

# **Identifying and addressing palliative care needs throughout the illness trajectory**

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# **Identifying and addressing palliative care needs throughout the illness trajectory**

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**Doctoral dissertation**

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To cure sometimes,  
To relieve often,  
To comfort always.

*Ambroise Paré, 16<sup>e</sup> eeuw*



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## **Chapters 2-7 are based on the following publications**

### **Chapter 2**

Beernaert K, Deliens L, De Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J. Do patients with chronic life-limiting illness perceive a need for early palliative care? Interview study about experienced care needs and help-seeking from diagnosis onwards. *Accepted for publication in American Journal of Hospice and Palliative Medicine*, 2015. Epub ahead of print. [SCI impact factor (2013): 1.347]

### **Chapter 3**

Beernaert K, Pardon K, Van den Block L, Devroey D, De Laat M, Geboes K, Surmont V, Deliens L, Cohen J. Palliative care needs occur early: a survey study in cancer patients at three phases in the disease trajectory: the curative, the life-prolonging and the most advanced phase. *(Submitted)*

### **Chapter 4**

Beernaert K, Deliens L, De Vleminck A, Devroey D, Pardon K, Van den Block L, Cohen J. Early identification of palliative care needs by family physicians: a qualitative study of barriers and facilitators from the perspective of family physicians, community nurses and patients. *Palliative Medicine*, 2014, 28(6):480-490. [SCI impact factor (2013): 2.845]

### **Chapter 5**

Beernaert K, Van den Block L, Van Thienen K, Devroey D, Pardon K, Deliens L, Cohen J. Perceived role of the family physician in early palliative home care: a qualitative study with family physicians, community nurses and patients. *(Submitted)*

### **Chapter 6**

Beernaert K, Cohen J, Deliens L, Devroey D, Vanthomme K, Pardon K, Van den Block L. Referral to palliative care in COPD and other chronic diseases: A population-based study. *Respiratory Medicine*, 2013, 107(11):1731-9. [SCI Impact factor (2013): 2.917]

### **Chapter 7**

Beernaert K, Deliens L, Pardon K, Van den Block, Devroey D, Chambaere K, Cohen J. What are physicians' reasons for not referring people with life-limiting illnesses to specialist palliative care services? A nationwide survey. *(Submitted)*



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## **PART I**

### **GENERAL INTRODUCTION**



## **CHAPTER 1**

### **GENERAL INTRODUCTION**

## **1.1. Introduction**

During the last decade, new models of palliative care have been developed and recently (2014) the World Health Organization (WHO) has published a resolution on the integration of palliative care<sup>1</sup> which emphasizes the importance of a palliative care approach throughout the illness course and beginning early in the trajectory of a life-limiting (or life-threatening) illness. Influential studies, most notably the one by Jennifer Temel and colleagues (2010)<sup>2</sup>, have shown that an earlier integration of a specialist palliative care service into standard oncology care benefits the quality of life and quality of care of advanced cancer patients. The results of these studies have convincingly put the need for an earlier initiation of palliative care on the agenda. However, these studies are limited in that they only demonstrate the effect of early involvement of specialist palliative care services (and not the advantage of early generalist palliative care approaches), focus only on cancer (and not on other life-limiting illnesses which might benefit from palliative care) and focussed only on advanced stages of the disease (and did not look at the possible benefit for people at earlier phases than what was defined as ‘early’ in these studies).

The present doctoral thesis focusses on palliative care needs and palliative care in both cancer and other chronic life-limiting illnesses throughout the illness trajectory, starting from diagnosis, and the role of generalist and specialist palliative care approaches in tackling these care needs. The driving idea behind it is that, in order to provide valuable information for practice and policy makers in the pursuit of better, and timelier, palliative care for everyone, a thorough understanding is needed of palliative care needs, the possible role of family physicians in palliative care and robust nationwide insights into the patterns (including extent, timing, and reasons) of referrals to specialist palliative care services.

Before addressing the specific research aims of this study, a short introduction will be provided in order to situate this dissertation into the changed and still changing societal, demographical and scientific context in which palliative care plays and will play a very important role. Next, the concepts used in this dissertation will be defined and clarified. I will then describe what is already known and what is not concerning palliative care throughout the illness course, starting from diagnosis, and guide the reader towards the main research objectives and specific research questions of this dissertation. In a subsequent part the different methods used to answer the research questions are described and the outline of this dissertation is specified.

## **1.2. Background**

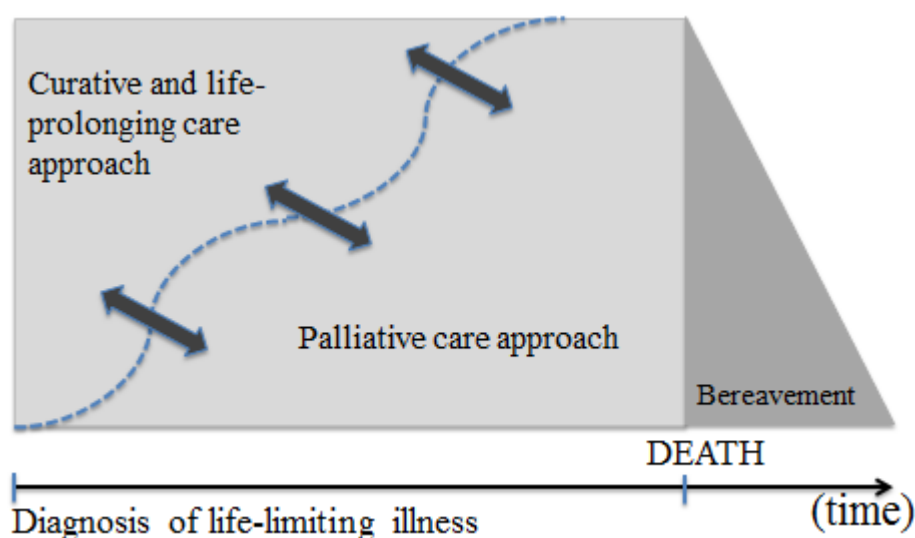
A century ago, death was typically quite sudden, and the leading causes were infections, accidents and childbirth. Today, due to medical advances, sudden death is less common and more people are living longer<sup>3</sup>. Globally, the number of older persons is expected to more than double, from 841 million in 2013 to more than 2 billion in 2050<sup>4</sup>. The global share of people aged 60 years or over increased from 9.2%, in 1990, to 11.7%, in 2013, and is expected to



reach 21.1% by 2050<sup>4</sup>. Towards the end of life, most people will acquire a serious chronic disease such as cancer, chronic obstructive pulmonary disease (COPD), heart failure or dementia that increasingly interferes with their activities until death<sup>5:6</sup>. One likely consequence of this change is a vast increase in the worldwide burden of these chronic and life-limiting diseases<sup>7:8</sup>. An increasing number of people will be living and dying with illnesses that can cause a wide range of physical, psychosocial and spiritual problems<sup>9:10</sup>. This growth in the number of (older) persons with a serious chronic disease will place stress on the health care system. The burden that these demographic and epidemiological developments places on society has been recognized by the World Health Organization (WHO) which has identified care for people at the end of life as an important public health issue<sup>1:9</sup>.

The delivery of palliative care, i.e.. care that assesses and tackles the care needs of these patients with a life-limiting illness has gradually become a recognized goal of medicine, next to curing the disease and prolonging life. The contemporary concept of palliative care finds its origin in the modern hospice movement, pioneered since the 1950s by people such as Dame Cicely Saunders. Hospices were designed and developed to counter the way in which society cared for the dying and the care that was offered for them in hospitals. Hospices, ‘homes for the dying’ were largely designated to accommodate those with terminal cancer for whom all active treatments had failed and whose treatment was exclusively palliative. The underlying philosophy of the modern hospice movement included holistic care (emphasizing emotional, social and spiritual needs) taken hand-in-hand with an approach to managing end-of-life symptoms medically. For many years palliative care largely meant the care for those with cancer in a terminal phase of their illness and people suffering from non-cancer conditions were denied access to these services despite prognoses and symptoms comparable to or worse than many cancers. This is beginning to change with a ‘newer’ model of palliative care, introduced in the early 2000s (see Figure 1), which emphasizes also non-cancer illnesses and earlier, and gradually increasing, involvement of a palliative care approach, possibly together with curative or life-prolonging treatments<sup>9-11</sup>.

*Figure 1.* The model of early palliative care starting from diagnosis onwards as propositioned in this dissertation (adapted from the model of Lynn and Adamson<sup>11</sup>)



As well as the increasing advocacy for earlier involvement of palliative care in the disease trajectory, there is also some research that has indicated its benefits<sup>2;12-14</sup>. The study of Temel and colleagues<sup>2</sup> was a randomized controlled trial of early specialist palliative care referral for 151 patients newly diagnosed with metastatic (stage IV) non-small cell lung cancer vs. usual oncology care. The investigators reported that patients assigned to palliative care intervention had measurably higher quality-of-life scores compared with those who received standard care alone. This study and many similar studies showed a positive effect of early specialist palliative care on quality of life, quality of care and even survival. However, these studies focus only on the effect of specialist palliative care in advanced stages of the cancer disease. Much more research on the topic of early palliative care is needed to provide insights into the need for and the implementation of an early integration of palliative care into regular care.

Despite the expansion of palliative care research in the past decades, empirical research into the palliative care needs of people throughout the illness trajectory, the role of generalist palliative care and palliative care in people suffering from non-cancer conditions are still scarce. However, the assessment and monitoring of the use of and need for palliative care as well as the evaluation of inequalities in the use of palliative care and palliative care services are the main public health functions outlined by the WHO as relevant in designing public policies of improvement<sup>15</sup>.

### **1.3. Definitions of concepts**

#### **1.3.1. Palliative care approach**

Palliative care is defined by the World Health Organization<sup>9</sup> 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.’*

The WHO continues by stating that *‘palliative care:*

- *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 patient 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.’*

Based on this definition, palliative care should be seen as an approach rather than as a specialist health service per se. It is an approach or ‘philosophy’ of healthcare that focusses on individuals and their families who are experiencing suffering from serious medical conditions that limit their quality and/or expected length of life. This approach is compatible with any plan of care, whether goals involve disease-modifying treatments, be they curative or palliative, or whether the exclusive focus is on palliation of symptoms and suffering without disease modification<sup>16</sup>. A palliative care approach can be specialist (when it is delivered by services or specialist palliative care providers specifically trained in palliative care) or generalist (when it is delivered by the regular care providers or services such as community nurses or family physicians).

### **1.3.2. Generalist and specialist palliative care**

As palliative care is often misunderstood as only referring to specialist palliative care, it is important to note that ‘palliative care’ as used in this dissertation is considered as both a part of regular care and as care delivered by specialist palliative care services supporting the regular caregivers.

Generalist palliative care is provided by caregivers not specialized in palliative care but caregivers involved in day-to-day care and support of patients and their caregivers in their care setting (home, hospital or nursing home) for whom palliative care is not the main focus of their clinical practice (for example primary caregivers, oncologists, geriatricians, nurses...)<sup>17</sup> Regular caregivers should, in principle, be able to assess and meet the patient’s palliative care needs under ordinary circumstances or to seek advice from or refer to specialist palliative care services in more complex and challenging situations.

Specialist palliative care is intended to be provided by professionals (and the services they compose) working solely in the field of palliative care and whose main activity is devoted to dealing with complex problems requiring specialist palliative care skills and competencies<sup>17</sup>. In Belgium, in 2002, the federal law on palliative care (in parallel with laws on patient rights and euthanasia) was approved<sup>18</sup>. The ensuing royal decrees regulated minimum service provision in different palliative care settings and funding of palliative care. In Belgium, five types of specialist multidisciplinary palliative care teams can be differentiated<sup>18-22</sup>:

- At home, a multidisciplinary home care team of primary health care professionals with specialist training in palliative care work together with the regular caregivers, as a second line consulting team. After consultation, they can also take over some aspects of the care;
- In the nursing homes, similar to the home care setting, the provision of palliative care usually relies on the regular nursing home caregivers, although they can be supported in this by the coordinating and advisory physician (‘CRA-arts’) of the nursing home and a nurse specialized in palliative care (‘reference nurse’);
- Mobile multidisciplinary support teams can operate throughout the different wards of a hospital. They can support regular caregivers in the hospital by consulting the patient at

the ward he or she is admitted to. The team is composed of at least three halftime members: a physician-specialist, a nurse and a psychologist. These teams are compulsory for every hospital in Belgium;

- Many hospitals also have a specialist inpatient palliative care unit with palliative beds reserved for patients in need of palliative care they cannot receive at home or in their usual place of residence. This unit, usually consisting of 6 to 12 beds spread over several hospital units, or united in an independent unit, has a multidisciplinary team that provides specialized palliative care, coordinated by a palliative care physician. There are 379 such beds available throughout the entire country;
- And finally, there are five palliative day care centres that provide ambulatory palliative support to homecare. These centres have been created as a complementary measure to home care to support informal caregivers by providing specialized palliative care that would not otherwise be possible at home.

In order to guarantee the continuity of care in the different care settings, palliative networks, specialized in palliative care are recognized (and subsidized). These 25 networks are cooperative ventures regarding palliative care between different care providers and care facilities in a particular region. They offer education, advice, information, support and coordination to all care providers who are dealing with palliative care and they coordinate and support palliative care services described above.

### **1.3.3. Palliative care needs**

In this dissertation we use a wide definition of palliative care needs that covers the different dimensions and domains of palliative care. To define these needs we use a conceptual framework based on the WHO definition of palliative care<sup>9</sup>, and scientific articles demarcating the domains that palliative care should cover to reach the highest quality of care and quality of life of the patient and his or her family<sup>23-28</sup>: 1) physical, 2) psychological, 3) social, 4) existential or spiritual, 5) information, communication and planning, 6) financial, 7) support to proxies, 8) coordination and continuity of care, 9) cultural aspects of the care, 10) structure of the care and 11) ethical and legal aspects of the care. In this dissertation we use the term palliative care needs when patients living with a chronic life-limiting disease, irrespective of the phase of the illness course, experience problems and care needs within the domains of palliative care and thus might benefit from a palliative care approach. We acknowledge that the WHO definition may be open to discussion<sup>29</sup> and may change over time. Some people will use a more narrow definition of palliative care, for instance as a specialist type of care pertaining to end-of-life situations<sup>30</sup>, but the WHO definition is considered as a standard definition and, hence, we believe that the use of a broader definition of palliative care needs is warranted.

### **1.3.4. Illnesses indicative of palliative care need**

For this dissertation we deliberately chose to explore palliative care needs and palliative care provision for both cancer and non-cancer patients (see above). Mixed-methods research by Rosenwax et al<sup>31</sup> has led to an estimation of the population that can potentially benefit from palliative care (both specialist and generalist) in the last year of their lives. Through this method minimally those people with cancer, organ failure (i.e. heart, renal, liver failure and COPD), dementia, Parkinson's disease, motor neurone disease, HIV/aids and non-cancerous neoplasm were considered as possibly in need of a palliative care approach.

In this dissertation we mainly focus on three illness groups that categorize most of the illnesses found in the study of Rosenwax. This classification of these three groups is based on the suggestion, found in a substantial part of the literature<sup>32-38</sup>, that most people who are dying non-suddenly tend to – ideal-typically - follow one out of three different trajectories of functional decline: those that maintain comfort and functioning for a substantial period, followed by a short period of evident decline and usually a clear terminal phase – mostly cancer patients; those that have long-term limitations with intermittent exacerbations and some recovery – mostly organ system failure patients (such as COPD or heart failure) and those with a prolonged gradual decline – mostly frail elder patients and those with a dementia-related disease<sup>32-35</sup>. Physical, social, psychological, and existential care needs of patients and their carers are likely to vary according to the trajectory they are following<sup>36,39</sup>. By using this categorization of trajectories we can provide insights into the differences and similarities in probable palliative care needs, treatment goals, interactions with health services, provision of palliative care and barriers to receiving palliative care for different diseases. Eventually, this may help caregivers to plan and deliver appropriate palliative care to meet their patients' and families multidimensional care needs better.

## **1.4. The palliative care needs experienced from diagnosis onwards by people with a life-limiting illness**

Despite growing attention to early integration of palliative care into regular care to improve the patient's quality of life it is still unclear when exactly palliative care needs emerge, and hence how palliative care is to be initiated and can possibly be of added value.

With research showing the referral rates to, mostly, specialist palliative care or studies showing the positive effect of palliative care it is difficult to draw inferences about the individual care needs experienced by patients throughout the illness trajectory irrespective of whether they are formally receiving palliative care<sup>40</sup>. The study by Temel et al<sup>2</sup>, as already outlined above, focussed on advanced cancer patients and did not evaluate which palliative care needs occur (and to what extent) throughout the whole cancer trajectory, starting from diagnosis. Also, this study did not investigate the value of palliative care for, or the presence of palliative care needs in a non-cancer population. To our knowledge, there is only scarce research focusing on palliative care needs starting from diagnosis onwards in various life-limiting illnesses indicative for palliative care.

To gain insight into the need for early palliative care integration from diagnosis onwards we need to know the patient's perspective on the care needs they experience during the trajectory of their illness. Previous research showed that people with advanced organ failure experience similar symptoms to those with advanced cancer<sup>41-43</sup>. However, these studies focussed mostly on the last year or even earlier phases before death and mostly focussed on physical symptoms and sometimes psychological domains. There is a lack of research studying the care needs within all the important domains of palliative care (described above) in earlier stages than the terminal phase of illness<sup>36;41;42;44-50</sup>. Additionally, most studies that did explore care needs in earlier stages e.g. around diagnosis did not look at these needs from a palliative care perspective and also usually focussed only on physical symptoms<sup>51;52</sup>. A better understanding of the needs of patients during the whole course of their illness, starting from diagnosis, can help to better understand the challenges of early palliative care in practice and what possible contribution a palliative care approach could make.

### **1.5. Early generalist palliative care: the role of the family physician**

People now live longer with serious chronic illness and spend much of the time at home, no matter where they eventually die<sup>53</sup>. Many such patients would benefit from a palliative care approach as outlined above<sup>54</sup>. It is, however, neither feasible nor desirable for a specialist palliative care giver (and the health care system) to provide this care approach in every case and throughout the entire disease trajectory<sup>16;55</sup>. There are currently not enough trained caregivers in palliative care and this is not likely to expand in the coming years<sup>56</sup>. Moreover specialist palliative care interventions for every case would be likely to be too costly<sup>57</sup>, especially taking into account also the focus on earlier phases and both cancer and non-cancer illnesses. In this respect the delivery of palliative care by regular caregivers might be an important and more feasible alternative to tackle the palliative care needs of many people.

In many countries, including Belgium, family physicians are responsible for palliative care at the primary level as well as for coordination and continuity of care, care decision-making, providing palliative care and referral to secondary care such as specialist palliative care services in more complex and difficult cases<sup>54;58-61</sup>. Almost 95% of the Belgian population has a family physician, whom they consult regularly (78% at least once a year)<sup>62</sup>. Consequently, they will play a central role in the primary identification and handling of palliative care needs.

However, what sort of palliative care related skills should be considered 'primary' or 'generalist' for a family physician is not known. Most previous studies on the role of the family physician in identifying and handling palliative care needs seem to have focussed on palliative care in cancer patients and during the final months of life usually shortly before death, and thus do not look at the early stages during which needs can emerge<sup>61;63-67</sup>. Delineating and clarifying the tasks for family physicians to integrate palliative care into regular primary care remains a challenge to palliative care as well as to health care policies in the many countries which are striving to support the patient in a home environment and through primary care. Identifying which basic palliative care tasks and skills can be integrated into regular or general practice and identifying ways for the family physician to recognize the

palliative care needs in a timely manner may allow more patients to benefit from a greater attention to their supportive care needs throughout the illness course<sup>55</sup>.

## **1.6. Use of specialist palliative care**

When the complexity and/or severity have reached the point where the generalist feels assistance is needed, it may be more appropriate to refer the patient to a specialist palliative care service. Previous research has repeatedly demonstrated that palliative care services improve the end-of-life care of patients and their families suffering from chronic life-limiting illness<sup>2;68-71</sup>. Despite this fact, many people suffering from a life-limiting illness will not be referred to such a service<sup>61;72</sup>. Moreover, specialist palliative care provision remains uneven, with many more people with cancer being referred than people suffering from non-cancer conditions<sup>61;73;74</sup>, although the latter experience similar care needs and would benefit from care with a palliative intent<sup>31;44;75-79</sup>. Research on the extent and timing of referral to palliative care among non-cancer patients, and especially separate results for COPD, heart failure, dementia and other diseases (e.g. Parkinson's disease), on a population-based level is lacking, with most studies limited to specific settings and services or small sample sizes<sup>80;81</sup>.

To evaluate and understand differences in palliative care referrals between disease groups it would also be important to look at what kind of care and treatment patients who are not referred to any palliative care service are receiving and to investigate the reasons why some patients or patient groups are not using specialist palliative care services. Previous research on reasons or barriers to why some patients or patients groups are not using palliative care services is limited to qualitative explorative studies<sup>82-87</sup>.

Robust population-based and nationwide data are necessary and will make it possible to assess and monitor the use and need for palliative care as well as enable an evaluation of inequalities in the use of specialist palliative care services in order to develop an effective public health policy for improvements of palliative care<sup>9;10;88</sup>.

## **1.7. Study objectives and research questions**

The main objective of this dissertation is to gain insight into how and when palliative care needs of people suffering from a life-limiting illness are recognized and handled. We will focus on the care needs throughout the disease trajectory, the barriers and facilitators in recognizing these palliative care needs by the family physician, the role of the family physician in tackling these care needs, the frequency and timing of referral to specialist palliative care services and the reasons for not referring patients to these services. In this dissertation we focus on three main disease groups that might benefit from palliative care, i.e. cancer, organ failure and dementia.

Three main aims, each with specific research questions, guide this dissertation:

The **first aim** is to explore and evaluate palliative care needs experienced from diagnosis onwards by people with a life-limiting illness. The following research questions will be answered:

- 1) How do patients with cancer, COPD, heart failure or dementia experience certain palliative care needs related to their condition during the whole course of their illness from diagnosis onwards?
- 2) What is the quality of life (based on physical, psychological, social, role and cognitive functioning, physical symptoms, financial issues and spiritual issues) and the proportion of patients with cancer with unmet care needs at three different time point in the cancer trajectory: the phase when people receive (or have planned) treatments with a curative intent, the phase when people receive (or have planned) treatments with a life-prolonging intent and the ‘most advanced’ phase, when people have no more curative or life-prolonging treatments and/or their life expectancy is less than six months?

The **second aim** is to explore the role of family physicians in identifying and handling generalist palliative care needs from diagnosis onwards. The following research questions will be addressed:

- 3) What are the perceived barriers and facilitators affecting the early identification of palliative care needs in patients with cancer, organ failure or dementia from the perspective of family physicians, community nurses and patients?
- 4) What do family physicians, community nurses and people with a life-limiting illness perceive as the role and the tasks of a family physician in tackling the palliative care needs of those with cancer, organ failure or dementia? Do the attributed tasks to the family physicians in generalist palliative care differ according to the timing in the illness course?

The **third aim** is to investigate and describe the use of specialist palliative care services .The following research questions will be addressed:

- 5) How often are patients with organ failure (e.g. COPD, heart failure), dementia or cancer referred to specialist palliative care services? How long before death are these patients referred? And which socio-demographic characteristics are associated with referral and timing of referral to palliative care services within those four disease groups?
- 6) What are the treatment goals for patients who were not referred to these services in the last three months of life?
- 7) What are the most frequent reasons for not referring people to specialist palliative care services? Are these reasons related to patient characteristics?



## 1.8. Methods

To answer the research questions of this dissertation, four different data collections are used, applying both qualitative and quantitative methods. We use qualitative interviews and focus groups to explore palliative care needs of patients (Chapter 2), the barriers and facilitators in recognizing palliative care needs by the family physician (Chapter 4), the perceived role of the family physician in early palliative care (Chapter 5). A quantitative cross-sectional survey study in patients with cancer from the university hospital of Ghent, Belgium, investigates the quality of life and palliative care needs throughout the disease trajectory (Chapter 3). To address the objective regarding specialist palliative care we use, on the one hand, the SENTI-MELC survey, i.e. a weekly registration of all deaths in the practices of the family physicians being a part of Belgian Sentinel Network of General Practitioners (Chapter 6), and on the other hand a post-mortem survey investigating end-of-life care, including specialist palliative care, using a representative sample of official death certificates in Flanders. In this survey the certifying physician is asked to fill in a questionnaire (Chapter 7). The methods are explained in the following paragraphs.

