O	O	O	O	O	
5.61) …that my physician is open to the concept of palliative care	O	O	O	O	O	
5.62) …that my physician has experience with palliative care	O	O	O	O	O	
5.63) …that my fellow sufferer(s) would support me	O	O	O	O	O	

READ: We would also like to know what fellow sufferers do. It's possible that you don't know this for sure. We are curious about what you think.

Instructions for interviewer: ***RED REPLY CARD***

Instructions for interviewer: Fellow sufferers = other people that also have cancer and have a similar experience with illness.

5.64) Do you think that, in general, other people with cancer or fellow sufferers start a conversation about palliative care with their physician themselves?

I am sure they DON'T	I think they DON'T	I don't know whether they do or not	I think they DO	I am sure they DO
O	O	O	O	O

6) GENERAL INFORMATION

Instructions for interviewer: if the participant seems too exhausted, it's possible to complete this part with the help of the partner or another family member. ***NO REPLY CARD, with the exception of question 6.5.***

READ*:* Now we will ask some general, informative questions… This data is important as background information about you and about your current situation.

6.10) What is your sex?

O Man

O Woman

O X

6.11) What is your age?

……….. years

6.12) What is your native language? *(1 answer)*

O Dutch

O French

O German

O English

O Other: ……………………………………………………………………………………

6.13) In which country were you and your parents born? *(1 answer per column)*

	you	mother	father
Belgium	○	○	○
France	○	○	○
The Netherlands	○	○	○
Germany	○	○	○
Italy	○	○	○
Spain	○	○	○
Portugal	○	○	○
Poland	○	○	○
Turkey	○	○	○
Morocco	○	○	○
Other: ……………………….	○	○	○
I don’t know/unknown	○	○	○

6.14) To what extent do your faith or beliefs determine your choices concerning your care?

Instructions for interviewer: someone’s beliefs indicate how they look at life and its value and how it should be lived. ***PURPLE REPLY CARD.***

Not at all	Barely	Somewhat	A lot	Very much
○	○	○	○	○

6.15) What is the **highest qualification** or level of education that you have **achieved**?

○ Primary education or no qualification

○ Lower secondary education (up to age 16)

○ Higher secondary education (age 16-18)

○ Post-secondary further education (e.g. vocational training)

○ Higher education, college (non-university)

○ Higher education, university

6.16) Have you ever worked in health care?

○ Yes

○ No

6.17) What is your current living situation? *(multiple answers possible)*

○ Living alone

○ Living with parents, spouse/partner, children…

○ Living in a healthcare institution

○ Other: ……………………………………………………………………………………….

6.18) Do you have any children or step-children?

O Yes

O No

Questions or remarks

Do you have any questions or remarks in response to the survey?

……

……

……

……

<u>**READ:**</u> You have reached the end of the survey! Thank you VERY much for participating in our research!

Appendix 4

Appendix 5

Topic guide interview study family carers

Question type	Question[a]	Prompts
Transition	In your opinion, did something or somebody partially contribute to the start of palliative care? Who or what facilitated the start of palliative care? Who or what hindered the start of palliative care?	
Key	I would like to understand how you influenced starting to use palliative care. - How did you support the start of palliative care? - I hear you played an active role in the start of palliative care for your seriously ill family member. Who or what helped you with this? - I hear you were not involved in the start of palliative care for your seriously ill family member. Who or what prevented you from being more involved? What would have helped you to be more involved?	Prompts related to the concepts of the Theory of Planned Behavior (depending on the content of the interview): - Which factors/beliefs facilitated or hindered your behaviors related to starting to use palliative care? (attitude) - What did people in your environment think about starting to use palliative care? (subjective norm) - What did people in your environment expect when you were about to behave in ways that contribute to starting to use palliative care? (subjective norm) - How confident were you about behaving in ways related to starting to use palliative care? (perceived behavioral control) Etc.

CURRICULUM VITAE AND LIST OF PUBLICATIONS OF ANNE-LORE SCHERRENS

Curriculum Vitae

Anne-Lore Scherrens, born November 5, 1992 (Brugge, Belgium) graduated with summa cum laude and as primus of the year as MSc in Health Education and Health Promotion (Ghent University, 2015). She also graduated with magna cum laude as Pediatric Nurse (2013). Since 2015 she joined the End-of-Life Care Research Group and Health Promotion Group as a junior researcher. She focused on using behavioral theories to gain insight into factors related to palliative care behaviors among people confronted with serious illness. She was granted a BOF UGent predoctoral fellowship (2017) and FWO predoctoral fellowship (2018).

List of publications

Articles in international peer-reviewed journals:

Piette*, V., Beernaert*, K., Cohen, J., Pauwels, N., **Scherrens**, **A**., van der Werff, J. & L. Deliens (2021). *Health care Interventions Improving and Reducing Quality of Life in children at the End of Life: A Systematic Review*. Pediatric Research [2018 SCI impact factor: 2,88

Robijn, L., Deliens, L., **Scherrens, A.,** Pauwels, N., Pype, P., Rietjes, J. & K. Chambaere (2021). *A systematic review of quality improvement initiatives for continuous sedation until death.* Palliative Medicine, 33(4). [2018 SCI impact factor: 4,956; journal ranking D1; ranking n° 6/98 in Health Care Sciences and Services]

Scherrens A, Beernaert K, Magerat L, Deliens L, Deforche B, Cohen J. (2020). Palliative care utilisation: family carers' behaviours and determinants – a qualitative interview study. *BMJ Supportive and Palliative Care.* [2018 SCI impact factor: 3,208; journal ranking Q1; ranking n° 21/98 in Health Care Sciences and Services]

Scherrens A, Cohen J, Mahieu A, Deliens L, Deforche B, Kim B (2020). The perception of people with cancer of starting a conversation about palliative care: a qualitative interview study. *European Journal of Cancer care* [2018 SCI impact factor: 2,421; journal ranking D1; ranking n° 5/120 in Nursing]

Scherrens A, Beernaert K, Robijn L, Deliens L, Pauwels N, Cohen J, Deforche B (2018). The use of health behavior theories in end-of-life care research: a systematic review. *Palliative Medicine* [2016 SCI impact factor: 4,22; journal ranking Q1; ranking n° 19/154 in Health Care Sciences and Services]

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Book chapter

Cohen J, **Scherrens A.** The physicians-general public divide in attitudes towards euthanasia: influence of cultural context? In: *Boundaries of Life and Changing Conceptions of Birth and Death – Social and Political Contexts of Assisted Reproduction and Assisted dying (2018)*. Beckets, T, Siegers, P. (editors). Springer [published]

Oral presentations given at (inter)national conferences and seminars

Identifying the most important behavioral determinants of starting a conversation about palliative care with the physician: a cross-sectional structured interview study in people with cancer. (2021). Nederlands Vlaamse Wetenschapsdagen Palliatieve Zorg. Tiel.

How can a behavioral theory be used to gain insight into critical factors of health promoting behavior during serious illness? A case example applied to people with incurable cancer starting a conversation about palliative care. (2021). 17th World Congress of the European Association for Palliative Care. Online.

Identifying the most important behavioral determinants of starting a conversation about palliative care with the physician: a cross-sectional structured interview study in people with cancer. (2020). Public Health Research in Palliative care: Towards Solutions for Global Challenges. Online.

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