### 1.8.1. Qualitative interviews with patients and separate focus groups with family physicians and community nurses

We performed qualitative focus groups with family physicians as well as separate focus groups with community nurses and semi-structured qualitative face-to-face interviews with patients. Given the scarcity of available data and the exploratory nature of this research topic (palliative care needs and role of family physician in generalist palliative care), a qualitative approach which allows open discussion was deemed necessary<sup>89</sup>. We chose to use focus groups because the group dynamics can uncover unconscious mechanisms<sup>90</sup> and can stimulate the provision of rich and experiential information<sup>91</sup>. For patients we chose to use semi-structured face-to-face interviews as we anticipated more reluctance to disclose personal and delicate information in a group.

Recruitment of family physicians for the focus groups was performed through local family physician peer-review groups across Flanders, i.e. geographically determined groups of family physicians who come together four times a year to discuss various general practice issues. We recruited nurses for separate focus groups by contacting nurse institutions and independent nurses. Three nurses from a palliative home care team were enrolled specifically to ensure experience of the terminal phase of life. Several methods were used to recruit patients: patients who responded to an announcement in a newsletter to all members of a national health care fund and recommendations by hospital physicians and participating palliative home care nurses.

We were interested in the care needs and the identification and handling of these care needs from diagnosis onwards. Therefore, we deliberately created a heterogeneous sample of patients in terms of the time frame between diagnosis and the end of life in order to strive for theoretical generalizability. Moreover, we were interested in different diseases who might

benefit from palliative care, so interviewed patients with life-limiting diseases such as cancer, organ failure and dementia (three typical disease trajectories<sup>34</sup>).

All interviews and focus groups were conducted in Dutch (the native tongue of the participants as well as the researchers) between February and May 2012 in Flanders (Belgium). A semi-structured topic guide was developed to elicit the key domains, with sub-questions to elicit detail. The interviewers asked the participants about 1) multidimensional care needs from diagnosis onwards by giving them examples, 2) how family physicians go about the identification of care needs, 3) which factors may contribute to not discovering certain care needs or discovering them too late, 4) what possible ways of identifying care needs there are and 5) and tasks or expectations of the family physician in handling these care needs across the illness trajectory.

One trained moderator and one observer led each focus group, each lasting about two hours. The author of this dissertation performed all interviews with the patient in their home. Interviews ranged from 45 minutes to two and a half hours.

More details on the method are described in Chapter 2, Part II and Chapter 4 and 5, Part III. We use the interviews with patients to answer research question 1, 3 and 4 of this dissertation. Focus groups (in combination with the interviews) were used to answer research questions 3 and 4.

### *Ethical considerations*

The study protocol was approved by the Ethical Review Board of Brussels University Hospital. We obtained written informed consent from study participants.

### **1.8.2. Quantitative cross-sectional survey study in patients with cancer**

We conducted a cross sectional survey of all patients older than 18 years with a diagnosis of cancer who had a consultation in the department of medical oncology (including the palliative care unit), pneumology or gastroenterology in the large (+/- 1000 bed) University Hospital of Ghent, Belgium between 1 March and 30 June 2014.

All patients coming for a consultation in the included wards were given a questionnaire by someone of the oncology team during their regular follow-up clinic visits. Patients were requested to hand or mail the questionnaire to the researchers. Patients were assessed on one occasion only. Participation rate was 80%.

Patients were asked questions about their quality of life (by the Dutch version of the EORTC QLQ-C30<sup>92</sup>, which is an internationally validated and widely used questionnaire to assess quality of life, psychosocial burden and physical symptoms in cancer patients and questions concerning spiritual issues). We additionally asked from which professional caregivers patients received help and evaluated patients' wishes for more help or assistance for functional scales (physical, role, social, emotional), symptoms (physical) and spiritual issues. Unmet care

needs were investigated by asking the patients whether they wanted more help or attention from a professional caregiver.

Clinical data about the patient were collected through a 1-page questionnaire filled in by the treating oncologist. On the basis of these data it was possible for the researchers to categorize the patients into three different groups across the disease trajectory: the phase when people receive (or have planned) treatments with a curative intent, the phase when people receive (or have planned) treatments with a life-prolonging intent and the ‘most advanced’ phase, when people have no more curative or life-prolonging treatments and/or their life expectancy is less than six months.

More details on the method are described in Chapter 3, Part II. The cross-sectional survey study was used to answer research question 2.

#### *Ethical considerations*

The study protocol was approved by the Ethical Review Board of Ghent University Hospital. We obtained written informed consent from all study participants.

### **1.8.3. Quantitative survey study via The Sentinel Network of General Practitioners**

We used data from the 2009 and 2010 nationwide mortality follow-back study in collaboration with the existing Belgian Sentinel Network of General Practitioners. This network has proved to be a reliable surveillance system for a wide variety of health-related epidemiological data for several decades<sup>61;93-95</sup> and since 2005, a nationwide mortality follow-back study has been set up in Belgium aimed at monitoring the care patients receive during the last three months of life. As general practice is highly accessible for patients often until the very end of life, the family physician can provide a good public health perspective on the care in the last three months of life.

The network is representative for all Belgian family physicians in terms of age, sex and geographical distribution<sup>94;96</sup>. In 2009 and 2010, the data collection used for this thesis, it consisted of respectively 161 and 142 participating practices (both solo and group practices), covering respectively 1.8% and 1.5% of the Belgian population.

Every physician certifying a death certificate in the sample was sent a four-page questionnaire about the end-of-life care (including use of specialist palliative care services) in the corresponding case. This was done for all patients of the family physician’s practice aged one year or more at the time of death. The sample was drawn on a weekly basis as new death certificates came in, minimizing the time period between the sending of the questionnaire and the time of death.

More details on the methods are described in Chapter 6, Part IV, and in other publications with these data<sup>97</sup>. The SENTI-MELC registration study was used to answer research question 5 and 6.

### *Ethical considerations*

Anonymity of patient and physician was preserved. The study protocol was approved by the Ethical Review Board of Brussels University Hospital<sup>98</sup>.

#### **1.8.4. Post-mortem survey using a representative sample of death certificates**

To answer research question 5 and 7, we used the death certificate study, which has been used in several studies on end-of-life issues for many years now<sup>99-101</sup>. It involves a quantitative, mortality follow-back design, looking backwards from death. Data used for this thesis were gathered within Flanders, the Dutch speaking part of Belgium in the first half of 2013.

The Flemish Agency for Care and Health selected a random stratified sample of all death certificates of persons aged one year or older from January 1st to June 30th 2013. Stratification was disproportionately based on the likelihood that an end-of-life care decision (ELD) had been made, as determined by the cause of death (larger sampling fractions were taken for deaths where an ELD was more likely eg those from cancer). Questionnaires were mailed to the physicians who signed the death certificates. The response rate was 60.6%.

Via these questionnaires, patients who had died non-suddenly were identified, and end-of-life care practices (including use of specialist palliative care services) were surveyed. Afterwards, the information from the death certificates was anonymously linked to the questionnaire data.

More details on the methods are described in Chapter 7, Part IV and in a previous publications with this method<sup>102-104</sup>. The death certificate study was used to answer research question 5 and 7.

### *Ethical considerations*

A lawyer was involved in the mailing procedure as trusted third party between responding physicians, researchers and the Flemish Agency for Care and Health to guarantee that completed questionnaires could never be linked to a particular patient or physician. The mailing and anonymity procedures were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, by the Belgian National Disciplinary Board of Physicians, and by the Federal Privacy Commission.

## **1.9. Dissertation outline**

Following this introduction, Chapters 2-7 of the dissertation are based on articles which have been published, accepted or submitted for publication. All of the Chapters can be read independently.

The three main aims of this dissertation are addressed in three separate parts. Each part consist of different Chapters that answer the specific research questions of each aim:

Part II (Chapter 2-3) of this thesis focussed on the care needs of people suffering from a life-limiting illness throughout the disease trajectory, starting from diagnosis. Part II aims to answer research questions 1 and 2 described on page 19.

In Part III we explore the identification of palliative care needs by the family physician and the perceived role of the family physician in early palliative home care. This part aims to answer research questions 3 and 4 described on page 20.

In Part IV we investigate the extent and timing of referral to specialist palliative care services in people suffering from a life-limiting illness and investigate the reasons for not being referred to these services. This part aims to answer research questions 5 to 7 described on page 20.

The final Chapter of the dissertation, Part V, consists of the main findings of the study, reflections on its strengths and limitations, discussion of the findings in the light of current challenges and state of affairs within palliative care research and practice and the implications of the findings for health practice, policy and future research.

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## **PART II**

### **THE PALLIATIVE CARE NEEDS EXPERIENCED FROM DIAGNOSIS ONWARDS BY PEOPLE WITH A LIFE-LIMITING ILLNESS**



## CHAPTER 2

**IS THERE A NEED FOR EARLY PALLIATIVE CARE IN PATIENTS WITH LIFE-LIMITING ILLNESSES? INTERVIEW STUDY WITH PATIENTS ABOUT EXPERIENCED CARE NEEDS FROM DIAGNOSIS ONWARDS.**

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**Abstract**

The early integration of specialist palliative care has been shown to benefit the quality of life of advanced cancer patients. In order to explore whether other seriously ill people and people at even earlier phases would also benefit from early palliative care, we conducted 18 qualitative interviews with people with cancer, COPD, heart failure or dementia at different phases of the illness trajectory about how they experienced care needs related to their disease from diagnosis onwards. Respondents experienced needs within the different domains of palliative care at irrespective of the stages of the illness, the illness type or duration of the illness. This study contributes to the understanding of primary care needs of patients for whom palliative care (not necessarily specialized palliative care) could be beneficial.



## Introduction

In most developed countries an increasing number of people are living with and dying from chronic life limiting illnesses, which can give rise to a wide range of physical, psychosocial and existential care needs. A palliative care approach focuses on the needs of people with a life-limiting illness and their families, emphasizes the early identification of these needs and addresses the processes and outcomes of a range of care dimensions including the physical, psychological, social and existential, and the need for information, communication, planning and decision making, coordination and continuity of care and support of family carers<sup>1-7</sup>. A palliative care approach is more than just terminal care and care delivered by specialist palliative care teams; it is in essence a broader approach to or philosophy of care that targets these physical, psychosocial and existential needs in people with a life-threatening illness and it may also be (and often is) provided by the regular care providers such as the family physician, home care nurses or hospital specialists.

Traditionally, palliative care has been perceived as relevant only for patients with cancer in their last few weeks of life when no other treatments are beneficial, and as care delivered by specialized services. Also the influential studies by Temel et al<sup>8</sup> and others<sup>9;10</sup> showing that earlier integration of specialist palliative care into oncology care benefits quality of life and quality of care only focussed on specialist palliative care services and on cancer patients in an advanced stage of the disease. Recently the World Health Organization (WHO) published a resolution on the integration of palliative care which emphasizes - even more strongly than in previous models and definitions - the importance of a palliative care approach throughout the life course beginning early in the illness for all life-limiting illnesses<sup>11;12</sup>. Moreover, its applicability and usefulness is not limited to cancer but also applies to other life-limiting illnesses<sup>7;13</sup>. Part of this palliative care can be provided by specialist palliative care services, focusing mostly on complex, refractory care needs, but a large part can be delivered by for example family physicians and oncologists, focusing mostly on general management of care needs<sup>14;15</sup>. Despite these theoretically proclaimed models and recommendations, research shows that many in potential need of palliative care are not referred to specialist palliative care and do not get care aimed at comfort or palliation and those who do usually receive such care late in the illness trajectory<sup>16;17</sup>. This might be an indication that patients do not receive the care they need or receive it too late.

However, using only these patterns of referral, i.e. the timing of referral and of the initiation of a palliative care approach, it is difficult to draw inferences about the individual care needs experienced by patients<sup>18</sup>. To gain insight into the need for early palliative care we need to know the patient's perspective on the care needs they experience during the trajectory of their illness. Most previous research on the patient's palliative care needs has been restricted to studies of people in the advanced or terminal stages of illness, those formally or administratively labeled as 'palliative patients' or those receiving care from a specialist palliative care service, which does not allow the exploration of the needs of all those who may potentially benefit from palliative care<sup>19-28</sup>. Additionally, most studies that did explore care needs in earlier stages, e.g. around diagnosis do not look at these needs from a palliative care perspective and usually focus only on physical symptoms<sup>29;30</sup>. Good empirical insights into the

experiences of the patient from a palliative care perspective throughout the disease trajectory, i.e. from diagnosis onwards, are lacking.

Understanding the challenges of early palliative care in practice implies a better understanding of the needs of patients during the whole course of their illness and how these can be considered as part of a palliative care approach. In this context our study explores how patients with a life-limiting illness experience certain care needs related to their condition from diagnosis onwards.

## **Method**

How someone experiences their illness and related care needs is the result of a complex interplay of meanings, events, processes and assumptions constructed by the patient and is best approached by qualitative methods<sup>31</sup>. Face-to-face semi-structured interviews were used in order to explore broadly the respondent's experiences and give them the opportunity to address issues that the researchers may not have anticipated<sup>32</sup>. This article follows the consolidated criteria for reporting qualitative research from the COREQ guidelines<sup>33</sup>. Our study took place between March 2012 and June 2012 in Flanders (Belgium).

### *Recruitment and sampling*

We purposefully selected a heterogeneous sample of patients with a life-limiting illness in terms of how far their illness had advanced since diagnosis in order to allow an in-depth understanding of care needs from early in the illness trajectory. Inclusion criteria are presented in Box 1. Several recruitment methods were used: responders to an announcement in a newsletter distributed among all members of a national health care fund, recommendation by hospital physicians and recommendation by palliative home care nurses. Respondents were included based on our inclusion criteria judged by the physicians or nurses. Inclusion of persons who reacted to the newsletter was decided after deliberation with DD (co-author, a family physician and professor in family medicine) based on information about their diagnosis, medication-use and described health problems. Due to our purposeful sample method we included the first patients meeting the inclusion criteria who were willing to participate.

### *Data collection*

KB performed all interviews at the respondent's home with the respondent alone apart from on four occasions where the respondent wished for someone to be with him/her. We used a semi-structured topic list that had been extensively discussed by the research team. The list began with general questions about the respondent's illness and was followed by a section about care needs and a section about care and treatments (Box 2). All interviews lasted between 45 minutes and two hours and were all audio recorded.

Box 1. Inclusion criteria for patients

We interviewed only patients older than 18 years living at home\* with one of the following illnesses:

1. Cancer which was expected to lead to death in the short or long term;
2. Chronic Obstructive Lung Disease (COPD) with a score from 1 to 4 on the Global Initiative for Chronic Obstructive Lung Disease Scale (GOLD), ie everyone with the clinical diagnosis of COPD;
3. Heart failure with a score of 2-4 on the New York Heart Association (*NYHA*) Functional Classification, ie everyone with the clinical diagnosis of heart failure;
4. Dementia with a Mini Mental State Examination (MMSE) score of 10-26, ie everyone with the clinical diagnosis of mild to moderate dementia capable of doing an interview.

\* Although nursing homes can be home-replacing settings, people living in a nursing home were excluded from our study due to the different context and organization of care and palliative care in those settings.

Box 2. Semi-structured interview guide

Introduction

Part I: general

1. With whom do you live at home?
2. When did you get your diagnosis of the illness?
3. How often do you see your GP?

Part II: care needs

1. Can you give some examples of problems, care needs you experienced since you have known you have this illness?

Prompts: other similar problems/needs, other problems/needs, aid card with categories of needs (physical, information, practical, social, psychological, existential)

2. When did these problems/care needs start?

Prompts: important moments, problems/needs changed, worsened, bettered?

Part III: care provision

1. Which care needs does your GP know/not know about?  
Prompts: how, on time?
2. Did your GP handle your problems/needs?  
Prompts: how, someone else, wanted more help?

### *Analysis*

Interviews were transcribed verbatim and managed with qualitative data software (NVIVO10). We analyzed the data based on thematic content and narrative analysis<sup>34-36</sup>, reflecting the research questions. KB and ADV independently coded a transcript from each respondent type and discussed until they reached agreement. Codes were categorized where possible into core domains of palliative care identified in previous research<sup>1-6</sup>: physical, psychological, social, existential, information, communication, coordination and continuity of care. KB constructed one codebook that was discussed within the research team, after reading all transcripts. KB then applied the codes consistently for the remaining transcripts. We described the problems, i.e. symptoms, concerns and burdens experienced by the respondents. We only use the term 'care needs' if the respondents explicitly expressed a need for help or support for these problems. Additionally, we looked for important moments in the illness course. The research team revised and refined the findings in an iterative comparative process and worked towards consensus about the interpretation and chose quotations that illustrate and support the findings.

### *Ethical considerations*

Ethical approval was obtained from the Ethical Review Board of Brussels University Hospital. We obtained written informed consent from all study participants.

## **Results**

The characteristics of the 18 respondents - with cancer (n=6), dementia (n=6), COPD (n=3) and heart failure (n=3) - are given in table 1.

Respondents identified care needs during their illness course that fell within six core domains of palliative care: physical, psychological, social, existential, information and communication, coordination and continuity of care. Within each domain we identified how patients experienced their problems and care needs. One important care need that did not fit into the above domains was financial need. We ordered the results according to these domains but it is important to note that the problems and care needs were often interwoven and influenced each other so it is more useful not to perceive these domains as fully independent entities.

### *1) Physical and practical needs*

Multiple physical symptoms such as pain, breathlessness, dry mouth and cognitive impairment, depending on the illness, seemed to occur throughout the illness course, already starting from before diagnosis. Persons in a more advanced stage of illness, e.g. patient numbers 6, 9, and 18 in table 1 for example often indicated physical care needs to have increased as the illness advanced. However, many in earlier stages also experienced burdensome physical symptoms such as the side effects of their treatment.

Table 1. Detailed characteristics of patients.

Number	Diagnosis	Time since diagnosis (years)	Age	Sex	Number of general practitioner visits/month	Status at the moment of interview*	Recruitment
1	Cancer: lung	2.5	72	F	>1	No more treatment	Newsletter
2	Cancer: breast	2.5	65	F	<1	Hormonal therapy	Newsletter
3	Cancer: breast	2	63	F	<1	Finished radiation therapy	Oncologist
4	Cancer: brain tumor + metastasis	10	47	M	1	Finished radiation therapy	Oncologist
5	Cancer: colon + metastasis	1	61	M	>1	Chemotherapy	Palliative home care nurse
6	Cancer: lung and renal	2	64	M	<1	Finished chemotherapy	Palliative home care nurse
7	COPD	8	72	M	<1	GOLD III	Pulmonologist
8	COPD	4	48	M	1	-	Newsletter
9	COPD	32	77	F	<1	GOLD IV	Pulmonologist
10	Heart failure	2.5	76	F	>1	-	Newsletter
11	Heart failure	18	65	M	1	-	Newsletter
12	Heart failure	9	74	M	>1	-	Palliative home care nurse
13	Dementia		86	M	>1	-	Newsletter†
14	Dementia	2.5	67	M	<1	-	Newsletter†
15	Dementia	0.5	75	M	<1	MMSE 26	Neurologist
16	Dementia	1.5	74	F	1	MMSE 22	Neurologist
17	Dementia	0.5	82	M	<1	MMSE 24	Neurologist
18	Dementia	1.5	72	F	1	MMSE 19	Neurologist

Abbreviations: GOLD= Global Initiative for Chronic Obstructive Lung Disease; MMSE = Mini Mental State Examination; <1= less, >1= more or 1= once a month, '-' = precise score for GOLD, NYHA, or MMSE not known for patient, but lies within range of inclusion criteria. Patients were in- or excluded after deliberation with DD (co-author, a FP and professor in family medicine) based on their diagnosis, medication-use, described health-problems.

\* Status reported by the hospital specialist or for cancer patients as reported by the patient

† The partner of the patient made contact with the researcher

Remarkably, some respondents did not define their experienced symptoms as problems for which they needed or sought care. Some viewed their physical symptoms, for example dyspnea and memory loss, as side effects inherent to their illness or as a part of getting older, about which not much can be done. This was also the case for memory loss in those with dementia. Some experienced it but claimed not to suffer from it.

*They give you, you know, the day of the week and a date, of course, that doesn't matter to me anymore, so uhm, I have a calendar, that will tell me the date, of course. In and of itself, I have no problem with this. Because you see, if you no longer work, you lose all your reference points. So essentially, I don't find that a problem. (respondent 15 with dementia, male, 75)*

*My body is giving me a lot of grief at the moment, I think it's all related. It's oxygen. If you don't have oxygen, then (...) I'm getting stiffer. That's also because I don't move as much. I think a lot about what I have. I think it all makes sense, rather. It's just the disease, you see. COPOD [COPD], if that starts affecting you, if you start getting symptoms, it is already much too late, isn't it? At least that's what I discovered myself. But no, nobody has found, that is to say, the hospitals don't have a solution for this either, do they? The only thing they can do is ensure it stays stable. (respondent 8 with COPD, male, 48)*

Due to their physical symptoms respondents experienced difficulties with various practical needs such as shopping, cleaning, cooking etc. We found that respondents often managed their practical needs together with their partner and other family members rather than appealing to caregivers such as community nurses:

*Is there also a nurse that comes by? (interviewer)*

*No, no, I don't need that, no, no. My daughter does all my shopping, she takes time off to bring it by and I am to ring her when necessary. (respondent 9 with COPD, female, 77)*

However, for those who had multiple physical limitations that seriously influenced their daily activities or people living alone a structure of formal help was enabled.

*The family doctor said: "Can you still manage by yourself?" I said: "I have somebody to clean, somebody to do the ironing, well, that's to say the ironing service". And I had already inquired about family assistance and these things. And so that woman came by and then the coordinator of Omega [palliative support team] and that will start next Tuesday (respondent 1 with cancer, female, 72)*

## 2) Psychological needs

Irrespective of the kind of underlying life-limiting illness, many respondents seemed to express feelings of anxiety, psychological distress or depression (this latter term was used in the respondents' narratives). Psychological needs were already pronounced early in the illness trajectory for many respondents. They were anxious about what to expect in the future, including in what setting they would be cared for, whether they would suffer and what would happen to their family after they had died. These psychological needs were present throughout

the illness trajectory, but only those with cancer clearly pointed out times in the illness trajectory that were associated with specific moments of anxiety: immediately after diagnosis and shortly after finishing their inpatient treatments when they returned home and did not know what to expect. Stress also increased before follow-up visits to hospital or as more acute concerns started to appear, inciting a fear of 'bad news'. Some people expressing their fears and sadness to their treating physician were referred to a psychologist but in most cases were prescribed medication such as antidepressants without consultation with a psychologist.

*At first, it made me quite depressed. But then I went to the family doctor and I told him: "that railway, that's about 200m away from me" [meaning to throw himself in front of a train]. So I really didn't see a way out anymore. And then he prescribed that Siprolexa [antidepressant]. After a couple of days that really started to kick in and I haven't had any problems since (respondent 6 with cancer, male, 64)*

Those taking antidepressants indicated they felt better after starting using them. However, some were still suffering psychologically at the time of the interview and some expressed a need to talk about their psychological needs to someone who has time, shows empathy and whom they can trust. This was found for all underlying illnesses.

*Sometimes I think I don't want to wake up (silence). And it is still so early to die, no? (respondent 18 with dementia, female, 72)*

*And can you talk to other people about that? (interviewer)*

*(sigh) No, actually, not really.*

*And would you like to talk to somebody about that?*

*Well, yes, actually.*

### *3) Social needs*

Strongly diminishing social contact since diagnosis was a widely experienced problem and this was associated with feelings of loneliness and social isolation in all types of terminal illness trajectories. Some indicated they had shut themselves off from contact with others because of the physical impossibility of going outside or because of an anticipated lack of understanding by others about their problems. Some stated having the feeling that people in their environment avoided contact with them because of their illness. Often, the illness indirectly impacted on their social life because they needed to quit their job or lost their driving license because of it. Most respondents mentioned missing social contact and indicated they realised that going outside would reinvigorate them.

*Also, I have a really great granddaughter, she is four, and then my son asks if I want to come along, you see. And then they go to an amusement park and I'm not coming along. I would love to but it's for an entire day and that is simply*

*more than I can deal with. I have had to cut back a lot in this respect and I am very sorry about that, really (respondent 2 with cancer, female, 65)*

However, some respondents did not, or only temporarily, experience social isolation as a problem. One person with cancer described this period of social isolation as having been shortly after diagnosis and only temporary, while a person with COPD described decreased contact with friends after every physical decline (acute exacerbation) or visit to the hospital. Some experienced increased social isolation as a chance to spend more time with the people that mattered to them most.

Most respondents did not seek help for social problems. They felt unable to communicate these problems to others. For two respondents, one with heart failure and one with cancer, the extra social contact provided by the involvement of volunteer carers from specialist palliative care services provided welcome help in addressing part of their social needs.

#### *4) Existential care needs*

Most respondents spoke about having thought about death and dying but did not clearly indicate it as a problem or care need. Most mentioned not talking about it to others or avoiding the topic in conversation. Some even avoided it during the interview by changing the subject of conversation.

*I'm not afraid of these things, I mean, there's nothing to be afraid of. Being dead doesn't hurt, you know. Everybody dies. So there you go. That's all. (respondent 17 with dementia, male, 82)*

*I don't speak of dying yet. No. (respondent 4 with cancer, male, 47)*

*You are thinking about it though. (interviewer)*

*Yes.*

*And also about, for instance, whether you would like to die at home and things like that.*

*Uhm, actually, I haven't talked about that yet, no. If I... I would like to die at home, yes.*

Further analysis of the narratives of those who claimed not to talk about death and dying to others revealed that they did, however, express concerns or fears during the interviews about what would happen to their families after they die, about where and how they would die and about their funeral. Those who did talk about death and dying to others (usually those with cancer or organ failure) realized they were suffering from a life-threatening illness. They talked with their family physician and their family about their wish to stay at home, about living wills and the option of euthanasia or sedation. They usually wanted to know if they could count on their family physician 'should the time come' in order to relieve them from



unbearable suffering. Talking about death, dying and/or euthanasia took place, with these people, at both earlier and later stages in the illness trajectory.

*Yes, that's what I tell my boys. When I come to die, when I'm terminal, then they know, I would ask for it myself, I don't want to lie there and suffer. That is something you have to determine for yourself. What happens immediately afterwards is cremation and be done with it (respondent 7 with copd, male, 72)*

### 5) Information & communication

Individual differences were found in the need for information about diagnosis and prognosis. While some preferred full disclosure and asked their physician for information others did not and trusted their physician with medication and other care decision-making.

*Doesn't doctor V. tell you why you are undergoing these little tests [MMSE]? (interviewer)*

*No. (respondent 17 with dementia, male, 82)*

*So you don't know what it means?*

*No*

*Don't you want to know?*

*Well, if he doesn't want to tell me, that means I don't need to know.*

It was apparent that some respondents seemed not to know or at least did not mention the exact diagnosis of the illness they have. For the respondents with dementia, only one mentioned the term 'dementia'. Others used such expressions as 'they think I'm going crazy', 'I am losing my memory'.

Most respondents with cancer or organ failure expressed a need to be informed about treatments (options, side effects, the illness course and what they can expect after the treatment), but mentioned that they were often not sufficiently informed by the physician.

*I went into surgery and I thought that was it, you see. And then that doctor came and said they would start radiation therapy in six weeks. I thought 'hah', nothing was said about chemo so I thought it hadn't spread and I was scot-free. I did get that radiation therapy in the end but before I figured out why somebody gets radiation therapy and somebody else chemo... that took a lot of doing and searching. Why are people not informed about these things? I find that very important." (respondent 2 with cancer, female, 65)*

*At first I thought I suffered from asthma. You know, asthma. I went to the family doctor next who said I had COPOD [COPD]. I had no idea what that was and he never explained what it was either. I never stopped to think about that. I did some research on the internet about it. But that doesn't help much in the end. (Respondent 8 with COPD, male, 48)*

Some respondents indicated they did not know who to address to ask specific questions about treatments for physical symptoms, or about practical help in the household. Often they wanted information about euthanasia and palliative sedation, well before they were at a 'terminal' stage, and these information requests were often left unanswered.

*The family doctor admits that those forms are VERY hard to fill out. And I brought them along with me to different places from the outset. You know, there is not a single doctor that is willing to do that with you. They don't have time for that (respondent 1 with cancer, female, 72)*

People in our interviews did not explicitly state they wanted more information about palliative care. We found that respondents not receiving specialist palliative care did not mention or raise the term 'palliative' and even the respondents with heart failure or dementia who we knew received specialist palliative care did not use the term palliative care; only those with cancer did.

#### *6) Coordination and continuity of care*

Problems of coordination of care were generally not experienced or mentioned by the respondents. They stated they trusted physicians to send medical files to each other and that they read these, although some were not sure they did:

*Everything that happens at the specialist is entered into your file. So it is in the file, but does he read it? I couldn't tell you (respondent 16 with dementia, male, 75)*

*So you are not sure he knows? (interviewer)*

*No.*

*You have never spoken a word about that [to your family doctor]?*

*Never. Not a word, nothing.*

*But you assume he knows?*

*Well yes... yes, he has to read it, right? But whether he has the time for it...*

One respondent with cancer mentioned difficulties with the continuity of care between treatments at the hospital and staying at home:

*After the radiation, when I was allowed to go home, I didn't feel I was well prepared for it. Everything in terms of care disappears and you are on your own. You can go to your family doctor when something's wrong, sure, but still,*

*I had many questions about a relapse and whether that was finally it, whether I could relax and .. and... Not much was said about that at all (respondent 3 with cancer, female, 63)*

### 7) Financial

Some respondents with cancer and organ failure complained about financial problems they experienced caused by their illness. These financial problems affected seeking help for their care needs. A respondent with cancer could not afford going to a psychologist and one with COPD said they were not to be able to afford visits to their hospital physician. Respondents complained that bills have to be paid out of pocket and are only later (partially) reimbursed. On the other hand, some also described themselves as lucky having good additional health insurance on top of the basic universal health insurance.

## Discussion

By using individual interviews our study reveals that people with a life-limiting illness experience various problems and care needs, physical, practical, psychological, social, existential and financial, as well as needs for information and communication. These needs were experienced in people with cancer, COPD and heart failure as well as dementia. They occurred at both earlier and later phases in the illness trajectory, starting from diagnosis. As these needs are also the key focus of a palliative care approach our results seem to justify the proposal that a palliative care approach might be relevant throughout the illness trajectory, possibly from diagnosis onwards and not only for patients with (advanced) cancer but also organ failure or dementia.

Our study is innovative because we describe the care needs experienced by a wide range of people who were at different stages of their illness and not at the stage of imminent death as in other studies<sup>27;37;38</sup>. A key finding of this study is that several care needs were experienced irrespective of the stage of the life-limiting illness, illness type or duration of the illness course. Palliative care has been shown to be relevant for these care needs in advanced or terminal patients<sup>39;40</sup> and more recent studies show the benefits (quality of life, satisfaction with care, mood, survival) of an integration of early palliative care with standard care in people with advanced cancer<sup>8</sup>. The care needs expressed by our respondents coincide with the important principles and domains of palliative care according to the WHO<sup>7</sup>. Our results also provide a useful context for the recent resolution of the WHO<sup>11</sup> which emphasizes that palliative care should be integrated early within the continuum of care, possibly together with other treatments, in order to address the needs of people with a life-limiting illness. Our results suggest that a palliative care approach might be beneficial prior to the advanced stages of an illness, and also in life-limiting illnesses other than cancer.

Based on the indication of the presence of palliative care needs from diagnosis onwards it seems warranted that policy and practice measures should be developed or adapted in order to enable and stimulate the integration of a palliative care approach into the care continuum. At

present, in health care policies and practices in many countries including Belgium, the emphasis is still on the terminal phase<sup>11</sup>. The focus on reducing suffering and multidimensional care needs is often made only after life-prolonging treatment is deemed ineffectual and death is imminent<sup>41;42</sup>. Yet, it has been demonstrated repeatedly that prognostication of death is not a good basis on which to initiate palliative care as it is often overestimated, which means many patients will not get palliative care or will get it too late<sup>43</sup>. More recent models of palliative care try to overcome this prognosis related structural barrier and recommend a 'needs-based' approach<sup>7</sup>. Although such an approach may overcome the prognosis barrier, it remains questionable whether it is the magic bullet to bring about the practice of early palliative care, considering the manifold factors that hamper the timely identification by health professionals of care needs. Notable in our study was the variation with which respondents voiced their problems and needs. In our interviews care needs were often described vaguely by the respondents and were elucidated only later in the in-depth interviews. Also, respondents seemed to vary in the manner and extent to which they want professional caregivers involved and did not always define their problems as involving the need for professional care. Hence, a needs-based approach can only successfully lead to an early and integrated palliative care approach if adequate needs-assessment methods or techniques are also instituted. Therefore, professional caregivers - with an important role for the family physician - should take the responsibility to assess and recognize the patients' primary palliative care needs in a timely manner (Chapter 4).

Our findings suggest a complexity of care needs and a variation in how people experience their care needs and deal with them. A multitude of types of care can probably address these care needs. The bulk of care is often provided by family carers throughout the illness course and certain care needs will be met by them; other important aspects of care will be delivered in general hospitals and in primary care<sup>44</sup> and by the caregivers in these settings and yet others are best addressed by additional professional caregivers, including specialist palliative care providers<sup>21</sup>. Hence we are not suggesting that one particular health professional should take the responsibility for dealing with all dimensions of care needs, or that specialist palliative care services should be involved with every patient. However, the identified needs experienced throughout the trajectory of various life-limiting illnesses demand attention from the health care system in order to integrate early palliative care through elucidation of needs, support and promotion of the roles of family physicians, family carers, hospital specialists and specialist palliative care teams.

Some of our findings are perhaps context specific. For instance, in Belgium a legal framework for euthanasia has been in place for over 10 years now, which makes it likely that communication about this topic (and other end-of-life care issues ensuing from this discussion) may be more open than in other countries where such a legal framework does not exist. The context of organization of the health care system (including the reimbursement system) may also strongly influence the extent to which patients experience financial problems or problems of coordination of care.

Certain limitations of the study need to be acknowledged. Some effects of recall bias and possible psychological post-hoc adjustments of earlier experiences in the patient's illness course cannot be ruled out, especially for dementia patients. It should also be taken into

account that those who agreed to participate in the interviews might have done so to express particular positive or negative experiences and might experience and cope with their care needs differently from others. We deliberately chose not to use the term ‘palliative’ and not to ask respondents directly if they need palliative care. Although relevant to other research, it was not the scope of this study to investigate whether people themselves perceived a need for palliative care, because their interpretation of palliative care might be, and can be expected to be, limited to terminal care<sup>45</sup>.

## Conclusion

A multidisciplinary palliative approach seems ideally suited to all people with a life-limiting illness and should not be confined only to those actively dying. The challenge is to integrate such an approach into the care continuum.

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*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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**Conflict of interest:** The authors declare that there are no conflicts of interest. The authors had full control of all primary data in the study and agree to allow the journal to review the data if requested.

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## **CHAPTER 3**

### **PALLIATIVE CARE NEEDS AT DIFFERENT PHASES IN THE ILLNESS TRAJECTORY: A SURVEY STUDY IN PATIENTS WITH CANCER**

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*Submitted*

## **Abstract**

*Background.* Despite the growing consensus on the benefits of initiating palliative care early in the disease trajectory it remains unclear at what point palliative care needs emerge. This study investigates quality of life and unmet palliative care needs at three phases in the cancer trajectory, curative, life-prolonging and most advanced (prognosis < six months/no further disease-modifying treatment).

*Methods.* We collected self-reported data from 620 patients with cancer in the University Hospital of Ghent, Belgium. They completed a questionnaire on quality of life (using the EORTC QLQ-C30) and unmet care needs within the domains of palliative care. The treating oncologist collected clinical data. We used European reference values of the EORTC QLQ-C30 to compare the mean scores with a norm group.

*Results* The patient groups further on in the cancer trajectory reported statistically and clinically significantly poorer functioning compared with earlier phases, also when controlled for the effects of sex, age or type of cancer. Higher symptom burdens for fatigue, pain, dyspnea and appetite loss were found in groups further into the trajectory,  $p < .001$ . Patients in the curative phase experienced physical symptoms and had clinically significantly worse functioning than a European reference group. Patients in all groups said that the professional help they wanted most was for emotional distress (14% of curative, 20% of life-prolonging and 25% of most advanced group).

*Conclusion.* A palliative care approach needs to be initiated in standard oncological care early in the care trajectory, and palliative needs will gradually become more important as the illness progresses.

## Introduction

Palliative care is often still seen as a final option for cancer patients, when disease-modifying treatments are no longer an option. However, earlier integration of palliative care into oncological treatment, alongside curative and life-prolonging care, is another model that has been proposed and endorsed. The influential study by Temel et al.<sup>1</sup> has indicated that integration of a specialist palliative care service early into oncology care of patients with advanced cancer improves the quality of care, quality of life and possibly length of survival<sup>1:2</sup>.

The idea of early palliative care integrated into regular care fits the definition of palliative care introduced by the World Health Organization (WHO) in 2002 (and reiterated in 2013) which advocates a needs-based model of care in which palliative care is initiated early, possibly in combination with curative or life-prolonging treatments, and becomes gradually more important as death approaches<sup>3-5</sup>. Need for palliative care, in this definition, does not necessarily equate to the need for specialist palliative care services but rather to the need for an approach embodying the principles of palliative care, which may be provided by regular care providers with basic palliative care skills. A palliative care approach addresses a range of care dimensions including the physical, psychological, social and existential and the coordination and continuity of care<sup>3:6-11</sup>. Despite growing awareness of the ability of early palliative care to improve the patient's quality of life it is still unclear when exactly palliative care needs emerge. The study by Temel et al, for instance, focussed on advanced cancer patients and did not evaluate whether and to what extent there were issues of unmet palliative care needs throughout the whole cancer trajectory from diagnosis. Previous research has evaluated care needs (mostly focusing on physical symptoms and psychological issues) at only one point in the cancer trajectory<sup>12-16</sup>. The use of different questionnaires and scales and different samples of patients inhibits clear and valid comparison between the different phases, and - apart from those focusing on the terminal phase - studies have not looked at care needs from a palliative care perspective<sup>17-19</sup>. In order to have insight into the extent of palliative care needs across different illness phases, and hence into the possible contribution a palliative care approach could make, robust quantitative and standardized data are needed about the quality of life, in terms of physical, psychological, social and existential functioning, and unmet care needs in the different phases, collected in one study using the same validated instrument.

This study in a population with cancer aims to describe the quality of life and unmet care needs at three different points in the cancer trajectory: the phase of planning or receiving treatments with a curative intent, the phase of planning or receiving treatments with a life-prolonging intent and the 'most advanced' phase, when no more curative or life-prolonging treatments are available and/or life expectancy is less than six months. The research questions are: 1) what is the quality of life (based on physical, psychological, social, role, cognitive and existential functioning, physical symptoms, financial issues and spiritual issues) of patients diagnosed with cancer in the three phases, 2) what is the proportion of patients within the three phases receiving care by a professional caregiver and expressing unmet needs for different palliative care domains?

## **Method**

### *Design, setting and participants*

We conducted a cross-sectional survey of all patients with a diagnosis of cancer who had a consultation in the University Hospital of Ghent, Belgium (with about 1,000 beds) between 1 March and 30 June 2014. Those considered for inclusion were patients coming for a consultation in three oncology departments: medical oncology (including the palliative care unit), pneumology and gastroenterology. Patients were eligible if they were older than 18 and diagnosed with cancer, regardless of type, stage and treatment. This provided the opportunity to compare groups at different phases in the illness course. Patients who came for a second opinion (coming from another hospital and thus having no medical file in the Hospital of Ghent) or those with severe cognitive impairment according to the physician were excluded.

### *Data collection*

All patients coming for a consultation in the included wards were given a questionnaire by the physician or medical secretary of the oncology team. Patients were requested mail the questionnaire to the researchers. Patients were assessed on one occasion only. Average time to fill in the questionnaire was 20 minutes.

Clinical data were collected through a one-page questionnaire filled in by the treating oncologist. Physicians were asked to categorize each patient into one of four groups: 1) those receiving (or planning to receive) treatments with a curative intent, 2) those who are probably cured and in follow up or who are in remission or a therapy-free interval, 3) those receiving or planning to receive treatments with life-prolonging intent and 4) those neither receiving nor planning any more treatments with a curative or life-prolonging intent. Oncologists were also asked if the patient had a life expectancy of less than six months.

The follow-up and the linking of information between the patient and physician questionnaires was possible by using encrypted unique identifiers based on the patient hospital identifier numbers (necessary for the physician to collect the medical information from the hospital medical files) for each patient. Researchers never had access to nominal information of the patient and physicians and other hospital staff never had access to the completed patient questionnaires (held by the researchers). The anonymous identifiers avoided double entries where patients came for a consultation more than once and allowed calculation of response rates (more detailed information see appendix of this chapter).

### *Patient questionnaire*

*Sociodemographic characteristics.* Questions on age, sex and living situation were asked in the patient questionnaire.

*Quality of life.* We used the Dutch version of the EORTC QLQ-C30 <sup>20</sup>, an internationally validated and widely used questionnaire to assess quality of life, psychosocial burden and physical symptoms in cancer patients. Thirty items were combined to make five functional scales (physical, social, role, cognitive and emotional functioning), one scale for global quality of life, three symptom scales (fatigue, pain, nausea/vomiting) and six single-

item scales (dyspnoea, appetite loss, insomnia, constipation, diarrhoea and financial difficulties). All questions requested a response pertaining to the past week. The items were scored on a four-point Likert scale reading ‘not at all,’ ‘a little,’ ‘quite a bit’ and ‘very much’. Only the global health items were scored on a seven-point numerical rating scale.

Because spiritual/existential wellbeing is an important domain of palliative care though the EORTC QLQ C-30 does not include it, two items asking about spiritual and existential problems were added. One was taken from the Sheffield Profile for Assessment and Referral to Care (SPARC) (Have you had worrying thoughts about death or dying?) and one adapted from the Distress Thermometer (Have you had troubles with your trust in God/religion?)<sup>21;22</sup>.

*Care provision and unmet needs.* We additionally asked which professional caregivers patients received help from and evaluated their wishes for more help or assistance for functional scales (physical, role, social, emotional), symptoms (physical) and spiritual/existential issues. The response options included: no help, physician (oncologist or family physician), nurse, psychologist, palliative caregiver, chaplain, physiotherapist (or ergotherapist or speech therapist) or other. More than one option could be indicated. Additionally, patients were asked whether they wanted more help or attention from a professional caregiver, ‘yes, more;’ ‘no, as much as now;’ ‘no, less than now’. For this question we used the same formulation as in the validated Problems and Needs in Palliative Care (PNPC) questionnaire<sup>23</sup>.

### *Statistical analyses*

For this study we selected only those patients 1) who had or had planned treatments with a curative intent i.e. the curative group, 2) those who had or had planned life-prolonging treatments i.e. the life-prolonging group and 3) those who were no longer receiving curative or life-prolonging treatments and/or for whom the treating physician estimated the prognosis to be less than six months i.e. the most advanced group). Patients who were in follow-up or remission were excluded from the analyses. To test for statistical significance of differences between the curative, life-prolonging and most advanced group, Chi-square tests, Jonckheere-Terpstra and Mann-Whitney U tests were used. ANCOVA analyses and multivariable logistic regression were performed to control for confounding effects of sex, age and cancer type. The statistical software IBM SPSS version 22 was used for all analyses.

A difference in mean scores on the QLQ-C30 questionnaire was regarded as clinically meaningful if it was ten or more, as outlined in the QLQ-C30 interpretation manual<sup>24;25</sup>.

We evaluated clinical and statistical differences between the three groups, but a reference or norm group was deemed necessary to have a reference point against which all three groups, and particularly the curative group, could be compared to evaluate any clinically significant differences with a general population. Because general population data are lacking in Belgium, we used aggregated reference data from the four European countries (Sweden, Norway, Germany and the Netherlands) that published population-based data on EORTC QLQ-C30 scales and items<sup>26</sup>. A direct standardization method, using the age and gender distribution of the European sample, was used to compare the three groups and the norm population.

*Ethical considerations*

The study protocol was approved by the Ethical Review Board of Ghent University Hospital. We obtained written informed consent from all study participants.

**Results**

Among the 620 patients who participated in the survey (79.8% participation rate; see online appendix) 101 received treatments with a curative intent, 188 received treatments with a life-prolonging intent and 86 had no more disease modifying treatments and/or had a life expectancy of less than six months (table 1). Other patients that were in follow-up or remission were excluded for this study. These three groups differed significantly in sex, age and type of cancer (see in appendix at the end of this Chapter).

Table 1. Patient characteristics according to phase in the illness trajectory.

	Curative group	Life-prolonging group	Most advanced group‡	p-value*
	N=101	N=188	N=86	
Sex				<.001
<i>Female</i>	82.0	60.8	44.7	
Age				<.001
18-39y	10.2	3.3	6.0	
40-49y	19.4	11.6	6.0	
50-59y	27.6	22.1	26.2	
60-69y	35.7	32.0	35.7	
70 or older	7.1	30.9	26.2	
Living situation				.45
<i>Alone</i>	12.9	15.1	17.1	
<i>With other(s)</i>	87.1	84.9	82.9	
Cancer type				<.001
<i>Breast</i>	65.3	31.4	11.6	
<i>Gastrointestinal</i>	22.8	28.2	27.9	
<i>Respiratory</i>	1.0	6.4	23.3	
<i>Gynecological</i>	3.0	8.5	4.7	
<i>Urological</i>	0.0	10.6	8.1	
<i>Skin</i>	1.0	2.1	7.0	
<i>Other†</i>	6.9	12.8	17.4	

Percentages are column percentages.

Missing values: for sex n= 4 (1%); for age: n= 12 (3%); for living situation n= 46 (12%), for cancer type: 0 (0%).

\*Pearson Chi squared test testing for differences between the three phases in the illness trajectory.

†Other: This group contains all other cancer types that were identified as soft tissue sarcoma (n= 11), head and neck (n=11), unknown primary (n=4), bone (n=2) and others that were not specified (n=24).

‡ Patients who received no more treatments or had a life expectancy of less than 6 months. Sixty five of those with prognosis less than six months had still life-prolonging treatments (of which 40 second line or more)

*Quality of life*

*Functional impairment.* The three groups differed significantly on the EORTC QLQ-C30 functional scales and on global quality of life (table 2). The patient groups further into the trajectory reported statistically ( $P<0.05$ ) and clinically significantly poorer functioning compared with earlier phases, indicating a poorer quality of life, even when controlled for the

effects of sex, age or type of cancer. In comparison with the European norm data, when standardized for age and sex, all three groups had clinically substantially impaired functioning (figure 1). All functioning scale scores were clinically significantly lower in the curative group compared with the European norm group, with the largest difference for role functioning. The differences with the norm group were larger for the life-prolonging and the most advanced group.

Table 2. Quality of life: comparisons of the EORTC QLQ-C30 mean scores between three illness phases on a scale from 0 to 100 (standard deviation) and differences between groups (▲).

	Curative (G1)	Life-prolonging (G2)	Most advanced (G3)	Statistical significance	Clinical significance§		
	N= 101	N= 188	N= 86		▲ G2 and G1	▲ G3 and G2	▲ G3 and G1
	Mean (SD)	Mean (SD)	Mean (SD)	P-value‡			
Global QOL*	67.4 (22.4)	59.0 (21.2)	49.1 (23.2)	<.001	-8	<b>-10</b>	<b>-18</b>
Functional scales*							
<i>Physical Function</i>	80.7 (20.4)	69.3 (23.9)	56.1 (31.8)	<.001	<b>-11</b>	<b>-13</b>	<b>-25</b>
<i>Social Function</i>	75.6 (24.8)	65.1 (30.9)	58.8 (35.5)	<.01	<b>-11</b>	-6	<b>-17</b>
<i>Emotional Function</i>	70.2 (27.0)	66.8 (26.2)	59.2 (28.4)	<.01	-3	-8	<b>-11</b>
<i>Role Function</i>	65.5 (30.4)	56.7 (33.1)	40.6 (37.0)	<.001	-9	<b>-16</b>	<b>-25</b>
<i>Cognitive Function</i>	74.2 (26.4)	73.3 (26.5)	70.7 (28.2)	.44	-1	-3	-4
Symptom Scales†							
<i>Fatigue</i>	35.1 (24.3)	45.3 (27.7)	56.2 (30.8)	<.001	<b>+10</b>	<b>+11</b>	<b>+21</b>
<i>Pain</i>	23.7 (26.5)	28.6 (30.1)	37.3 (31.9)	<.01	+5	+9	<b>+14</b>
<i>Nausea and vomiting</i>	9.1 (18.9)	12.5 (21.4)	13.9 (23.6)	.16	+3	+1	+5
Single items†							
<i>Insomnia</i>	37.4 (32.4)	29.4 (28.9)	37.7 (32.6)	.94	-8	+8	0
<i>Appetite loss</i>	14.3 (28.1)	20.9 (30.9)	43.7 (41.1)	<.001	+7	<b>+23</b>	<b>+29</b>
<i>Dyspnoea</i>	11.9 (22.1)	21.6 (27.9)	30.9 (34.1)	<.001	<b>+10</b>	+9	<b>+19</b>
<i>Constipation</i>	14.3 (28.1)	19.3 (29.4)	20.2 (31.5)	.15	+5	+1	+6
<i>Diarrhoea</i>	11.3 (23.3)	13.4 (24.0)	12.8 (25.6)	.76	+2	-1	+2
<i>Financial worries</i>	9.6 (20.9)	13.0 (25.2)	15.0 (24.1)	.08	+3	+2	+5
Other†							
<i>Spiritual issues</i>	14.6 (20.8)	25.3 (24.9)	26.7 (26.1)	<.001	<b>+11</b>	+1	<b>+12</b>

SD= standard deviation, ▲ = difference

The frequencies of missing items were low and comparable between groups. In total, for the EORTC QLQ-C30 the missing items ranged from 2.1% on the insomnia and appetite loss scale to 6.1 % on the fatigue scale. For spiritual issues there were 9.1% missing values.

\*Mean scores can vary from 0 to 100, higher score means better quality of life or better functioning.

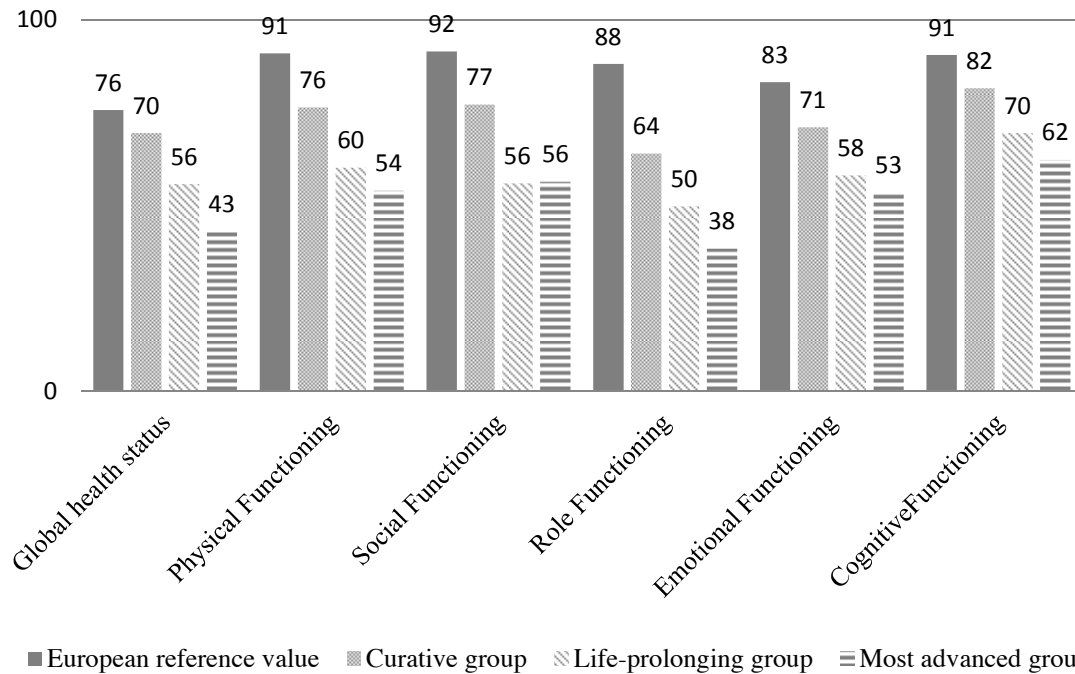
†Mean scores can vary from 0 to 100, higher score means more severe symptom burden.

‡ Jonckheere-Terpstra test testing for differences between the three groups, G1, G2 and G3.

The same statistical significance was found as in the Jonckheere-Terpstra analysis after ANCOVA with the scales and items as dependent variable and sex, age categories and cancer types (four categories: breast + gynecological, gastrointestinal, respiratory and other) and phase group as independent variables. Only the differences between the three groups on cognitive functioning became statistically significant, with average estimated means respectively 78.6, 72.6 and 67.5 (p<.05). Also insomnia becomes statistically significant with means respectively 35.4, 29.0 and 40.2 , p<.05.

§ Bold denotes clinically significant ▲>=10<sup>24:25</sup>.

Figure 1. EORTC QLQ-C30 mean scores, adjusted for age and sex, in the three phase groups and a European population based reference group. Higher score means better quality of life or better functioning.



We used European reference values for the EORTC QLQ-C30 from a study summarizing the only European general population normative studies done in Sweden, the Netherlands, Norway and Germany<sup>26</sup>.

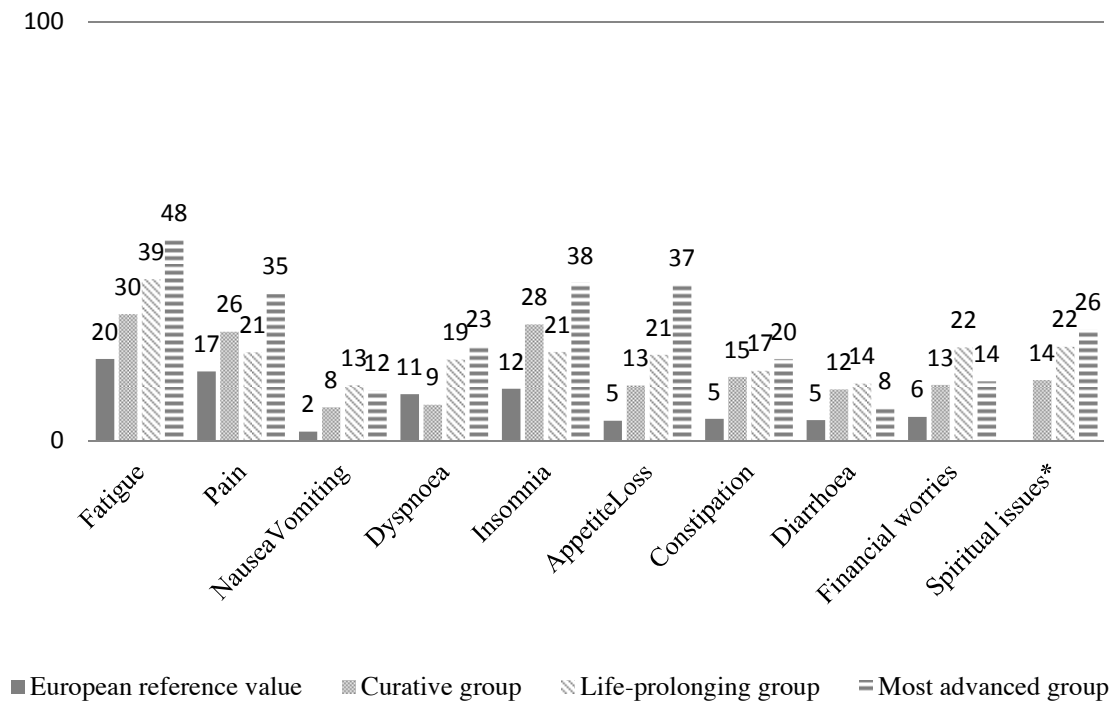
*Symptom burden.* Higher scores implying more symptom burden for fatigue, pain, dyspnea and appetite loss were found in groups further into the cancer trajectory,  $P < 0.01$ . Symptom burden due to nausea, constipation and diarrhoea did not significantly differ between the cancer phases. Insomnia was worse in the curative and most advanced group than in the life-prolonging group.

Fatigue and constipation were clinically significantly worse in all three groups compared with the European norm data, standardized for age and sex (figure 2). Insomnia was worse in the curative and the most advanced group. Financial worries were clinically significantly worse in the life-prolonging group. Appetite loss, pain and dyspnea were clinically significantly worse only in the most advanced group.

*Spiritual/existential issues.* Spiritual/existential issues scores were not significantly different between the life-prolonging and most advanced group, but were worse in these latter two groups than in the curative group.



Figure 2. EORTC QLQ-C30 mean scores, adjusted for age and sex, in the three phase groups and a European population based reference group. Higher score means more severe symptom burden.



We used European reference values for the EORTC QLQ-C30 from a study summarizing the only European general population normative studies done in Sweden, the Netherlands, Norway and Germany<sup>26</sup>.

\*Spiritual issues was additionally added to the questionnaire for this study only. It is not a standard measure in the EORTC QLQ-C30, consequently there is no reference value available.

### Unmet care needs

Patients in the curative group were less likely to have received help from a professional care giver for physical functioning (61%), emotional functioning (57%), physical symptoms (56%), social and role functioning (21%), and spiritual issues (21%) than those in the most advanced group (respectively 78%, 74%, 81%, 50% and 52%) (table 3). Also patients in the life-prolonging group were less likely to have received help from a professional caregiver for emotional functioning (52%), physical symptoms (69%) and social and role functioning (31%) than were those in the most advanced group.

The help from a professional caregiver that patients in all three groups most frequently said they wanted was on emotional functioning (14% in the curative, 20% in the life-prolonging and 25% in the most advanced group) (table 4). Unmet spiritual care needs were found in respectively 10%, 19% and 20%. Also a need for more professional care for social and role functioning was found in respectively 12%, 18%, 19%. For physical functioning and physical symptoms more professional care was wanted in respectively 9%, 13% and 18%. Controlling for relevant confounders, there was no statistically significant difference between the life-prolonging group and the most advanced group in the chances of having unmet care needs.

Table 3. Care provision: proportions\* and chances† of receiving help from a professional caregiver for the three phase groups.

Received help from a professional care giver for:	Curative group		Life-prolonging group		Most advanced group	
	%	OR (95% CI)	%	OR (95% CI)	%	Ref cat
Physical functioning	61.4	<b>.45 (.20-.99)</b>	74.1	.81 (.40-1.62)	77.5	Ref cat
Symptoms (physical)	55.8	<b>.23 (.10-.55)</b>	69.4	<b>.47 (.23-.97)</b>	80.6	Ref cat
Emotional functioning	57.1	<b>.41 (.18-.95)</b>	51.7	<b>.36 (.18-.72)</b>	74.2	Ref cat
Social and role functioning	20.6	<b>.20 (.08-.50)</b>	31.2	<b>.37 (.19-.74)</b>	50.0	Ref cat
Spiritual/existential issues	21.0	<b>.29 (.10-.81)</b>	29.1	.73 (.34-1.54)	51.7	Ref cat

Abbreviations: OR= Odds Ratio; CI= confidence interval; Ref cat= reference category.

Professional caregiver= physician (oncologist or family physician), nurse, psychologist, palliative caregiver, chaplain, physiotherapist (or ergo therapist or speech therapist)

Missing values: varied from 16% for physical functioning to 31% for social and role functioning.

\*Pearson  $\chi^2$  test testing for differences in need for more professional help for each phase group. Physical functioning  $P = .05$ , symptoms  $P < .01$ , emotional functioning  $P < .01$ , spiritual functioning  $P = .001$ , social and role functioning  $P < .01$ .

†Multivariable binary logistic regression analyses with the variables received professional help as a dependent variable (yes vs no) and sex, age categories and cancer type (four categories: breast + gynecological, gastrointestinal, respiratory and other) as independent variables.

Bold denotes significant at  $p < .05$ .

Table 4. Unmet care needs: proportions\* and chances† of wanting more professional help for the three phase groups.

Wanted more professional help for:	Curative group		Life-prolonging group		Most advanced group	
	%	OR (95% CI)	%	OR (95% CI)	%	Ref cat
Physical functioning	8.8	<b>.23 (.08-.64)</b>	13.4	.50 (.23-1.10)	18.7	Ref cat
Symptoms (physical)	9.2	<b>.29 (.10-.81)</b>	14.2	.58 (.27-1.27)	18.4	Ref cat
Emotional functioning	13.8	<b>.37 (.15-.92)</b>	20.0	.61 (.30-1.13)	24.7	Ref cat
Social and role functioning	11.9	.41 (.15-1.12)	17.5	.73 (.35-1.56)	18.9	Ref cat
Spiritual/existential issues	9.6	<b>.29 (.10-.81)</b>	18.6	.73 (.34-1.54)	20.0	Ref cat

Abbreviations: OR= Odds Ratio; CI= confidence interval; Ref cat= reference category.

Professional help= physician (oncologist or family physician), nurse, psychologist, palliative caregiver, chaplain, physiotherapist (or ergo therapist or speech therapist)

Missing values: varied from 10% for physical functioning to 15% for social and role functioning.

\*Pearson  $\chi^2$  test testing for differences in need for more professional help for each phase group. For none of the variables we found significant differences between the three phase groups.

†Multivariable binary logistic regression analyses with the variables “need for more help” as a dependent variable (yes vs no) and sex, age categories and cancer type (four categories: breast + gynecological, gastrointestinal, respiratory and other) as independent variables.

Bold denotes significant at  $p < .05$ .

## Discussion

Our study provides an empirical confirmation of a model of early palliative care needs<sup>4</sup> by showing that particularly from the life-prolonging phase onwards symptoms and problems that are core domains of palliative care are present and increase towards the most advanced phase. In the curative phase patients were already experiencing physical symptoms and had clinically significantly worse functioning than a European reference group. Our results provide an indication of how a palliative care approach (not necessarily a specialist one), focusing on physical, psychological, social and existential needs, may already need to be integrated into standard oncological care earlier than in the most advanced stage of cancer and will gradually become more important as the illness progresses.

As compared with previous research, our results can contribute to a clarification of what ‘early’ could mean in ‘early palliative care’. The WHO definition merely states that it should be initiated early in the illness trajectory, in conjunction with other therapies that are intended to prolong life<sup>3;5</sup>. Others seem to have interpreted this in terms of the likelihood that death will occur rather soon (eg within 6 or 12 months using a ‘surprise question’)<sup>27</sup>. Yet others have implicitly suggested that early palliative care refers to care for those patients for whom disease is no longer responsive to curative treatment<sup>28</sup>, or for whom the disease is in an *advanced stage*<sup>1;29</sup>. The model of early palliative care built on the study by Temel et al<sup>1</sup> and the many similar studies<sup>30;31</sup> based on that is one in which a specialist palliative care team starts collaborating with the oncologists as soon as patients are diagnosed with advanced cancer. The WHO further propagates a needs-based rather than a prognosis-based model of palliative care. In that respect, based on our findings regarding the occurrence of palliative care needs, our study seems to suggest that ‘early’ might mean earlier than proposed in previous studies<sup>1;2</sup>.

To implement such a model of early integration of a palliative care approach into standard oncology care (ideally from diagnosis onwards, even when people are still receiving curative treatments) there should be a thorough comprehensive assessment of care needs from the early stages throughout the cancer trajectory. There can be multiple ways to respond to possible care needs. Many can be met through a palliative care approach by the oncologist, family physician or other care giver<sup>32</sup> instead of specialist palliative care teams, but when the care needs become too complex for the regular caregivers to handle, specialist palliative care should be consulted or initialized. Of course this implies that the regular oncology care givers should be sufficiently trained or educated and acquire basic palliative care skills and attitudes<sup>32</sup>. Additionally, it also implies that there should be enough service capacity to handle the number of patients needing such an approach. According to our study this need will be smaller in the earlier than the later phases (albeit that individual patient trajectories may vary strongly).

A number of limitations of this study have to be taken into account. Firstly, a longitudinal design could have made it possible to describe an evolution of care needs in individual patients, but due to often long cancer trajectories we believed a cross sectional study in a population of cancer patients to be best suited for the purpose of the study<sup>33</sup>. Secondly, due to inclusion at first consultation in the hospital, patients in a terminal situation at home are probably underrepresented in our most advanced group because they are often no longer coming to the hospital for consultations (although research has found that a considerable proportion of cancer patients in Belgium are still admitted to hospital in the final weeks even if they die at home<sup>34</sup>). This might nevertheless imply that scores in the most advanced group in actual practice may be worse than presented in our study.

## **Conclusion**

From the moment where people begin receiving life-prolonging treatments, even if they have a prognosis of more than six months, we found a deteriorated quality of life and profound unmet care needs in the core domains of palliative care, but even in the phase in which people are receiving curative treatments many experienced problems for which a palliative care approach could be meaningful. The model of palliative care as specialist palliative care teams working together with oncologists might therefore be insufficient, unfeasible or too expensive. In practice this will mean that comprehensive assessments of care needs need to be performed by regular caregivers throughout the trajectory, starting from diagnosis. The intensity of care will gradually rise and the involvement of specialist palliative care teams will be necessary when certain triggers appear or when some unmet care needs become too complex for the regular caregivers. The challenge will be to develop a model in which caregivers in the oncology setting have the necessary skills for assessing and tackling care needs early in the disease trajectory. Future research needs to evaluate the extent to which such a model can improve the quality of life of patients with cancer in earlier phases of their disease and throughout their disease trajectory.

## **Appendix: Additional information for the method and result section**

### **Methods**

#### *Data collection*

The invitation to participate was slightly adapted at each hospital ward. Patients were approached either by the study nurse (pneumology), the treating oncologist (gastroenterology and palliative care unit) or the medical secretary of the treating oncologist (medical oncology). They explained the aims of the study to the patients, obtained written informed consent, and if consent was obtained they gave the questionnaire to the patient. At each ward all oncologists were instructed to give additional information when patients wished so. Patients could fill in the questionnaire in the hospital or at home, depending on their preference.

Clinical data about the patient were collected through a 1-page questionnaire filled in by the treating oncologist. This questionnaire was developed and elaborated together with the oncologists at the ward to ensure validity and usefulness of dividing patients into groups across the cancer trajectory.

The follow-up and the linking between information from the patient and the physician questionnaires was possible by using encrypted unique identifiers based on the patient hospital identifier numbers. The anonymous identifiers used also allowed avoiding any incidental double entries (in case patients came for a consultation more than once) and a calculation of response rates. Due to our informed consent and privacy protocol it was impossible to collect the reasons and characteristics of the patients for not responding.

### **Results**

#### *Participation rate*

#### *Sex, age and type of cancer differences in three groups*

Of the 620 patients, 245 were judged in remission by the treating oncologist and were not selected for this study, another 101 were receiving treatments with a curative intent, 188 received treatments with a life-prolonging intent and 86 had no more treatment and/or had a life expectancy of less than six months. These three groups differed significantly in sex, age and type of cancer. There were more females in the curative group (82%) than in the life-prolonging group (61%) or most advanced group (45%) and more older patients in the groups further in the cancer trajectory. In the curative group most patients had breast cancer (65%), in the life-prolonging group most patient had breast cancer (31%) or a gastrointestinal cancer (28%), and in the most advanced group most patients had a gastrointestinal cancer (28%) or a respiratory cancer (23%).

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*Conflict of interest.* No conflict exist for the specified authors

*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

*Author Contributions.* KB, JC, LV, KP, DD and LD conceived the idea of the study and JC and LD obtained funding. KC, JC, VS, KG and MDL contributed to the planning of the data collection and the actual collection of data. KB was responsible for the integration of the data and KB and JC for the analyses on this file. KB and JC led the writing of the paper. All listed authors contributed to the writing of the article and approved the final version of the manuscript.

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## **PART III**

### **EARLY GENERALIST PALLIATIVE CARE: THE ROLE OF THE FAMILY PHYSICIAN**



## **CHAPTER 4**

**EARLY IDENTIFICATION OF PALLIATIVE CARE NEEDS BY FAMILY PHYSICIANS: A QUALITATIVE STUDY OF BARRIERS AND FACILITATORS FROM THE PERSPECTIVE OF FAMILY PHYSICIANS, COMMUNITY NURSES AND PATIENTS.**

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## **Abstract**

*Background:* There is a growing recognition that a palliative care approach should be initiated early and not just in the terminal phase for patients with life-limiting diseases. Family physicians (FPs) then play a central role in identifying and managing palliative care needs, but appear to not identify them accurately or in a timely manner.

*Aim:* To explore the barriers to and facilitators of the early identification by FPs of the palliative care needs.

*Design, setting & participants:* 6 focus groups (4 with FPs, n=20 and 2 with community nurses, n=12) and 18 interviews with patients with cancer, copd, heart failure and dementia were held. Thematic analysis was used to derive themes that covered barriers and facilitators.

*Results:* Key barriers and facilitators found relate to communication styles, the perceived role of a FP, and continuity of care. FPs do not systematically assess non-acute care needs and patients do not mention them or try to mask them from the FP. This is embedded within a predominant perception among patients, nurses and FPs of the FP as the person to appeal to in acute and standard follow-up situations rather than for palliative care needs. FPs also seemed to pay more often attention to palliative care needs of patients in a terminal phase.

*Conclusion.* The current practice of palliative care in Belgium is far from the presently considered ideal palliative care approaches. Facilitators such as pro-active communication and communication tools could contribute to the development of guidelines for FPs and policymakers in primary care.

**What is already known on this subject**

-The currently promoted model of palliative care asserts that many patients may benefit from a palliative care approach early in their disease course

-FPs play a central role in identifying and managing palliative care needs, but at present they often appear not to be identifying them accurately or in good time

-Research on barriers to and facilitators for identifying palliative care needs by the FP is scarce

**What this study adds**

-The lack of pro-active communication by both FP and patient tends to veil palliative care needs or to delay discussion of such needs

-Perceptions of the FP's role as dealing mainly with acute care needs, and lack of continuity of care, additionally hinder the timely identification of palliative care needs

**Implications for practice and policy**

-Making time, building up a trusting relationship, pro-active communication, knowledge of care options by patients and FPs, assessment scales and communication tools could all be facilitating factors in implementing an early palliative care approach

-Successfully shifting to a model of early generalist palliative care will require guidelines and training for FPs and structural health policy measures.

**Introduction**

Palliative care is considered a holistic approach that encompasses pain relief and the care of physical, psychosocial and spiritual needs of patients with life-limiting diseases<sup>1;2</sup>. There is increasing advocacy for and evidence of the benefits of the earlier involvement of palliative care in the disease trajectory<sup>3;4</sup>. Research has suggested that many patients with life-limiting diseases, not only cancer, develop multidimensional needs from diagnosis onwards and may benefit from palliative care early in the disease course<sup>2;3;5-7</sup>.

There is a growing recognition that many palliative care needs should be identified early and met by generalist, alongside specialist, palliative care<sup>8</sup>. In many countries family physicians (FPs) are responsible for palliative care at the primary level as well as for coordination and continuity of care, care decision-making and referral to secondary care such as specialist palliative care services in more complex and difficult cases<sup>1;9-12</sup> and thus play a central role in the primary identification of palliative care needs. However, some studies show that FPs often do not identify care needs in a timely and accurate manner. FPs often seem not to recognize needs and symptoms such as nausea, anxiety and depression<sup>13-15</sup>, find it harder to identify needs in non-cancer than in cancer patients<sup>16</sup> and often involve specialist palliative care services late in the disease course if at all<sup>12;17</sup>. Most previous research about early palliative care or the role of the FP in identifying palliative care needs has, however, been focussed on specialist palliative care, often in an oncology setting<sup>4</sup> and usually shortly before death and does not look at the early stages during which needs can emerge. Additionally, nothing is known about the reasons why certain needs are not recognized by the FP.

In order to add understanding to the increasing interest in earlier palliative care our study explored the identification by the FP of palliative care needs from diagnosis onwards. We aimed to map and understand the perceived barriers and facilitators affecting this identification for patients with cancer, organ failure or dementia from the perspective of family physicians, community nurses and patients.

## **Method**

### *Design*

Given the scarcity of available data and the exploratory nature of this research, a qualitative approach which allows open discussion was deemed necessary<sup>18</sup>. This article follows the consolidated criteria for reporting qualitative research from the COREQ guidelines<sup>19</sup>.

The identification of palliative care needs by the FP does not happen in isolation but in interaction with for example the patient and other caregivers. To map out more fully the richness and complexity of attitudes, beliefs and behavior we explored more than one standpoint (triangulation), which gives a more detailed picture of the practice. We performed focus groups with FPs as well as separate focus groups with community and palliative care nurses and semi-structured face-to-face interviews with patients. We chose to use focus groups because the group dynamics can uncover unconscious mechanisms impeding early identification<sup>20</sup>. For patients we chose to use semi-structured face-to-face interviews as we anticipated more reluctance to disclose personal and delicate information in a group. We were interested in the identification of palliative care needs from diagnosis onwards, so interviewed patients with life-limiting diseases such as cancer, organ failure and dementia (three typical disease trajectories<sup>21</sup>) who may have experienced palliative care needs during their disease course<sup>2:22</sup>.

### *Sampling and recruitment*

*FP and nurse participants.* Recruitment of FPs for the focus groups was performed through local FP peer-review groups across Flanders, ie geographically determined groups of FPs who come together four times a year to discuss various general practice issues. We recruited nurses for separate focus groups by contacting nurse institutions and independent nurses. Three nurses from a palliative home care team were enrolled specifically to ensure experience of the terminal phase of life. These recruitment strategies were considered the best guarantee to achieving heterogeneity of respondents in terms of potential role in and experience with palliative care.

*Patient participants.* Because of our assumptions of the relevance of palliative care needs and identification of those needs by the FP from diagnosis onwards, we deliberately created a heterogeneous sample in terms of the time frame between diagnosis and the end of life in order to strive for theoretical generalizability. Several recruitment methods were used: patients who responded to an announcement in a newsletter to all members of a national health care fund and recommendations by hospital physicians and participating palliative home care nurses. Patients were included according to our inclusion criteria (box 1). In cases of

uncertainty a physician (DD) was consulted. Inclusion lasted until saturation was judged to have been reached within each patient category.

#### Box 1. Inclusion criteria for patients

We interviewed only patients older than 18 years living at home with one of the following illnesses:

1. Cancer which was expected to lead to death in the short or long term;
2. Chronic Obstructive Lung Disease (COPD) with a score from 1 to 4 on the Global Initiative for Chronic Obstructive Lung Disease Scale (GOLD), ie everyone with the clinical diagnosis of COPD;
3. Heart failure with a score of 2-4 on the New York Heart Association (NYHA) Functional Classification, ie everyone with the clinical diagnosis of heart failure;
4. Dementia with a Mini Mental State Examination (MMSE) score of 10-26, ie everyone with the clinical diagnosis of mild to moderate dementia capable of doing an interview.

#### *Data collection*

All interviews and focus groups were conducted in Dutch (the native tongue of the participants as well as the researchers) between February and May 2012 in Flanders (Belgium). A semi-structured topic guide was developed to elicit the key domains, with sub-questions to elicit detail. The protocol was reviewed and modified by the research group. The interviewers asked the participants about 1) multidimensional care needs from diagnosis onwards by giving them examples, 2) how FPs go about the identification of care needs, 3) which factors may contribute to not discovering certain care needs or discovering them too late and 4) what possible ways of identifying care needs there are. The interviewers did not use the term 'palliative' until participants used it to avoid placing too much emphasis on terminal care. One trained moderator and one observer led each focus group, each lasting about two hours. KB performed all interviews with the patient alone in their home; in four cases the patient wished for a relative to be present. We also analyzed these partner's comments relating to the patient's experiences. Interviews ranged from 45 minutes to two and a half hours. All interviews and focus groups were audiotaped and transcribed verbatim.

#### *Analysis*

An inductive, exploratory analysis was necessary to collect and understand the barriers and facilitators surrounding identification of palliative care needs. Therefore, we analyzed the data based on thematic content analysis procedures<sup>23</sup> aided by the use of NVIVO10 software. KB and ADV firstly familiarized themselves by reading the data and then independently openly coded one interview and one focus group from each respondent type and discussed until they reached agreement. KB constructed one codebook and applied the codes consistently for the remaining transcripts. All coded transcripts were reviewed multiple times and new codes were added as appropriate and others were lumped together into broader categories. After this, coding saturation was judged to have been achieved and no further recruitment was deemed necessary. Next, overarching themes were deduced and interpreted. The views from three

perspectives, ie family physicians, community nurses and patients, were compared to determine areas of agreement as well as divergence. Through cross-verification of three perspectives (data triangulation) we aimed at stronger data validation. Regular review and discussion by the authors, who are from multiple backgrounds and disciplines, contributed to data synthesis and interpretation (investigator triangulation). We sought quotations to illustrate and support our themes.

### *Ethical considerations*

The study protocol was approved by the Ethical Review Board of Brussels University Hospital. We obtained written informed consent from study participants at the time of interview.

## **Results**

We performed six focus groups, four with FPs and two with community nurses, and 18 interviews. The characteristics of the participants are shown in Table 1. Table 2 presents more detailed characteristics of the patients.

Table 1. Characteristics of family physicians, community nurses and patients.

	Family physicians (n= 20)				Community nurses (n= 12)		Patients (n=18)
	FG1 (n=3)	FG 2 (n=5)	FG3 (n=6)	FG 4 (n=6)	FG1 (n= 5)	FG2 (n= 7)	
Sex							
Male	1	4	5	3	1	2	11
Female	2	1	1	3	4	5	7
Age (years)							
<39	1	1	0	1	2	4	0
40-49	0	1	0	1	2	0	2
50-59	0	3	6	2	1	3	0
60-69	2	0	0	0	0	0	6
70-79	0	0	0	0	0	0	8
>79	0	0	0	1	0	0	2
Clinical work experience (years)							
1-9	1	0	0	0	1	0	n/a
10-19	0	1	0	2	2	2	n/a
20-29	0	2	2	3	2	0	n/a
>29	2	2	2	1	0	2	n/a

Abbreviation: FG= focus group, n/a= not applicable

Missing values: age: FPs= 3 and nurses= 1; clinical work experience: FPs= 2 and nurses= 3.

Family physicians, community and palliative home care nurses and patients were all independent from each other, except for three patients that were recruited by a palliative home care nurse.



Table 2. Detailed characteristics of patients.

Number	Diagnosis	Timing diagnosis	Age	Sex	Number of general practitioner visits/month	Status at the moment of interview*	Recruitment
1	Cancer: lung	2009	72	f	>1	No more treatment	Newsletter
2	Cancer: breast	2009	65	f	<1	Hormonal therapy	Newsletter
3	Cancer: breast	2010	63	f	<1	Finished radiation therapy	Oncologist
4	Cancer: brain tumor + metastasis	2002	47	m	1	Finished radiation therapy	Oncologist Palliative home care nurse
5	Cancer: colon + metastasis	2011	61	m	>1	Chemotherapy	Palliative home care nurse
6	Cancer: lung and renal	2010	64	m	<1	Finished chemotherapy	Palliative home care nurse
7	COPD	2004	72	m	<1	GOLD III	Pulmonologist
8	COPD	2008	48	m	1	-	Newsletter
9	COPD	1980	77	f	<1	GOLD IV	Pulmonologist
10	Heart failure	2009	76	f	>1	-	Newsletter
11	Heart failure	1994	65	m	1	-	Newsletter Palliative home care nurse
12	Heart failure	2003	74	m	>1	-	Palliative home care nurse
13	Dementia	-	86	m	>1	-	Newsletter†
14	Dementia	2009	67	m	<1	-	Newsletter†
15	Dementia	2011	75	m	<1	MMSE 26	Neurologist
16	Dementia	2010	74	f	1	MMSE 22	Neurologist
17	Dementia	2011	82	m	<1	MMSE 24	Neurologist
18	Dementia	2010	72	f	1	MMSE 19	Neurologist

Abbreviations: GOLD= Global Initiative for Chronic Obstructive Lung Disease; MMSE = Mini Mental State Examination; <1= less, >1= more or 1= once a month, '-' = precise score for GOLD, NYHA, or MMSE not known for patient, but lies within range of inclusion criteria. Patients were in- or excluded after deliberation with DD (co-author, a FP and professor in family medicine) based on their diagnosis, medication-use, described health-problems.

\* Status reported by the hospital specialist or for cancer patients as reported by the patient

† The partner of the patient made contact with the researcher

The participants reported various barriers and facilitators regarding the identification of palliative care needs and after a thorough inductive analysis we categorized those into six different themes, explored below (table 3):

### 1) FPs' knowledge, skills and communication styles

All three perspectives stated that active, deliberate questioning about care needs by FPs facilitates their identification, but many of the patients indicated that their FP asked mostly about their acute care needs in acute situations when consulting the FP (such as low blood pressure, a cold) and that they would not mention their non-acute care needs themselves:

*“Oh, if he [FP] asks for it, I would do it, but he doesn't ask. If you yourself don't mention you have social problems...”* (patient 5 with cancer, male, 61)

Some FPs confirmed this. Not having knowledge, skills and experience relating to palliative care needs were all considered important barriers to timely recognition by the FP. Nurses criticized FPs for often underestimating the imminence of death.

Table 3. Perceived barriers and facilitators for identification of palliative care needs as explicitly mentioned in the focus groups or interviews.

	Family physicians (focus group) N=20	Community nurses (focus group) n= 12	Cancer patients (interview) n=6	Organ failure patients (interview) n=6	Dementia patients (interview) n=6
<b>1) Family physicians' knowledge, skills and communication styles</b>					
<u>barriers</u>					
FP does not actively ask about non-physical/disease related care needs	x		x	x	x
FP lacks knowledge, skills, experience to talk about existential needs	x				
FP has difficulty seeing the patient is in the dying phase		x			
<u>facilitators</u>					
FP takes the initiative to talk about care needs	x	x	x	x	
FP uses quick assessment scales	x				
<b>2) Patient's communication styles</b>					
<u>barriers</u>					
Patient does not talk about all his/her care needs to anyone	x	x	x	x	x
Patient talks with other people (but not FP) about his/her care needs			x	x	
Patient waits until problems are unbearable		x	x	x	
Patient pretends to be better than he/she actually is	x	x		x	x
Patient forgets to mention care needs		x	x		
Patient has lost ability to communicate	x	x			
<u>facilitators</u>					
Patient is open about care needs	x	x	x	x	
Patient write questions and needs on a paper		x	x		
<b>3) Relationship and contact between family physician and patient</b>					
<u>barriers</u>					
FP's time is limited	x	x	x	x	x
FP and patient do not have a long history together	x				
<u>facilitators</u>					
FP takes the necessary time for the patient	x	x	x	x	x
FP-patient relationship is longstanding	x	x		x	x
FP creates a sense of trust in the patient			x	x	x
FP makes regular contact (visit, phone) with the patient	x	x			
FP makes regular home visits	x	x			
<b>4) Perceptions regarding the role of the family physician</b>					
<u>barriers</u>					
FP is mainly responsible for acute situations, follow up and medication	x	x	x	x	x
FP should not talk about existential issues early in the disease trajectory	x				
Hospital physician takes care of disease related needs, not the FP	x	x	x	x	x
<u>facilitators</u>					
FP pays attention to non-physical needs	x	x	x		
FP is the person to whom you can say anything				x	
FP contacts the patient during treatment phase		x			

**5) Collaboration with other caregivers and continuity of care**

barriers

FP involves nurses too late											X	
Nurses do not call the FP											X	X
FP does not use communication tools to coordinate care											X	
FP does not participate in multidisciplinary meetings											X	X
FPs do not see their patients during treatment phase											X	
Medical files from the hospital are not sent (on time)											X	X
Medical files from the hospital only consider treatment related aspects											X	
Family hides care needs											X	X

facilitators

FP involves a nurse											X	X										X	
Nurses inform the FP											X												
FP uses communication tools											X	X											
FP joins multidisciplinary meetings											X	X											
Medical files from the hospital are sent (on time)											X			X		X							X
Medical files include non-physical issues											X												
Hospital ensures continuity of care with the FP											X	X		X									X
FP gives good instructions to patient/family/nurse when they have to call the FP											X	X											
Family tells care needs to FP											X	X											

**6) Other factors**

barriers

FP does not realize the patient suffers from a life-threatening disease																									
FP is afraid of taking away the hope of their patients/family																									

facilitator

FP has features typical related to women (e.g. empathy)											X	X												X
FP realizes the patient suffers from a life-threatening disease											X	X												
Patient is in the terminal phase											X													

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If FPs are familiar with what needs may occur, they are easier to identify. Awareness of care options was also perceived as a facilitator to FPs offering and patients requesting help. This proved to be particularly the case for specialist palliative care services, which FPs admitted to not really considering as an option for patients with organ failure or dementia as opposed to those with cancer, even though they acknowledged that they would probably benefit from them.

A small number of FPs proposed the use of short assessment scales for common palliative care needs such as pain and insomnia because they want to follow up their patients gradually and do not want to overlook problems.

2) Patients’ communication styles

We detected considerable variation in patients’ levels of openness towards their FP about their care needs. According to nurses, many do not admit how much they suffer or wait until their problems are unbearable before mentioning them:

*“There are patients who can express themselves well to the FP, but I think you often see patients who pretend feeling better towards the FP than they do towards us. Partly, I often think, out of fear of what is going to happen, “I am not going to have to go back to that hospital, am I” (nurse, female, 53)*

Patients said they also hold back because they perceive the FP as busy and are reluctant to bother them. Some patients, especially those with dementia, stated they did not have any palliative care needs and did not wish to talk about their disease, even though - after the interview - their partner usually mentioned how much the patient relied on them for various needs for example practical, such as cooking and psychological, such as relief of anxiety.

### 3) Relationship and contact between FP and patient

People in all groups stated that enough time and regular contact between the patient and FP are essential for the FP to identify needs:

*“I know he doesn’t have much time. The stories I’m telling you now [about his fear, where he wants to die, his funeral etc.], I won’t tell them to him that easily. I will tell them to someone who has the time. I know this, he schedules [an appointment of] 5 minutes and while you are sharing your story he receives 2 phone calls and a fax and a message.”* (patient 4 with cancer, male, 47)

All groups considered a long and trusting relationship was necessary to enable patients to ask for a visit when needed and FPs to make spontaneous visits. FPs and nurses agreed that home visits provide the best overall information about the patient’s needs because they give them the opportunity to evaluate the relevant circumstances such as housing conditions and the caring capacity of the family:

*“The family physician comes in and is offered something, like a glass of jenever, or sometimes a bite to eat, and this physician is usually very well informed, because he has much more time he also knows those people much better and is familiar with the home situation, he knows the family situation and those other doctors just don’t have the time for that.”* (nurse, male, 42)

Only FPs said they make enough time to visit patients (often out of hours), but admitted that this ‘privilege’ is mainly reserved for patients in the terminal stage. Many patients and nurses mentioned that the FP’s limited time is a barrier to identifying needs.

### 4) Perceptions regarding the role of a FP

All three groups stated that the FP is mainly responsible for medication prescriptions, regular follow-up contacts (eg for measuring blood pressure) or acute situations (eg a cold) and patients believed it is not their role to deal with non-acute issues. Patients often viewed the specific manifestations of their disease (eg memory problems in dementia) as something to be addressed by a specialist rather than the FP. Patients believe hospital physicians to be more capable of dealing with these needs:

*“After all I won’t talk to my FP about my teeth huh. It’s true, isn’t it. Especially neurology, that’s something very peculiar. It’s not physical. It’s not a sore throat, it’s not pain in your legs.”* (patient 15 with dementia, male, 75)

FPs disagreed on who should handle non-acute care needs, the FP him/herself or another qualified person like a psychologist.

#### 5) Collaboration with other caregivers and continuity of care

FPs highlighted a lack of continuity in the care of the patient (particularly cancer patients) and complained that they often have no contact with them during treatment phases or hospital admissions:

*“Cancer patients that we often haven’t seen for years suddenly arrive, no longer curable, and with a lot of care needs [...] then it’s a shame, because if you would continue to see that patient, even just for measuring blood pressure, you could take your time for that, and you too could gradually follow things up. But now you are no longer able to assess the care needs [...]”* (FP, female, 39)

Some FPs suggested the specialist should send the patient to them regularly for example for measuring blood pressure in order to avoid this. Nurses remarked that FPs should visit or call patients receiving care from hospital specialists if they want to remain involved. Sending the medical file in good time and adding information other than about treatment, for example the patient’s reaction to diagnosis/bad news, were regarded as facilitators by many FPs.

Community nurses and FPs saw nurses, if involved, as important information sources as they visit the patients more often than the FP. However, according to nurses, a few factors hinder their collaboration with FPs. Firstly, FPs often involve them too late, often in the terminal phase. Secondly, multidisciplinary meetings and communication tools (eg a shared notebook), which FPs and community nurses regarded as useful for exchanging information, are rarely used effectively according to nurses. Much depends on the FP’s good will and attitude to cooperation with other caregivers. Thirdly, they are sometimes afraid to bother the FP; FPs said that nurses often do not call them and try to solve a problem themselves.

Both FPs and nurses considered the family as an essential source of information for the FP, especially when patients do not express their care needs:

*“Those patients often say something like: “I’m OK, I’m OK”, and then his partner says: “he is moaning all night in his bed”, or “he is very restless”, or ...”* (FP, female, 52)

But FPs realized that the family may also hide the care needs of the patient, even from the FP, because they feel embarrassed about the patient’s behavior or situation, particularly with dementia.

#### 6) Underlying fears and beliefs related to the prognosis

In all focus groups it emerged that FPs are often afraid of taking away a patient’s hope by discussing their existential and palliative care needs, but some FPs also expressed the importance of discussing these topics:

*“ (...) it may remove all their fears for those people. And you have to talk about fear. “What are you afraid of? Are you afraid to die? Are you afraid to...? Do you know what it means? What is it to you?” (FP, female, 60)*

*‘Yes, but M., that's of course your principle about life and dead, but who likes to talk about death? It gives people traumas when you ask about it. Right, 'cause no traumas is equally important to me. (FP, male, 60)*

Both FPs and patients found these discussions easier when they realized that the prognosis was short and no more treatment was available. This seemed to be clearer for cancer patients than for others:

*“I'm not afraid to also discuss this [non-physical care needs] with patients, but the timing must be right. So I would say I do it less often in case of COPD, also because I do not have terminal COPD patients at the moment, I do see someone who receives some oxygen therapy, but I don't think that is the right moment to discuss this. Whereas in case of cancer, the prognosis is worse and shorter, you will discuss it more easily. But I definitely do dare to discuss it with the patient and I would do it, yeah.” (FP, female, 27)*

## **Discussion**

FPs, community nurses and patients revealed several factors impeding early identification of palliative care needs by the FPs of patients with cancer, organ failure or dementia. Key barriers and facilitators identified relate to communication styles, the perceived role of the FP and continuity of care.

By using separate focus groups with FPs and nurses and individual interviews with patients, all participants could speak more freely. This method is particularly preferred for gathering in-depth understanding of the complex mechanisms of a contested topic like palliative care and life-limiting diseases<sup>24</sup>. Our strategy of both data and investigator triangulation, increases the validity of the findings. However, the addition of the perspectives of others for example hospital physicians could have provided additional insights.

We deliberately chose to explore care needs within the perspective of the currently promoted model of early palliative care and avoided focusing only on terminal stage care, unlike in most previous studies on this topic. We used a wide definition of palliative care needs, related to the WHO definition<sup>2</sup>, including physical, psychosocial, practical and existential/spiritual needs, that may be experienced from diagnosis onwards. We acknowledge that this definition is open to discussion<sup>25</sup> and may change over time, but our findings remain useful beyond semantic discussion as the perceived barriers and facilitators exist even if people do not necessarily consider the care to be ‘palliative’.

The themes we derived capture all expressed barriers and facilitators but they are often interwoven and influence each other so it is more useful not to define them as fully independent entities.

A key finding of our study is that patients will not introduce discussion of their non-acute care needs and also FPs do not initiate such conversations, which is in line with previous research about end-of-life communication<sup>26;27</sup>. Our study seems to indicate that this situation is most prevalent in dementia cases. A possible explanation is that the stigma associated with dementia leads many FPs and patients, who often had a fatalist, uncomplaining attitude ('nothing can be done anyway'), to avoid discussing the disease until the symptoms are apparent. As a result, care needs are identified too late<sup>28</sup>. Some communication processes or methods were considered by our participants as facilitators and could be useful recommendations for FPs: pro-active questioning about care needs (including non-acute care needs), gentle exploration, short assessment scales, communication notebooks and medical files containing non-physical information, for example how the patient reacted to bad news and consider palliative care for non-cancer patients.

Another important finding is that identification by the FP of palliative care needs seems to be more problematic in the earlier stages than the terminal phase. FPs themselves indicated that it was easier to discuss and identify palliative care needs in the last weeks of life when prognosis is clearer; FPs also make more time, do more home visits and more often involve nurses in that phase. Additionally, they are often minimally involved when patients are under curative or life-prolonging treatment at a hospital. We found that different underlying factors may explain this finding such as time constraints, fear of depriving the patient of hope and lack of clarity about prognosis. This implies that it is 'easier' to identify the palliative care needs of patients with advanced cancer, for whom a prognosis is clearer. Another possible explanation is that FPs, and also cancer patients themselves, more often realize they have a life-threatening disease and are more aware of approaching death<sup>29;30</sup>. The recognition that a patient's condition is or may be becoming terminal is essential for ensuring an 'open awareness' between the FP and the patient<sup>31</sup>. However, we found that even at the very end these factors seem to hinder identification of palliative care needs by the FP. These barriers are similar to those identified in previous research for advance care planning and provision of palliative or terminal care<sup>31-36</sup>. Our results seem to indicate that an early palliative care approach is not yet applied in general daily practice. FPs, but also patients, should be aware of palliative care needs and the possible role of the FP in handling these needs early in the disease trajectory.

In definitions of family practice and opinion pieces in influential journals FPs are attributed a critical role in dealing with palliative care needs<sup>8;32;37;38</sup>. However our results seem to show that they are perceived primarily as people to whom patients appeal in acute and standard follow-up situations, although many patients indicated they would like to discuss their non-acute needs with their FP, particularly if they had more time. This suggests patients might be open to early palliative care intervention by the FP focusing on the identification of care needs. This result could be explained by the fact that societal views about, and organization of, health care have not kept pace with the decline in acute health problems and the increase in chronic conditions that are not a series of disconnected complaints but that require continuity of care and more and longer visits, mainly in the community<sup>39</sup>. Internationally, in order to

meet the changing nature of diseases, some initiatives have, nevertheless, been put in place: financial incentives for FPs who coordinate patients with chronic diseases such as diabetes and heart failure (eg in Belgium and Australia) and a ‘palliative lump sum’ [forfait] for patients with a life expectancy of between 24 hours and three months to enable them to cover the costs of nurses, physiotherapists and FPs (eg Belgium). The Gold Standard Framework in the UK<sup>1</sup> or the development of other tools to identify patients with chronic conditions in need of palliative care (eg Spain<sup>40</sup>) are examples of palliative care approaches developed within primary care to identify and handle palliative care needs in the last months of life by the FP<sup>1;40</sup>. Most initiatives, however, focus on particular diseases and a specific time for beginning palliative care, which confirms the still predominant paradigm that palliative care needs apply only to those who are clearly dying and illustrates how the health care system is not tailored to the recommended needs-based model where early palliative care delivered by the FP is available for all life-limiting diseases.

## **Conclusion**

Due to a lack of effective communication styles or tools, reliance on prognosis and persisting societal perceptions of the FP as someone to appeal to only in acute situations, current daily practice seems to be far from the promoted palliative care models that put emphasis on early identification of palliative care needs and give a central role to FPs. Making time, building up a trusting relationship, pro-active communication, knowledge of care options by patients and FPs, assessment scales and communication tools could all be facilitating factors in implementing the early palliative care approach and should be considered in the formulation of policy in primary care and future guidelines for FPs.



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*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

*Author Contributions.* KB, JC, LV and LD conceived the idea of the study and JC, LV and LD obtained funding. JC and KB contributed to the planning of the data collection and the actual collection of data. KB was responsible for the integration of the data and KB, ADV and JC for the main analyses on this file. KB and JC led the writing of the paper. All listed authors contributed to the writing of the article and approved the final version of the manuscript.

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## **CHAPTER 5**

### **THE ROLE OF THE FAMILY PHYSICIAN IN PALLIATIVE CARE THROUGHOUT THE CARE CONTINUUM: PERCEPTIONS OF FAMILY PHYSICIANS, NURSES AND PATIENTS.**

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*Submitted*

## **Abstract**

*Background:* While palliative care is still often viewed as health care for the final stage of life provided usually by specialist health care professionals, ideally, a palliative care approach would start at an earlier stage, with an important role being assigned to the family physician (FP). However, the description of what the FP's tasks would be in the integration of a palliative care approach into the care continuum remains vague.

*Aim:* To explore the views of FPs, nurses and patients about the tasks of the FP in palliative care for people with a life-limiting illness from diagnosis onwards.

*Design and setting:* We performed 18 interviews with people with cancer, organ failure or dementia and six focus groups, four with FPs and two with community nurses.

*Methods:* Analysis was guided by a thematic content analysis procedure to categorize perceived tasks into overarching themes.

*Results:* The tasks attributed to the FP could be categorized into four roles: FP as 1) available medical expert, 2) communicator, 3) collaborator and 4) life-long learner committed to improving their palliative care competencies by training. Some perceived tasks varied depending on the different phases of illness (such as around diagnosis), while others were applicable throughout the whole illness course. Participants mostly had the same perception of the FPs' tasks, but there was disagreement on eg the timing of care planning.

*Conclusion:* Our results help to elucidate the tasks and roles required of FPs to make integration of a palliative care approach into the care continuum possible.

**What is already known on this subject**

-The currently promoted model of palliative care asserts that many patients may benefit from a palliative care approach early in their disease course

-The concept of FPs providing palliative care integrated into the continuum of care is accepted at a theoretical level but seems much more problematic in actual practice.

-One of the underlying problems is that a clear delineation of the tasks and roles for FPs in early palliative care is lacking.

**What this study adds**

-Using qualitative interviews with patients, nurses and family physicians this study provides insights into perceptions on the roles and tasks for the family physician in tackling 'primary' palliative care needs throughout the illness trajectory

-Various tasks can be allocated to four overarching roles for the family physician: available medical expert (e.g. clarifying diagnosis and implications), communicator (e.g. communicating terminal status), collaborator (e.g. exchanging medical and non-medical information with other involved clinicians), and life-long learner (e.g. following relevant training).

-While certain tasks of the family physician change with different phases of the illness (i.e. around diagnosis, during treatment and follow up, around acute episodes or exacerbations, and during the terminal phase) others are applicable throughout the complete illness course.

**Implications for practice and policy**

-The tasks and roles described in this study can be used as a preliminary framework to support, promote and develop a strengthened integration of a palliative care approach into primary care.

**Introduction**

People with chronic life-limiting illnesses form an increasingly large patient population which experiences complex symptoms and care needs<sup>1,2</sup>. Palliative care intends to improve the quality of life for these patients and awareness and evidence is growing that an early palliative care approach would benefit people with any type of chronic life-limiting illness<sup>2-5</sup>. This implies that much of the care would not be met by 'specialist' palliative care but by other generalist care givers such as the family physician (FP)<sup>6-9</sup>.

Although the concept of FPs providing palliative care which is integrated into the continuum of care is accepted at a theoretical level (eg in the latest World Health Organization resolution on palliative care)<sup>6,10</sup> little is known about how it is perceived and experienced by people directly involved in it such as FPs, nurses and patients. Moreover, previous studies seem to have focussed on palliative care during the final months of life, thereby excluding the earlier stages of the illness course in which a palliative care approach by FPs may play an important role<sup>11-13</sup>. There is an almost complete absence of evidence examining what primary care can contribute, as most of the scant research focuses on barriers to palliative care without offering solutions<sup>14-17</sup>. Studies on patient perceptions about palliative care in primary care are

particularly scarce<sup>12</sup>. Delineating and clarifying the tasks for FPs in early palliative care remains a challenge to palliative care as well as to health care policies in the many countries which are striving to support the patient in a home environment and through primary care.

This study aims to explore the views of FPs themselves, of those receiving care from FPs and of community nurses who assist and cooperate with the FP<sup>18;19</sup>, about the tasks of the FP in palliative care from diagnosis onwards. The following specific research questions are addressed: What do FPs, community nurses and people with a life-limiting illness perceive as the role and the tasks of a family physician in tackling the palliative care needs of those with cancer, organ failure or dementia? Do these attributed tasks differ according to the timing in the illness course?

## **Method**

### *Design*

A qualitative focus group and interview study was considered the most suitable design for this study. Because of the multidisciplinary nature of palliative care and the importance of patient-centeredness, we interviewed people from different disciplines and background that look at the issue from different perspectives. This stimulates the provision of rich and experiential information<sup>20</sup>. By using separate focus groups with FPs and nurses and individual interviews with patients, all participants could speak more freely. This method is particularly preferred for gathering in-depth understanding of the complex mechanisms of a contested topic like palliative care and life-limiting illnesses<sup>21</sup>. More details on the methods used are published elsewhere<sup>22</sup>. This article follows the consolidated criteria for reporting qualitative research from the COREQ guidelines<sup>23</sup>.

### *Participants*

#### *FP and nurse participants*

To recruit FPs, existing peer-review groups (geographically determined groups of FPs that meet regularly to discuss aspects of FP-practice required for accreditation) were used. We recruited nurses for separate focus groups by contacting nurse institutions, independent nurses and nurses from palliative home care teams.

#### *Patient participants*

Because patients with various types of illness and also those early in their illness course may need palliative care delivered by their FP, we used a purposeful sampling method and created a heterogeneous sample in terms of the time frame between diagnosis and the end of life for patients with cancer and COPD, heart failure and dementia (three typical illness trajectories<sup>24</sup> described for people who often experience palliative care needs during their illness course<sup>2;25</sup>). Several recruitment methods were used: patients who responded to an announcement in a newsletter to all members of a national health care fund and patients we contacted based on recommendations by hospital physicians and participating palliative home care nurses. Patients were included according to our inclusion criteria (box 1).



**Box 1. Inclusion criteria for patients**

We interviewed only patients older than 18 years living at home with one of the following illnesses:

1. Cancer which was expected to lead to death in the short or long term;
2. Chronic Obstructive Lung Disease (COPD) with a score from 1 to 4 on the Global Initiative for Chronic Obstructive Lung Disease Scale (GOLD), ie everyone with the clinical diagnosis of COPD;
3. Heart failure with a score of 2-4 on the New York Heart Association (NYHA) Functional Classification, ie everyone with the clinical diagnosis of heart failure;
4. Dementia with a Mini Mental State Examination (MMSE) score of 10-26, ie everyone with the clinical diagnosis of mild to moderate dementia capable of doing an interview.

*Data collection*

All interviews and focus groups were conducted in Dutch (the native tongue of the participants). The focus group discussions were moderated and observed by two experienced researchers and lasted two hours. Interviews with the patient, alone in his or her home, were conducted by KB. Interviews ranged from 45 minutes to two and a half hours.

The interview and focus group manual consisted of open-ended and supplementary questions which had to cover the following key areas: multidimensional care needs from diagnosis onwards and tasks or expectations of the FP in handling these care needs (see appendix of this chapter). The interviewers did not use the term ‘palliative’ until participants used it to avoid placing too much emphasis on terminal care.

*Data analysis*

Focus group discussions and interviews were audio-recorded and transcribed verbatim. Analysis was guided by a thematic content analysis procedure<sup>26</sup>. The data were openly coded, ie. line by line review of the transcripts, with focus on ‘tasks and no tasks of the FP’ concerning the care for patients eligible for palliative care with special attention not only on the terminal phase. KB and KVT independently coded all transcripts and codes were added, modified or merged where necessary. Next, overarching themes were deduced from the categories and ‘roles’ were deduced from the tasks attributed to FPs and then interpreted. The views from three perspectives, ie physicians, nurses and patients, were compared. The deduction of the categories and interpretation of the content were discussed in the multidisciplinary research team (investigator triangulation). When coding saturation was judged to have been achieved no further recruitment was deemed necessary. Qualitative data analysis software (QSR NVIVO 10) was used.

*Ethical considerations*

Ethics approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital. We obtained written informed consent from all study participants.

**Results**

We performed six focus groups, four with FPs (n=20) and two with community nurses (n= 12) (table 1) and 18 interviews with patients (table 2).

Table 1. Characteristics of community nurses and family physicians

Focus group	Participants	Male	Average age (range)	Solo practice
Nurses 1	7	1	44 (36 – 53)	n/a
Nurses 2	5	2	43 (35 – 53)	n/a
FPs 1	6	5	54 (51 – 59)	3
FPs 2	3	1	49 (27 – 60)	0
FPs 3	6	3	54 (37 – 85)	4
FPs 4	5	4	49 (39 – 55)	3

Table 2. Detailed characteristics of patients.

Diagnosis	Timing diagnosis	Age	Sex	Number of general practitioner visits/month	Status at the moment of interview*	Recruitment
Cancer: lung	2009	72	f	>1	No more treatment	Newsletter
Cancer: breast	2009	65	f	<1	Hormonal therapy	Newsletter
Cancer: breast	2010	63	f	<1	Finished radiation therapy	Oncologist
Cancer: brain tumor + metastasis	2002	47	m	1	Finished radiation therapy	Oncologist
Cancer: colon + metastasis	2011	61	m	>1	Chemotherapy	Palliative home care nurse
Cancer: lung and renal	2010	64	m	<1	Finished chemotherapy	Palliative home care nurse
COPD	2004	72	m	<1	GOLD III	Pulmonologist
COPD	2008	48	m	1	-	Newsletter
COPD	1980	77	f	<1	GOLD IV	Pulmonologist
Heart failure	2009	76	f	>1	-	Newsletter
Heart failure	1994	65	m	1	-	Newsletter
Heart failure	2003	74	m	>1	-	Palliative home care nurse
Dementia	-	86	m	>1	-	Newsletter†
Dementia	2009	67	m	<1	-	Newsletter†
Dementia	2011	75	m	<1	MMSE 26	Neurologist
Dementia	2010	74	f	1	MMSE 22	Neurologist
Dementia	2011	82	m	<1	MMSE 24	Neurologist
Dementia	2010	72	f	1	MMSE 19	Neurologist

Abbreviations: GOLD= Global Initiative for Chronic Obstructive Lung Disease; MMSE = Mini Mental State Examination; <1= less, >1= more or 1= once a month, ‘-’ = precise score for GOLD, NYHA, or MMSE not known for patient, but lies within range of inclusion criteria. Patients were in- or excluded after deliberation with DD (co-author, a FP and professor in family medicine) based on their diagnosis, medication-use, described health-problems.

\* Status reported by the hospital specialist or for cancer patients as reported by the patient

† The partner of the patient made contact with the researcher

The respondents identified a multitude of tasks in the data that could be attributed to the FP and we categorized these into four overarching ‘roles’: FP as 1) an available medical expert, 2) a communicator, 3) a collaborator, and 4) a life-long learner. During analysis we noticed that the perceptions of some tasks changed with different phases of the illness, while others were applicable throughout the complete illness course. Hence the findings could be categorized into five broader stage-related contexts: 1) around diagnosis, 2) during treatment and follow up, 3) around acute episodes or exacerbations, 4) during the terminal phase and 5) throughout the complete illness course. Within the themes we looked for agreement as well as divergence between the views of FPs, nurses and patients (Table 3). The stages and the different perspectives are processed within the four roles described below.

Table 3. Perceived family physician tasks in different phases of the illness trajectory.

	Around diagnosis	During treatment and follow up	At the time of acute episodes or exacerbations	During terminal phase	Throughout illness course
<b>FP as an available medical expert</b>	Clarify diagnosis & implications*†‡	Receive and read medical information from specialist‡ Physical examinations*‡  Knowledge about adverse effects of medicine*†‡	Being available, eg unplanned home visits, decision on emergency hospital admission*†‡	Symptom control*†‡  Making euthanasia or sedation possible‡	
<b>FP as a communicator</b>	Talking and listening*†‡ Psychological issues*†‡ Discuss the patient prognosis and disease course*†‡	Discuss test results and treatment decisions with patient*‡  Encouraging patients about their illness trajectory*‡  Actively make contact patients†		Communicate terminal status†  Make more time to talk eg about existential issues*†‡	Advance care planning*†‡  Pro-active questioning care needs*†‡  Communicate with family carers about their burden*†
<b>FP as a collaborator</b>	Exchange information, both medical and non-medical with hospital physician*†‡	Discuss test results and treatment decisions with other care givers*†‡	(re-)evaluate the organization of care and involve other care givers if necessary*†	Referring to or consulting specialist palliative care services*†	Instruct and manage the care with other care givers, such as community nurses, social workers etc. involved; advise the patient on alternative options*†‡  Attend multidisciplinary meetings*†
<b>FP as a life-long learner</b>					Follow training on symptoms, treatment, communication*†

Perceived by \*family physicians, †community nurses, ‡patients

Tasks are displayed as they are expressed by at least one of the respondents. There was some discussion or disagreement for some tasks however, as is described in the result section



*FP as an available medical expert*

All participants (except people with dementia) stated that after the specialist had initially communicated the diagnosis the FP should be able to clarify the diagnosis and the implications of the illness for the patient. During the treatment phase or follow-up period most patients expect their FP to read the medical information from their specialist. FPs, nurses and patients thought that it is the task of the FP to manage the physical symptoms and have knowledge of possible adverse effects of treatment. Some patients, however, stated that the involvement of a specialist in relation to illness-related symptoms is sufficient and FPs should not be involved.

Another important task of the FP, according to all respondent groups, is being available in case of emergency, such as an exacerbation of the illness or an acute complication. Being available includes unplanned and out-of-hours home visits, urgent treatment and decisions on emergency hospital admission.

*"The FP sees you more frequently in crisis situations, specialists don't do home calls, do they? So perhaps he is in a better position to estimate the impact of the pain, not the specialist." (respondent with lung cancer, female, 72)*

*"I once became really unwell. My neighbour went to fetch the FP. The FP gave me an injection. And she told me to keep calm, to lie down. Then in the evening, she said she had consultations to do, she said 'I'll come by again this evening'. And she did come back. Just to check how I was doing. Everything was fine." (respondent with COPD, male, 72)*

FPs said they often give their personal telephone numbers to terminal patients. During the terminal phase, FPs, nurses and patients with cancer or organ failure think that the main responsibility of the FP is to make sure the patient is free from burdensome physical symptoms and that the FP should provide psychological and existential care. However, some FPs believe that providing psychological and existential care is not their task and can be delegated to other professionals.

*FP as a communicator*

FPs, nurses and patients saw psychological support as a task of the FP because patients are often overwhelmed by the combination of bad news and complex information around diagnosis and the follow-up consultation with the hospital specialist. However, some patients believed it is not the FP's role to deal with any issues that are non-acute.

*"In the beginning the frequency [of visits to FP] was at least every month, three four weeks, at times I had to go twice a week, I even went the day before the operation, or a few days before the operation, I just had to go and see the FP, just for a chat about it" (respondent with breast cancer, female, 63)*

FPs, nurses and most patients think that talking about future care eg in terms of treatment and place of care, is necessary. More specifically they think that the FP should discuss and provide help with possible end-of-life decisions such as euthanasia or sedation. Respondents with dementia did not express a wish to talk about these issues with their FP, although one did express her fear about not knowing where she would go to die. Some FPs stated that this communication should take place before the terminal phase, early in the illness course, but indicated that this is often not the case.

*"Yes, it sometimes takes quite some time before dying comes up in the conversation. While you should really discuss it in an early stage ... knowing what they want, and how they want to die, where they want to die, what they do with it, fears about dying." (FPs 1, male, 51)*

*"Maybe when dementia is discussed it is necessary to consider the progression of the disease, the needs and how best to manage the needs: 'how would you like to be treated when you are incapable of making a decision'. You have to talk about this during lucid moments and talk about 'how do you want to be treated at the end'. But it is not always clear when is a good time to have this conversation." (FPs 3, male 45)*

Nurses considered that FPs should tell the patient and the family when death is imminent. Some FPs stated this as an important moment, but said it was a rather difficult thing to do.

*"There was a terminal patient and she lived another day or ten and she didn't stop saying "I am dying. What is wrong with me and no one tells me anything?" We referred this to the FP [...] We said, she is asking if she is going to die. Don't ignore it, talk about it. We had to repeat it 4 to 5 times. [...] This is the task of the FP, but if he doesn't do what he is supposed to do... You see this woman getting more and more afraid ..." (nurses1, male, 35)*

According to FPs, nurses and patients it is important to make enough time for contact and communication between the FP and the patient:

*"I think that if you offer palliative care, you have to have or make time for it. I notice that palliative people are not always within your legitimate hours. Sometimes they are, but sometimes outside these hours. Commonly you stop by early in the morning and in the evening. (FPs1, female, 52)*

FPs and nurses acknowledged that a life-limiting illness not only affects the patient but also their family and FPs should therefore be able to communicate effectively with the family; they should also assess family involvement in the patient's care in order to measure the caring capacity of the environment.

#### *FP as a collaborator*

All respondents indicated that an FP does not have to take care of every care need personally, but is expected to advise the patient on or refer to alternative options.

*"But those social needs, for example, that is something that we learned here, that you [the interviewers] are being told that patients talk about that a lot. Yes, but the fact that we are being told, does not mean we have to solve it .... We can offer paths, options or give people advice." (FPs 1, male, 53)*

To collaborate effectively, FPs and nurses indicated that the exchange between different caregivers about medical as well as non-medical information (eg how a patient copes with the prognosis) would be valuable.

Most FPs stated that palliative care becomes their task and responsibility when death becomes imminent, when no more treatment is available or when the illness is in an advanced phase. Nurses and FPs perceived it the task of an FP to engage or consult specialist palliative home care teams as soon as he or she begins to feel that they have not got enough time for the patient, that they have reached the limits of their expertise or that they are experiencing an emotional barrier. Many FPs emphasized that at this stage they are still, and want to continue to be, responsible for or 'leading' the patient's care at the end of their life:

*"Palliative care is a task from ourselves." (FPs 1, male, 51)*

*"Yes it is" (female, 52)*

*"We are palliative care! Palliative care is not something outside our job, it is our job." (male)*

*"And sometimes you have extremely crazy things" (female, 52)*

*"Yes, all right, then you ask for technical instructions, but in the end, how it is done and what is done, that's our job" (male)*

FPs viewed the use of specialist palliative care teams as a possibility mainly for people with cancer, but stated that they would also be of benefit to people with other life-limiting illnesses such as COPD, heart failure or dementia.

#### *FP as a life-long learner*

FPs and nurses thought it the FP's responsibility to stay informed about the latest developments in diagnosis and treatment of chronic life-limiting diseases and palliative care eg by following training courses. Some FPs indicated they sometimes feel incompetent in this area and others stated that it depends on their own abilities or talents because they were often not educated enough about palliative care during their basic MD training.

*"But I do believe that FPs should be trained in palliative care, and in all related aspects. I think we play a crucial role in it; yes and that we ... yes ... are more capable of guiding people than what, well, we are doing today, right." (FPs 1, male, 51)*

## Discussion

### *Summary of findings*

Our study reveals important tasks for FPs in providing a palliative care approach for people suffering from life-limiting illness, as perceived by FPs themselves, community nurses and people with cancer, COPD, heart failure or dementia. These tasks can be allocated to four overarching roles: the FP as an available medical expert, as a communicator, as a collaborator and as a life-long learner. Some of the tasks attributed to the FP apply to different phases in the illness trajectory, showing the importance of the involvement of the FP in a palliative care approach integrated into the care continuum, starting from diagnosis.

### *Comparison with other studies and implications for practice*

The tasks and roles attributed to FPs in our study largely reflect the palliative care principles of improving the quality of life by means of early identification and treatment of physical, psychosocial and spiritual care needs<sup>2;10</sup>. The roles also align with the CanMEDS Physician Competency Framework describing the abilities required to meet people's needs effectively<sup>27</sup> and with the principles of the European Academy of Teachers in General Practice ie communication, collaboration with other care givers and training. Our results thus suggest that to provide care for patients with a life-limiting illness FPs need to combine the abilities required for good generalist care with the tasks and roles specific to this (palliative) patient population outlined in our study. By providing tasks and roles for the family physician we developed a preliminary framework that can contribute to the promotion and development of the integration of a palliative care approach into primary care from diagnosis onwards.

It is noticeable that FPs, nurses and patients do not usually refer explicitly to care provided throughout the illness course as palliative care but use the term only for care during the terminal phase. However, from a semantic and theoretical perspective, what they are describing covers the tasks and roles of an early palliative care approach exactly<sup>2;10</sup>. The reason for not using the term 'palliative' in this context could be that palliative care originates in 'terminal' care for patients with cancer and is still perceived as synonymous with care for an imminently dying patient at a time when no more treatment is available, rather than care for a patient with an illness from which they are expected to die sooner or later. Several studies (in oncology hospital settings) have suggested that use of the term 'palliative care' may be a deterrent to the adoption of early palliative care and that 'supportive care' may be better<sup>28</sup>. The attitudes towards and perceptions of the term palliative care, at patient, caregiver and policy level, should be taken into account when health care systems are developing structures for integrating palliative care into the care continuum.

Not all our respondents agreed on the necessity of all tasks and particularly on their timing. FPs for example disagreed on the timing of conversations about advance care planning with the patient and the family and said how difficult it was to do this at earlier phases in the illness trajectory, despite the risk of postponing the discussions until it was too late<sup>29;30</sup>. Education and training of FPs, also raised by our respondents, could improve these skills, which are often perceived as difficult<sup>31</sup>. However, patients also might benefit from 'training' or 'awareness-raising' as they still tend to view their FP mainly as the person to turn to in acute situations



and often do not see them during treatment phases<sup>12;32;33</sup> and are unaware of the things the FP may be able to do to alleviate their various problems.

### *Strengths and limitations*

To our knowledge this study is the first to explore the tasks and roles of FPs in palliative care throughout the illness trajectory of people suffering from a life-limiting illness. Our strategy of both data and investigator triangulation, increases the validity of the findings. However, the addition of more perspectives could have provided insight, for example, into expectations and perceptions of the collaboration of FPs with hospital physicians. Using pre-existing groups for focus groups might mean that some family physicians restricted their thoughts or opinions – they might have felt safer not questioning their own or others' competencies in front of their colleagues. On the other hand, the whole purpose of the pre-existing peer-review groups is to stimulate critical self-reflection and there is research showing that pre-existing groups benefit discussions<sup>34</sup> and also our focus groups elicited great discussion and found dissent between participants within focus groups. Another limitation is that the role of the FP as a life-long learner is shorter in comparison with other themes, but our data did not allow more development. More research is needed for this topic. Although we expect our findings to be applicable to FPs in several countries, expectations and experiences of care in Belgium may be different from those of other countries, especially those with dissimilar primary care systems.

### **Conclusions**

In summary, if palliative care is to be integrated earlier into the care of patients with life-limiting illnesses, FPs will have an important role to play, next to specialist palliative care services. Our study illustrates what are considered the key tasks and roles of the FP in palliative care throughout the course of a life-limiting illness, starting with diagnosis. These findings can be used as an important starting framework to support, promote and develop an integration of a palliative care approach into the care continuum.

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*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

*Author Contributions.* KB, JC, LV and LD conceived the idea of the study and JC, LV and LD obtained funding. JC and KB contributed to the planning of the data collection and the actual collection of data. KB was responsible for the integration of the data and KB, KVT and JC for the main analyses on this file. KB and JC led the writing of the paper. All listed authors contributed to the writing of the article and approved the final version of the manuscript.

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## **Appendix. Semi-structured interview and focus group guide (adapted for patients, nurses and family physicians)**

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### Introduction

#### Part I: general

##### Patients

1. With whom do you live at home?
2. How often do you see your FP?

##### Physicians and nurses

1. Where do you work? And whom do you work with?
2. How many years of experience do you have?

#### Part II: Care needs

3. Can you give some examples of problems, care needs you\*/your patients experienced since you/they have known you\*/they have this illness? When did these problems/care needs start?

Prompts: other similar problems/needs, other problems/needs, aid card with categories of needs (physical, information, practical, social, psychological, existential)

#### Part III: care provision by the FP

4. How do FPs/you† go about the identification of care needs?

Prompts: how, actual examples, what hampers or favours this identification?

5. Which care needs do you think the FP/you† should handle?
  - a. Are these care needs handled (by the FP) in practice?
    - i. If not, who should handle these care needs?
  - b. Is it the task of the FP to refer to specialist palliative care?

Prompts: actual examples

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\*In case of interviews with patients

†In case of focus groups with FPs

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**PART IV**

**USE OF SPECIALIST PALLIATIVE CARE SERVICES**



## **CHAPTER 6**

### **REFERRAL TO PALLIATIVE CARE IN COPD AND OTHER CHRONIC DISEASES: A POPULATION-BASED STUDY**

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**Abstract**

*Aim:* To describe how patients with COPD, heart failure, dementia and cancer differ in frequency and timing of referral to palliative care services.

*Methods:* We performed a population-based study with the Sentinel Network of General Practitioners in Belgium. Of 2,405 registered deaths respectively 5%, 4% and 28% were identified as from COPD, heart failure or cancer and 14% were diagnosed with severe dementia. GPs reported use and timing of palliative care services and treatment goals in the final three months of life.

*Results:* Patients with COPD (20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services ( $p < .001$ ). The median days between referral and death was respectively 10, 12, 14 and 20. Patients with COPD who were not referred more often received treatment with a curative or life-prolonging goal and less often with a palliative or comfort goal than did the other patients who were not referred.

*Conclusion:* Patients with COPD are underserved in terms of palliative care compared to those with other chronic life-limiting diseases. Awareness of palliative care as an option for patients with COPD needs to increase in palliative care services, physicians and the general public.

## Introduction

Palliative care services have been demonstrated to improve the end of life of people suffering from chronic life-limiting illness<sup>1;2</sup>. Recent studies have also found that earlier referrals to palliative care improve quality of life<sup>3;4</sup>. Although chronic obstructive pulmonary disease (COPD), responsible for an increasing proportion of deaths<sup>5</sup>, is a chronic life-limiting disease, the scarce data for COPD patients seem to indicate that many patients do not receive adequate palliative care which may leave them with reduced quality of life in the final months, weeks or days<sup>6;7</sup>. In contrast, patients with a cancer diagnosis relatively often receive palliative care<sup>8-12</sup>. Part of this inequality between disease groups is historical, due to the initial focus of palliative care on oncology in the countries in which it was first developed<sup>13</sup>; part of it is due to the difference in disease trajectories<sup>14</sup>. Prognostication of death, which often remains the basis for determining whether a person is eligible for palliative care<sup>15</sup>, is in practice usually easier for cancer patients with a rapid decline and a distinct terminal phase than for those with conditions with a less-recognizable terminal phase e.g. COPD, heart failure or dementia<sup>14;16</sup>. Previous review studies<sup>17;18</sup>, an interview study with informal carers<sup>19</sup> and a large scale survey study with proxies<sup>20</sup> and with patients<sup>21</sup> showed us that patients with advanced COPD experience many palliative care needs similar to those of advanced cancer patients, such as pain, insomnia, fatigue and low mood<sup>18-21</sup>. Dyspnea was even found to be more experienced in COPD patients than in patients with lung cancer<sup>19</sup>. This indicates that COPD patients would equally benefit from care with a palliative intent<sup>22;23</sup>. Research on referral to palliative care among patients with COPD is scarce and most has been limited to specific settings and small sample sizes<sup>10;24</sup>.

Although fewer or later referrals may indicate a disadvantage or inequity, a lack of referral to palliative care services does not necessarily mean the patient did not get any form of care or treatment with a palliative or similar intent through which their potential palliative care needs may have been met<sup>8</sup>. Therefore, to evaluate and understand differences in palliative care referrals between disease groups it would also be important to look at what kind of care and treatment patients who are not referred to any palliative care service are receiving.

This population-based retrospective study aims to describe differences in the extent and timing of referrals to palliative care services for people dying from COPD compared with three other relevant disease groups: heart failure, following the same disease course with a comparable clinical picture, and dementia and cancer, following different disease courses<sup>14</sup>. The study also describes treatment goals when not referred. The following research questions are addressed:

- 1) How often are patients with COPD, heart failure, dementia or cancer referred to palliative care services?
- 2) How long before death are these patients referred?
- 3) Which socio-demographic characteristics are associated with referral and timing of referral to palliative care services within those four disease groups?
- 4) What are the treatment goals for patients who were not referred to these services in the last three months of life?

## Methods

### *Study design*

We conducted a population-based retrospective survey studying deaths registered by a sample of general practitioners (GPs) in Belgium, i.e. the existing nationwide Belgian Sentinel Network of General Practitioners' <sup>25;26</sup>. The Sentinel Network of General Practitioners is a relative stable network of practices or community based physicians, operational since 1979. It has proved to be a reliable epidemiologic surveillance system for health care data e.g. on diabetes, stroke, cancer <sup>27;28</sup> and is representative for all Belgian GPs in terms of age, sex and geographical distribution <sup>29;30</sup>. In 2009 and 2010 it consisted of respectively 161 and 142 participating practices (both solo and group practices), covering respectively 1.8% and 1.5% of the Belgian population.

### *Procedures*

From 1 January 2009 to 31 December 2010 GPs registered weekly all deaths of patients in their practice on a standardized registration form providing information about care in the final three months of life. The registration form was first developed in Dutch and then forward-backward translated into French, as the study covers both language regions (Flanders and Wallonia) in Belgium. More details on this study protocol have been published elsewhere <sup>26</sup>.

### *Measurements*

*Referral and timing of referral to palliative care services.* For each case the GP was asked to tick one or more of four possibilities: palliative care team at home, hospital based palliative care team (excluding palliative care unit), inpatient palliative care unit or in-house palliative care in a nursing home. The GP also indicated the timing of a referral i.e. the number of days between the first referral to a palliative care service and death.

*Treatment goals.* The importance of three treatment goals i.e. cure, life-prolonging and comfort/palliation was judged by the GP for respectively the last week of life, second to fourth week before death and second to third month before death, on a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important). Concurrence of more than one treatment goal was possible in each period.

*Socio-demographic and disease characteristics.* GPs recorded the cause of death in a manner that is identical to that on the official death certificates in accordance to WHO guidelines: the GP was asked to fill in the immediate, intermediary and underlying causes of death. Causes of death reported by the GPs for our survey were thoroughly checked and encoded (International Classification of Diseases, 10th ed., ICD-10) by the Flemish Ministry of Welfare, Public Health and Family, who also process the official death certificates. Also GPs registered whether the patient suffered from severe, mild or no dementia, age, sex, main place of residence in the last year of life of the patients and whether they experienced symptoms (pain, breathing problems, feeling drowsy, feeling sad, feeling nervous) in the last week of life.

### *Analysis*

For this study we selected only those patients who were 18 years or older and had died from COPD, heart failure, cancer or had suffered from severe dementia. Patients were attributed to one of four disease groups based on the underlying cause of death (as registered by the GP and encoded by the Ministry of Health into ICD10 codes), and on a question about whether the patient suffered from severe, mild or no dementia: COPD (ICD-10 codes J40-47), heart failure (ICD-10 codes I50, I110, I130, I132), cancer (ICD-10 codes C00-D48) or dementia (when the GP indicated that the patient suffered from severe dementia).

In order to explore differences between the four disease groups for referral to palliative care services we conducted Pearson chi square tests. Multivariate binary logistic regression was performed to control for confounding effects of sex, age and main place of residence. We evaluated differences between the disease groups in terms of time of onset of referral with the non-parametric Kruskal-Wallis test. We performed ordinal logistic regression to control for confounding effects.

In order to investigate the association between referral and age, sex and main place of residence within each disease group we performed Pearson chi<sup>2</sup> tests as well as multivariate binary logistic regression for each disease separately.

To further understand the differences in referral between the disease groups we explored treatment goals for patients who were not referred to palliative care services using Pearson chi<sup>2</sup> tests. All analyses were performed using SPSS (version 19.0).

### *Ethical considerations*

Anonymity of patient and physician was preserved. The study protocol was approved by the Ethical Review Board of Brussels University Hospital <sup>26</sup>.

## Results

In total, GPs registered 2,405 deaths of which 1,197 were from COPD, heart failure, cancer or involved severe dementia (Table 1). The proportions of all deaths of the disease groups are comparable to the official death certificate data from 2008.

Table 1. Sample characteristics of deceased patients with COPD, heart failure, severe dementia and cancer; (%)

Number (% of all deaths)	COPD 111 (4.6)	Heart Failure N=88 (3.7)	Dementia N= 325 (13.5)	Cancer N= 673 (28.0)	p-value
<b>Sex</b>					<.001*
Male	62.7	39.8	35.2	56.3	
<b>Age at death, in years</b>					<.001*
18 - 64y	7.2	2.3	2.5	27.2	
65 - 84y	63.1	33.0	38.9	53.7	
≥ 85y	29.7	64.8	58.6	19.0	
<b>Main residence last year of life</b>					<.001*
Home	71.2	54.5	31.9	88.5	
Nursing home	27.9	42.0	65.6	9.4	
Other institute	0.9	3.4	2.5	2.1	
<b>Symptoms in last week of life†</b>					
Pain	29.1	27.0	30.8	55.4	<.001*
Breathing problems	88.4	75.3	46.1	56.3	<.001*
Feeling drowsy	54.4	52.0	69.7	76.0	<.001*
Feeling nervous	48.9	34.8	20.1	44.6	<.001*
Feeling sad	44.7	30.9	18.2	56.2	<.001*

Percentages are column percentages.

\* Pearson  $\chi^2$  test testing for differences between the four disease groups.

† Missing values: for pain n= 193 (16%); for breathing problems n= 171 (14%); for feeling drowsy n= 179 (15%); for feeling nervous n= 286 (24%); for feeling sad n= 314 (26%).

Other institute comprised (psychiatric) hospitals, rehabilitation center or monastery.

Symptoms in the last week of life were rated as present (yes) or not present (no) by the GP.

Eleven patients with COPD as an underlying cause of death also suffered from dementia and were allocated to the COPD group as this disease is the focus of our study.

Proportions of cause of death of all deaths from our study (n= 2405) were compared with the proportion of cause of death from the most recent official death certificate data (2008) in Belgium (n= 101685). The proportions in the latter were for COPD 4.5%, heart failure 4.4% and cancer 27.1%.

### *Referral to palliative care services and timing of referral.*

In the last three months of life patients with COPD (20%) were less often referred to any type of palliative care service than were those with heart failure (34%), severe dementia (37%) or cancer (60%) (table 2). Of all patients with COPD, 4% were referred to a palliative care team at home, 6% to a hospital-based palliative care team and 6% to an inpatient palliative care unit, all less often than cancer patients; 8% were referred to in-house palliative care in a nursing home, which was less often than patients suffering from dementia (25%). Multivariate logistic regression analyses confirmed the differences between the four disease groups in the chances of referral independently of sex, age and main place of residence.

Patients with COPD had a lower median number of days between referral and death (10d) than those with heart failure (12d), dementia (14d) and cancer (20d). However, this difference was not significant when controlled for sex, age and main place of residence.

Table 2. Referral to and time of onset of palliative care services in the last three months of life for the four disease groups

	COPD N= 111		Heart Failure N= 88		Dementia N= 325		Cancer N= 673		p-value
	%	OR (95% CI)§	%	OR (95% CI)§	%	OR (95% CI)§	%	OR (95% CI)§	
<b>Referral to palliative care services (any type)</b>	20.0	Ref cat	34.1	<b>1.99 (1.02-3.90)</b>	37.4	<b>2.32 (1.34-4.02)</b>	60.3	<b>6.07 (3.64-10.13)</b>	<.001†
Palliative care support at home	3.6	Ref cat	5.9	1.55 (0.37-6.49)	6.0	2.61 (0.85-8.04)	28.7	<b>8.56 (3.08-23.76)</b>	<.001†
Hospital based palliative care service (excl. palliative care unit)	5.5	Ref cat	3.5	0.73 (0.17-3.05)	3.5	0.85 (0.29-2.47)	20.3	<b>3.53 (1.50-8.32)</b>	<.001†
Palliative care unit	5.5	Ref cat	7.1	1.64 (0.50-5.40)	2.8	0.68 (0.23-2.07)	21.7	<b>4.06 (1.73-9.54)</b>	<.001†
Inhouse PCS in a nursing home	8.2	Ref cat	21.2	2.23 (0.85-5.83)	26.4	<b>2.41 (1.08-5.40)</b>	6.1	1.49 (0.64-3.45)	<.001†
<b>Time of onset of palliative care services*</b>	Median (P25-75)	OR (95% CI)¶	Median (P25-75)	OR (95% CI)¶	Median (P25-75)	OR (95% CI)¶	Median (P25-75)	OR (95% CI)§	p-value
Days prior to death	10 (7-30)	Ref cat	12 (6-35)	1.34 (0.58-3.09)	14 (7-30)	0.92 (0.31-2.72)	20 (8-45)	1.20 (0.48-2.99)	<.05‡

Abbreviations: Ref cat = reference category; OR= Odds Ratio; CI= Confidence Interval; P25-75= percentile 25 to 75.

Percentages are column percentages. Percentages may not add up to total percentage of referrals because more than one palliative care service was used in some cases.

\* Calculations for only patients with a referral to palliative care services.

† Pearson  $\chi^2$  test testing for differences in referral between the three disease groups.

‡ Kruskal-Wallis test testing for differences in time of onset between the four disease groups.

§ Odds ratios with 95% confidence intervals from multivariate binary logistic regression analyses with palliative care services as dependent variable (referral vs no referral). Controlled for sex, age and main place of residence. Bold denotes significant differences with COPD at  $p < .05$ .

¶ Odds ratios with 95% Confidence Intervals from ordinal logistic regression analyses with time of onset of palliative care services as dependent variable (ordinal variable with 3 categories: 1-7 days (ref), 2-4weeks and 2 or more months). Controlled for sex, age and main place of residence.

Table 3. Proportion\* and chances† of referrals to palliative care services by socio-demographic characteristics for the four disease groups

	<b>COPD</b> N= 111		<b>Heart Failure</b> N= 88		<b>Dementia</b> N= 325		<b>Cancer</b> N= 673	
	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)
<b>Sex</b>								
Male	19.1	Ref cat	36.4	Ref cat	31.2	Ref cat	57.7	Ref cat
Female	22.0	1.26 (0.46-3.51)	32.7	0.49 (0.16-1.48)	40.9	1.49 (0.88-2.53)	63.5	<b>1.46 (1.05-2.05)</b>
<b>Age</b>								
18 - 64y	25.0	Ref cat	0	Ref cat	25.0	Ref cat	62.6	Ref cat
65 - 84y	17.4	0.60 (0.11-3.40)	33.3	n.a.	39.8	1.90 (0.36-10.05)	60.5	0.96 (0.65-1.42)
≥ 85 y	24.2	1.03 (0.16-6.54)	35.7	n.a.	36.6	1.42 (0.27-7.49)	54.9	0.83 (0.50-1.38)
<b>Main residence last year of life</b>								
Home/ with family	20.5	Ref cat	<b>23.9</b>	Ref cat	<b>28.3</b>	Ref cat	<b>61.7</b>	Ref cat
Nursing home	16.1	0.62 (0.19-2.00)	<b>44.4</b>	<b>3.33 (1.07-10.43)</b>	<b>41.6</b>	<b>1.75 (1.02-2.99)</b>	<b>47.5</b>	<b>0.55 (0.31-0.99)</b>

Abbreviations: OR= Odds Ratio; CI= confidence interval; Ref cat= reference category; n.s.= not significant.

Percentages and odds ratios of patients being referred to palliative care services for each disease separately.

\* Pearson  $\chi^2$  test testing for differences in referral between characteristics for each disease group.

†Multivariate binary logistic regression analyses with palliative care services as dependent variable (referral vs no referral) and sex, age and main place of residence as independent variables.

Bold denotes significant at  $p < .05$

*Socio-demographic characteristics associated with referral within the four disease groups*

Female cancer patients were more likely to be referred to palliative care services than their male counterparts. Patients with heart failure and dementia were more likely to be referred when they lived in a nursing home than when they lived at home, while the opposite was found for cancer patients. No significant associations were found in the multivariate analyses for patients with COPD (table 3). There were no significant associations between socio-demographic characteristics and the timing of onset of palliative care services for the four disease groups (not in table).

*Treatment goals for patients not referred to palliative care services*

The proportion of patients not referred decreased as death approached. This was the case for all disease groups (Figure 1). Of those not referred, patients with COPD received fewer treatments aimed at comfort/palliation than did other patients. Even in the last week of life 40% of patients with COPD were not given treatment with comfort or palliative intent. Patients with COPD more often received treatment aimed at cure and at life-prolonging throughout the last three months, up to the last week of life, than those with heart failure, dementia and cancer.

**Discussion**

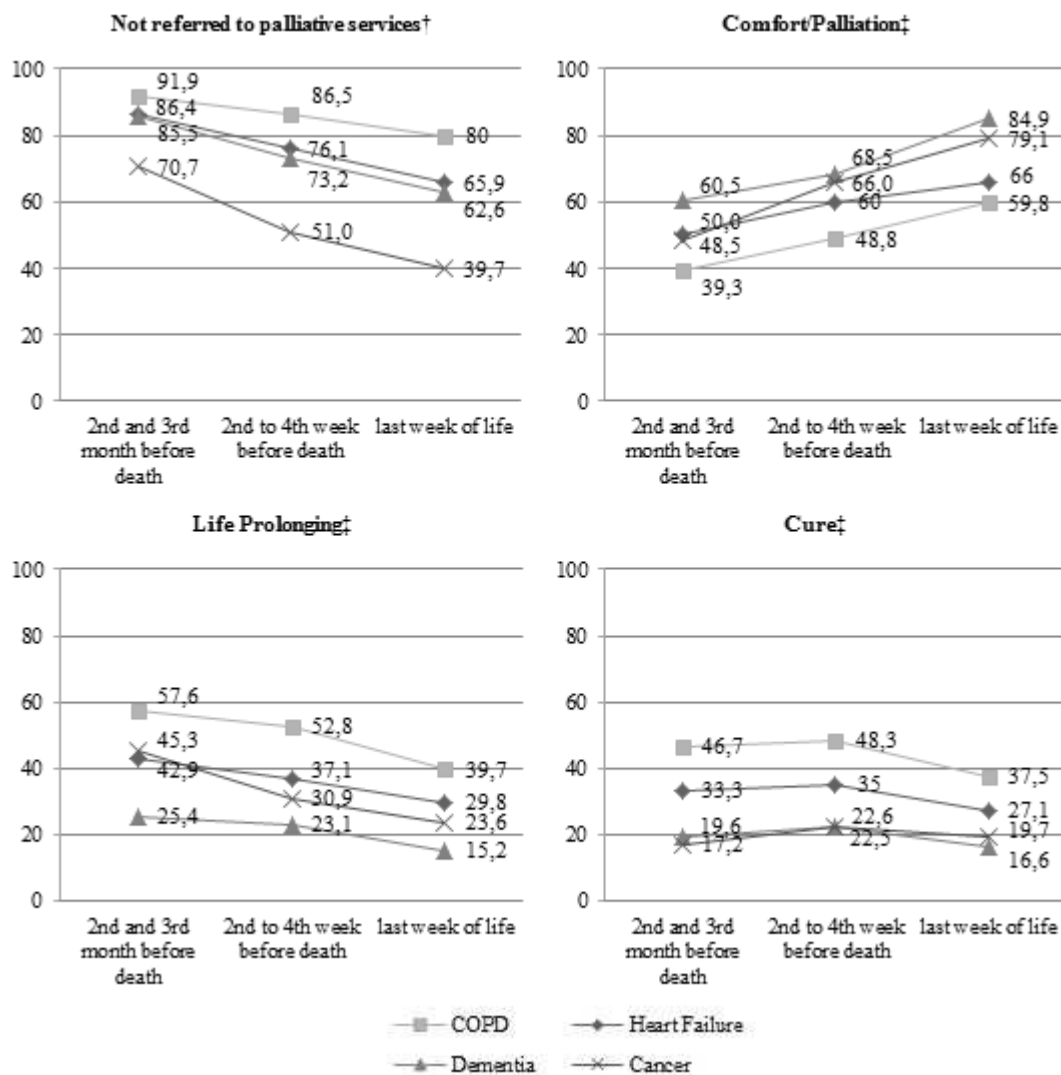
This retrospective study shows that patients with COPD (20%) were much less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to any palliative care service. All patients were referred relatively late in the disease course. Patients with COPD who were not referred more often received treatment with a curative or life-prolonging goal and less often with palliative or comfort intent than did those with heart failure, dementia or cancer who were not referred.

To our knowledge this is the first study comparing the extent and timing of referral to palliative care services, as well as treatment goals of those not referred, for people with COPD, heart failure, dementia and cancer. Our retrospective design and the use of an established representative GP network allowed us to describe these differences on a population-based level in a representative sample of all deaths in Belgium. While retrospective designs may have their limitations to resurrect certain aspects of the treatment histories of dead patients<sup>31</sup> it is the most appropriate design to make population-based estimates about who received palliative care<sup>32;33</sup>. This study also has several limitations. Inherent to retrospective designs, memory bias cannot be excluded. However, we limited recall bias by weekly registrations, leaving little time between death and registration<sup>34</sup>. Another possible weakness is that although GPs are often the main treating and coordinating physicians of patients nearing the end of life, they may not always fully be aware of all treatments and care their patients receive in the last months of life, particularly in institutional settings. With a low number of patients with COPD and heart failure referred statistical power for subanalyses for those patients (e.g. timing of referral) was low. While more disease groups are probably eligible for palliative care services<sup>23</sup> we chose to compare COPD patients with patient groups representing



one of three typical end-of-life disease trajectories identified as eligible for palliative care in previous studies<sup>14;16</sup>. We did not measure whether patients or their families had expressed a preference for palliative care and it could well be that such preferences is one of the reasons (but not necessarily therefore a justification) for the unequal chances between disease groups of receiving palliative care. Additionally it should be kept in mind that patterns of referral are not necessarily a good basis on which to make inferences about the quality and appropriateness of the individual care needs of patients<sup>35</sup>.

Figure 1. Proportion of patients not referred to palliative care services and their treatment goals\* over the course of the last three months of life. (%)



Missing values (not responded) for comfort/palliation, life prolonging and cure in month 2-3, week 2-4 and the last week ranged from 9%-11%.

† Percentages of patients that were not referred to any palliative care service at the time given.

‡ Percentages of patients for which GP indicated a score of 4 or 5 on a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important) for the question: ‘How important were the following aspects of patients care according to you?’ are displayed. These results are for patients that were not referred to palliative care services at the time given.

Multiple treatment goals were possible per period.

Differences between disease groups for each treatment goal and for proportion of referral for each time category were calculated using Pearson  $\chi^2$  test. All p-values were significant  $p < .01$

Our study shows that palliative care services still serve mainly cancer patients in comparison with others<sup>9;12;23</sup>, despite the World Health Organisation<sup>36</sup> calling for palliative care for all chronic life-limiting diseases and the Belgian law on palliative care which gives equal rights to all patients to use palliative care services and regulates its equal availability across the country<sup>37</sup>. The historical focus on cancer and the easier predictability of the cancer disease trajectory may explain the emphasis on cancer<sup>38</sup>, but it is particularly remarkable that COPD, with disease symptoms and a trajectory comparable to heart failure and an unpredictable prognosis comparable to dementia, has a significantly lower proportion of referrals than do those patient groups and differs a great deal in terms of treatment goals at the end of life. A possible explanation is that many patients with COPD and their caregivers do not consider the disease to be life-threatening or to be suitable for palliative care<sup>39;40</sup>. As a result, curative or life-prolonging treatments more often are continued until the last days of life in patients with COPD<sup>41</sup>. Even when treatment is not primarily curative or life-prolonging, the absence of noninvasive ventilation in many palliative care settings<sup>6</sup>, as opposed to in pulmonology wards<sup>42</sup>, may additionally lead physicians to less often consider referring patients with COPD to palliative care services.

Although palliative care services have been shown to improve the quality of care<sup>3</sup>, not all patients need specialized care and it would be unrealistic to refer all patients with a life-limiting chronic disease to palliative care services<sup>43</sup>. Many palliative care needs can be managed by GPs or respiratory specialists. Our findings, however, show that people with COPD are less likely than those with other chronic life-limiting diseases to receive generalist treatment with a palliative or comfort intent. There is evidence that COPD patients experience similar palliative care needs in their last months of life to patients with other chronic life-limiting diseases such as cancer<sup>19;21</sup>; we found high frequencies of pain, feelings of drowsiness and sadness and even higher frequencies of nervousness and difficulties breathing in the last week of life, which suggests referral to a palliative care service or at least changing treatment to include palliative or comfort intents may be of benefit to them<sup>7;14;44;45</sup>.

Another important finding, applicable to all disease groups but perhaps most particularly so for COPD patients, is that palliative care is still seen mainly as terminal care. Half of the referred patients were referred to a palliative care service less than 10 to 20 days before death. This is considerably shorter than the time between referral and death found in studies of cancer patients in the US (42 days) and Australia (54 days)<sup>46;47</sup>. These late referrals may imply that the services used did not have time enough to achieve the goals of palliative care<sup>36</sup>. An over optimistic prognosis and the attitude of physicians and patients to their disease, in combination with a reimbursement criterion in Belgium that stipulates that a 'palliative patient' should have a predicted survival time of less than three months, may impede early referral to palliative care. These barriers may apply particularly to COPD patients.

People with COPD receive palliative care less often than those with other chronic life-limiting diseases, both in terms of referral to specialist palliative care services and in terms of receiving generalist care aimed at comfort. An increasing awareness of palliative care services as an option for COPD patients is needed. However, bearing in mind that involving specialist palliative care services may not necessarily be required or realistic for every patient with a chronic life-limiting disease it is also particularly important that palliative care expertise and

knowledge is cascaded to professional groups such as GPs and respiratory physicians. By combining the skills of general practitioners, respiratory physicians and palliative care services, the care of patients with COPD can be advanced.

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*Conflict of interest.* No conflict exist for the specified authors

*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

*Author Contributions.* KB, JC, LV and LD conceived the idea of the study and JC, LV and LD obtained funding. LV and KV contributed to the planning of the data collection and the actual collection of data. KB and KV were responsible for the integration of the data and KB and JC for the analyses on this file. KB and JC led the writing of the paper. All listed authors contributed to the writing of the article and approved the final version of the manuscript.

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## **CHAPTER 7**

### **WHAT ARE PHYSICIANS' REASONS FOR NOT REFERRING PEOPLE WITH LIFE-LIMITING ILLNESSES TO SPECIALIST PALLIATIVE CARE SERVICES? A NATIONWIDE SURVEY**

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*Submitted*



**Abstract**

*Background:* Many people who might benefit from specialist palliative care services are not using them.

*Aim:* We examined the use of these services and the reasons for not using them in a population in potential need of palliative care.

*Design, setting and participants:* We conducted a population-based survey regarding end-of-life care among physicians certifying a large representative sample (n=6188) of deaths in Flanders, Belgium.

*Results:* Palliative care services were not used in 79% of cases of people with organ failure, 64% of dementia and 44% of cancer. The most frequently indicated reasons were that 1) regular care already sufficiently addressed palliative and supportive needs (56%), 2) palliative care was not deemed meaningful (26%) and 3) there was insufficient time to initiate palliative care (24%). The reasons differed according to patient characteristics: in people with dementia the consideration of palliative care as not meaningful was more likely to be a reason for not using it; in older people their care needs already being sufficiently addressed was more likely to be a reason. For those patients who were referred the timing of referral varied from a median of six days before death (organ failure) to 16 days (cancer).

*Conclusions:* Specialist palliative care is not initiated in almost half of the people for whom it could be beneficial, most frequently because physicians deem regular caregivers to be sufficiently skilled in addressing palliative care needs. This would imply that the safeguarding of palliative care skills in this regular ‘general’ care is an essential health policy priority.

**What is already known on this subject**

-The use of specialist palliative care services improves the quality of life of patients suffering from chronic life-limiting illnesses, but many people who might benefit from these services are not using them.

-No previous quantitative or population-based studies have provided information about the reasons why palliative care is not used and the relative importance of these reasons.

**What this study adds**

-In people with chronic life-limiting illnesses who might benefit from specialist palliative care most physicians judged palliative care needs to be already sufficiently addressed by regular care (56%) or did not consider specialist palliative care as meaningful (26%).

-Insufficient time to initiate palliative care was also an important reason for not referring (24%). Those who were referred were also referred rather late, with a median of 10 days before death.

-Health care policies should pay attention to guaranteeing adequate palliative care skills in regular caregivers and to sensitisation to why timely palliative care is beneficial to people with various chronic conditions.

**Introduction**

Evidence is growing that the involvement of specialist palliative care services in the care of people with life-limiting illness results in improved quality of life and quality of dying<sup>1;2</sup>. However, those who might benefit from palliative care services are not always using them<sup>3;4</sup>. Cancer patients in particular more often receive palliative care than those in other illness groups<sup>5;6</sup>. Most research on use of palliative care services is limited to specific illnesses, settings and services and has small sample sizes. Population-based data are necessary to address the public health challenges regarding palliative care. According to the main public health functions outlined by the WHO, these challenges include the assessment and monitoring of the use of and need for palliative care as well as the evaluation of inequalities in the use of palliative care services in order to design public policies of improvement<sup>7</sup>.

In line with these challenges, it is important to explore and understand why people are not using these services and why some groups have a better chance of being referred than others<sup>8-10</sup>. Previous explorative qualitative studies have suggested that not using palliative care services may be due to barriers or obstacles to the initiation of palliative care at the level of the patient, the family, the illness, the physician and the health care system<sup>11;12</sup>. Previous studies evaluating reasons for non-referral to palliative care services have been merely explorative and qualitative and hence do not provide information on the relative importance of the reasons given for not referring, or were based on patient records hence making it impossible to evaluate systematically the reasons given for non-referral beyond basic clinical characteristics.

This large scale population-based retrospective study aims to describe the use of palliative care services and the reasons for not using these services in a population of people who have potentially had palliative care needs before they died based on their underlying cause of death<sup>13</sup>. For people dying from cancer, organ failure, dementia and other life-limiting diagnoses we will address the following research questions: 1) what are the referral rates and timing of referral to palliative care services, 2) what patient characteristics are associated with non-referral, 3) what are the most frequent reasons for not referring people and 4) how are these reasons related to patient characteristics?

## **Method**

### *Study design*

We conducted a nationwide death certificate survey in the first half of 2013 based on a large and representative sample of deaths (n=6871) in Flanders, Belgium. The study design has been repeatedly applied and validated in earlier studies to evaluate end-of-life care decision making<sup>14;15</sup>. The Flemish Agency for Care and Health selected a random stratified sample of all death certificates of persons aged one year or older from January 1st to June 30th 2013. Stratification was disproportionately based on the likelihood that an end-of-life care decision (ELD) had been made, as determined by the cause of death (larger sampling fractions were taken for deaths where an ELD was more likely eg those from cancer).

Every physician certifying a death certificate in the sample was sent a four-page questionnaire about the end-of-life care and decision-making in the corresponding case. The sample was drawn on a weekly basis as new death certificates came in. After data collection a one-page questionnaire was mailed to all non-responding physicians, asking for the reasons for not participating.

### *Measurements*

The questionnaire asked whether death had occurred ‘suddenly and totally unexpectedly’. If this question was answered negatively – and referral to palliative care would not have been precluded – the physician was asked to answer a number of questions regarding the care received by the patient.

*Use of palliative care services and timing of referral.* The physician was asked whether one or more of the four existing types of palliative care services in Belgium had been involved in the care of the deceased person. These are: multidisciplinary palliative home care teams (multidisciplinary team skilled in palliative care who support the caregivers at home), mobile hospital-based palliative care teams (multidisciplinary team that guides palliative care in the different wards of the hospital), inpatient palliative care units (separate wards in the hospital devoted to palliative care) and a reference person (usually a nurse) trained in and responsible for palliative care in a nursing home.

The physician was also asked to indicate the timing of the referral, i.e. the number of days between the first referral to a palliative care service and death.

*Reasons for not using palliative care services.* When no palliative care services had been used, physicians were asked about the reasons why no such services were used: 1) palliative care was not meaningful or not meaningful enough, 2) palliative care was not available, 3) existing care already sufficiently addressed the patient's palliative and supportive needs, 4) there was not enough time to initiate palliative care, 5) in order not to deprive the patient and/or family of hope, 6) the patient did not want it, 7) the family did not want it or 8) another reason (with the request to specify the reason in text). The reasons in this category were afterwards checked by the researchers and allocated to one of the previous categories where possible. Concurrence of more than one reason was possible for each patient. The possible reasons were selected based on relevant literature about factors hindering the use of palliative care services<sup>11;12;16-19</sup> and on preceding qualitative research on reasons for not using palliative care<sup>20</sup>.

Coded demographic and clinical patient characteristics were obtained from the death certificates and were anonymously linked to questionnaire data by the trusted third party: age, sex, place of death, living situation and underlying cause of death coded in three digits ICD-10 codes.

#### *Data analysis*

Data were weighted for disproportionate sampling and for differences due to nonresponse between the response sample and all deaths in terms province of death and place of death (for all other characteristics no response bias was found). After this complex weighting procedure there were no significant differences between response sample and all deaths for the combination of age, sex, marital status, province of death, cause of death and place of death.

For this study we selected a population comprising deaths from underlying causes that, as identified through mixed-methods research based on Rosenwax et al<sup>13</sup>, can be considered as indicative of a need for a palliative care approach ie both specialist and non-specialist palliative care. The following underlying causes of death were selected: cancer (ICD-10 C00-C97), organ failure ie heart, renal, liver failure or COPD (ICD-10 J40-47, I11-13, I50, K70-72, N10-12, N18-19), dementia (ICD-10 F01, F03, G30) and other illnesses, ie Parkinson's disease, motor neurone disease, HIV/aids and non-cancerous neoplasm (ICD-10 D00-48, G20, G12 and B20-24). Any case where dementia was reported as intermediate cause of death or comorbidity was also considered a dementia case. We deliberately chose to do this because dementia as a cause of death is known to be underreported more than other causes of death<sup>21</sup>. Also taking dementia comorbidities into the analysis allows us to give a more representative view of patients living with (and dying with) dementia for whom palliative care is recommended<sup>22</sup>. Persons younger than 18 years were not considered in the analysis. This was only a small group (n=9) and the palliative care system for children is organized differently from that for adults in Belgium.

Pearson chi square tests analyses for use of palliative care and reasons for not using palliative care services were calculated. We also performed multivariable logistic regression to explore characteristics associated with use of palliative care and reasons for not using palliative care services. The non-parametric Kruskal-Wallis test and multivariable ordinal logistic regression were used to test for differences in time of onset of referral. All calculations were made using the complex samples function in SPSS 22.0.

#### *Anonymity and ethical considerations*

A lawyer was involved in the mailing procedure as trusted third party between responding physicians, researchers and the Flemish Agency for Care and Health to guarantee that completed questionnaires could never be linked to a particular patient or physician. The mailing and anonymity procedures were approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, by the Belgian National Disciplinary Board of Physicians, and by the Federal Privacy Commission.

## **Results**

Response rate was 60.6%. We obtained a response for 3,751 cases and from the non-response survey we found that response was impossible for 683 deaths e.g. because the physician did not have access to the patient's medical file or the patient could not be identified (3751/6188 eligible cases). Of the 3,751 deaths, 1,917 (weighted percentage: 51.1%) were from a cause of death indicative of palliative care need: 25% died from cancer, 12% from organ failure, 12% with dementia and 3% from another illness indicative of palliative care need (Table 1). The causes of death differed significantly in terms of distribution for sex, age, place of death, living situation, and a sudden vs. non-sudden death.

#### *Use of palliative care services*

In 29% of all deaths and 47% of all non-sudden deaths palliative care services were used (Table 2). Of those dying non-suddenly palliative care services were used in 34% of people with organ failure, 48% with dementia and 73% with cancer. Half of the patients who used palliative care were referred less than ten days before death. People with cancer were referred to any type of palliative care service earlier (median: 16 days before death) than those with organ failure (five days), dementia (eight days) or other illnesses (ten days). The differences in use of palliative care services and days between referral and death between illness groups were also significant in multivariable analyses when controlled for age, sex and place of death (not in table).

Table 1. Characteristics of all deaths and of illness groups considered as indicators for potential benefit of palliative care use (weighted %).

	All deaths	Cancer	Organ Failure	Dementia	Other illness within palliative subset*	p-value†
Weighted number (weighted % of all deaths)	3751	919 (24.5)	458 (12.2)	436 (11.6)	104 (2.8)	
Sex						<.001
<i>Male</i>	50.6	57.1	50.9	36.1	55.2	
Age at death						<.001
18-64y	15.4	23.8	10.5	0.9	15.2	
65-84y	46.6	58.5	42.3	38.6	56.2	
≥ 85y	38.0	17.7	47.3	60.5	28.6	
Place of death						<.001
<i>Hospital</i>	47.5	53.2	45.9	21.4	26.4	
<i>Home</i>	22.3	33.2	19.0	13.4	31.1	
<i>Nursing home</i>	26.9	12.4	33.4	63.7	38.7	
<i>Other</i>	3.2	2.3	1.7	1.8	3.8	
Living situation						<.001
<i>Alone</i>	20.6	21.5	21.0	7.9	18.1	
<i>In household with others</i>	50.2	65.8	43.0	28.3	56.2	
<i>Institution</i>	28.6	12.1	35.8	63.3	24.8	
<i>Other</i>	0.6	0.4	0.2	0.5	1.0	
Sudden non-sudden deaths						<.001
<i>Non-sudden</i>	61.4	77.9	62.9	73.6	62.3	
<i>Sudden</i>	38.6	22.1	37.1	26.4	37.7	
Attending physicians						<.001
<i>Family physician</i>	46.1	45.5	50.7	75.9	58.4	
<i>Specialist</i>	49.6	51.9	45.1	20.0	54.3	
<i>Other</i>	4.2	2.6	4.3	4.0	3.5	

Percentages are weighted for representativeness.

Percentages are column percentages.

†Pearson  $\chi^2$  test testing for differences between the four causes of death: cancer, organ failure, dementia and other illnesses.

\*Other illnesses within palliative subset: Causes of death from benign neoplasm, in situ neoplasms or neoplasms of uncertain or unknown behaviour (n=50), Parkinson's disease (n=29), Motor neurone disease (n=22), HIV/aids (n=3).

Table 2. Referral and time of onset of specialist palliative care services;  
% of all deaths (% of non-sudden deaths)

	All deaths (non-sudden deaths) N=3751 (2305)	Cancer N=919 (715)	Organ Failure N= 458 (288)	Dementia N=436 (320)	Other illness within palliative subset N=104 (66)	p-value
Any type	29.1 (47.6)	56.4 (72.6)	21.1 (33.7)	35.6 (48.4)	27.6 (44.6)	<.001† (<.001‡)
<i>Palliative care support at home</i>	8.9 (14.6)	25.6 (33.0)	4.2 (6.7)	4.8 (6.6)	10.5 (16.9)	<.001† (<.001‡)
<i>Hospital-based palliative care service (excl. Palliative care unit)</i>	11.4 (18.6)	23.4 (30.1)	9.0 (14.4)	7.9 (10.7)	6.7 (10.8)	<.001† (<.001‡)
<i>Palliative care unit</i>	3.8 (6.2)	11.5 (14.8)	0.7 (1.1)	0.9 (1.3)	4.8 (7.7)	<.001† (<.001‡)
<i>Palliative care reference person in a nursing home</i>	8.2 (13.4)	5.0 (6.5)	8.4 (13.3)	24.5 (33.3)	9.4 (15.2)	<.001† (<.001‡)
Time of onset of palliative care service*						
<i>Median days prior to death [p25-p75]</i>	10 [5-30]	16 [7-31]	5 [3-14]	8 [4-20]	10 [5-30]	<.001‡

Abbreviations: P25-75= percentile 25 to 75.

Percentages are column percentages. Percentages may not add up to total percentage of referrals because more than one palliative care service was used in some cases.

\*Calculations for only patients with a referral to palliative care services (only available for non-sudden deaths). Missing values for time of onset n= 139 (12.8%).

†Pearson  $\chi^2$  test testing for differences in referral between the four illness groups.

‡Kruskal-Wallis test testing for differences in time of onset between the four illness groups.

### *Reasons for not using palliative care services*

The most prevalent reason for not using palliative care according to physicians was that the patient's palliative and supportive care needs were already being sufficiently met by regular care (56%, table 3). Other reasons indicated by physicians included that palliative care was not or not sufficiently meaningful for the patient (26%), there was not enough time to initiate palliative care (24%), the patient did not want palliative care (6%), the family did not want palliative care (4%), palliative care was not available (1.5%) or the physician did not want to deprive the patient and/or family of hope (0.5%).

Table 3. Reasons given by physicians for not using palliative care services (PCS) in people with an illness indicative of palliative care need and who died non-suddenly\*.

	Not using PCS (N(% within category))	Care sufficient (%)	Not meaningful (%)	Not enough time (%)	Patient did not want (%)	Family did not want (%)	Not available (%)	Not take away hope (%)
Total number (%)	N=583 (42.0)	N=304 (56.3)	N=142 (26.3)	N=127 (23.5)	N=34 (6.3)	N=23 (4.3)	N=8 (1.5)	N=3 (0.5)
Cause of death								
<i>Cancer</i>	<b>194 (27.4)</b>	<b>51.4</b>	<b>22.5</b>	<b>26.7</b>	<b>13.0</b>	<b>5.1</b>	1.1	0.6
<i>Organ Failure</i>	<b>189 (66.3)</b>	<b>51.4</b>	<b>24.2</b>	<b>28.1</b>	<b>4.5</b>	<b>6.2</b>	2.8	0.6
<i>Dementia</i>	<b>163 (51.4)</b>	<b>66.4</b>	<b>35.5</b>	<b>13.7</b>	<b>0.0</b>	<b>1.3</b>	0.7	0.0
<i>Other illnesses within palliative subset</i>	<b>37 (55.2)</b>	<b>62.5</b>	<b>15.6</b>	<b>28.1</b>	<b>8.6</b>	<b>2.9</b>	0.0	0.0
Sex								
<i>Male</i>	300 (43.0)	<b>50.0</b>	27.3	26.4	<b>8.3</b>	4.7	1.4	0.4
<i>Female</i>	282 (41.7)	<b>62.9</b>	25.3	20.5	<b>4.2</b>	3.8	1.9	0.4
Age at death, in years								
<i>18-64 y</i>	<b>68 (30.6)</b>	<b>31.7</b>	29.0	<b>36.5</b>	<b>12.7</b>	3.2	4.8	0.0
<i>65-84 y</i>	<b>258 (37.6)</b>	<b>55.1</b>	22.7	<b>26.3</b>	<b>8.0</b>	3.0	1.7	1.3
<i>≥ 85 y</i>	<b>256 (55.1)</b>	<b>63.5</b>	29.2	<b>17.1</b>	<b>2.9</b>	5.8	0.8	0.0
Place of death								
<i>Hospital</i>	<b>244 (41.5)</b>	<b>41.7</b>	25.4	<b>42.6</b>	<b>3.0</b>	<b>3.0</b>	<b>3.4</b>	0.9
<i>Home</i>	<b>137 (37.0)</b>	<b>64.2</b>	23.0	<b>7.3</b>	<b>20.0</b>	<b>8.9</b>	<b>0.8</b>	0.8
<i>Nursing home</i>	<b>186 (47.7)</b>	<b>68.2</b>	29.9	<b>10.3</b>	<b>1.7</b>	<b>2.3</b>	<b>0.0</b>	0.0
Living situation								
<i>Alone</i>	<b>93 (39.9)</b>	52.2	23.3	<b>29.7</b>	<b>7.8</b>	4.4	0.0	0.0
<i>In household with others</i>	<b>282 (39)</b>	52.4	24.3	<b>28.0</b>	<b>9.7</b>	5.8	2.4	1.2
<i>Institution</i>	<b>196 (49.0)</b>	63.0	30.4	<b>15.2</b>	<b>0.5</b>	2.2	1.1	0.0
Reporting physicians								
<i>Family Physician</i>	340 (42.8)	<b>67.6</b>	27.0	<b>8.7</b>	<b>8.6</b>	5.4	0.6	0.3
<i>Specialist</i>	238 (41.8)	<b>41.1</b>	25.8	<b>44.2</b>	<b>3.1</b>	3.1	1.8	0.9

Full response answers which physicians could indicate as a reason for not using palliative care services were respectively: the care already sufficiently addressed the patient's palliative and supportive needs; palliative care was not meaningful or not meaningful enough; there was not enough time to initiate palliative care; patient did not want it; family did not want it; palliative care was not available; to not take away the hope of the patient and/or the family.

Abbreviations: PCS= palliative care services.

Percentages are row percentages. Percentages may not add up to 100 because more than one reasons could be indicated in some cases.

Missing values for reason not using palliative care n=43 (7%).

\*Bivariate Pearson  $\chi^2$  test testing for differences in reasons of not using palliative care services between causes of death, sex, age groups, places of death, living situations and reporting physicians. Bold denotes significant at p<.05.



Table 4. Reasons given by physicians for not using specialist palliative care services (PCS) controlled for cause of death, place of death, sex and age: multivariate analyses.

	Not using PCS*	Care sufficient†	Not meaningful†	Not enough time†	Patient did not want†	Family did not want†
Cause of death						
<i>Cancer</i>	Ref	Ref	Ref	Ref	Ref	Ref
<i>Organ failure</i>	<b>4.80 (3.42-6.74)</b>	0.91 (0.56-1.48)	1.12 (0.66-1.92)	0.95 (0.53-1.69)	0.51 (0.21-1.25)	1.54 (0.58-4.07)
<i>Dementia</i>	<b>2.68 (1.90-3.78)</b>	1.11 (0.66-1.88)	<b>1.90 (1.08-3.34)</b>	0.92 (0.43-1.94)	n/a	<b>0.18 (0.03-0.92)</b>
<i>Other illnesses within palliative subset</i>	<b>2.96 (1.76-4.98)</b>	1.21 (0.53-2.76)	0.73 (0.28-1.88)	1.65 (0.67-4.07)	0.64 (0.23-1.78)	<b>0.07 (0.09-0.62)</b>
Place of death						
<i>Hospital</i>	Ref	Ref	Ref	Ref	Ref	Ref
<i>Home</i>	0.97 (0.74-1.27)	<b>2.38 (1.49-3.80)</b>	0.83(0.48-1.43)	<b>0.10 (0.05-0.21)</b>	<b>9.74 (4.04-23.47)</b>	<b>4.43 (1.61-12.17)</b>
<i>Nursing home</i>	0.75 (0.53-1.05)	<b>2.17 (1.29-3.64)</b>	1.00 (0.56-1.80)	<b>0.17 (0.09-0.34)</b>	1.45 (0.35-6.02)	0.84 (0.20-3.53)
Age						
<i>18-64 y</i>	Ref	Ref	Ref	Ref	Ref	Ref
<i>65-84 y</i>	1.17 (0.83-1.64)	<b>2.27 (1.18-4.38)</b>	0.67 (0.34-1.31)	0.85 (0.42-1.72)	0.73 (0.32-1.67)	0.91 (0.14-5.77)
<i>≥ 85 y</i>	<b>1.88 (1.27-2.80)</b>	<b>2.50 (1.22-5.12)</b>	0.83 (0.40-1.71)	0.75 (0.33-1.66)	0.42 (0.16-1.12)	2.75 (0.41-18.66)
Sex						
<i>Male</i>	Ref	Ref	Ref	Ref	Ref	Ref
<i>Female</i>	0.79 (0.62-1.00)	1.43 (0.96-2.14)	0.77 (0.50-1.19)	0.92 (0.55-1.52)	0.80 (0.38-1.68)	0.75 (0.30-1.87)

Abbreviations: PCS= palliative care services; n/a= not applicable because no cases.

\* Complex samples multivariate logistic regression analyses with palliative care services as dependent variable (no referral vs referral) cause of death, place of death, sex and age as independent variables.

†Complex samples multivariate logistic regression analyses with reasons for non-referral as dependent variable (indicated vs not indicated) and cause of death, place of death, sex and age as independent variables.

Bold denotes significant at  $p < .05$ .

*Characteristics associated with not using palliative care services and reasons for not using it*

Those dying from non-cancer conditions, particularly organ failure, had higher chances of not using palliative care services than those dying from cancer (Table 4). Not using palliative care services was more likely in patients older than 85 than in those younger than 65 years. Use of palliative care services did not differ between place of death or between men and women.

For non-referred people who died at home, compared with those who died in hospital, physicians more often stated that the regular care was sufficient. For older patients it was more likely that their palliative care needs were considered to be sufficiently addressed than it was for younger people. Not using palliative care because it was not meaningful was more likely to be indicated in people with dementia than in those with cancer or other illnesses. The reason that there was not enough time for initiating palliative care was more likely to be mentioned for people who died in hospital than for those dying at home or in a nursing home. It was less likely for people with dementia than for those with cancer or organ failure that the family did not want palliative care. The reason that patients or family refused to initiate palliative care services was more likely to be given for people who died at home compared with those dying in hospital. There were no differences between men and women in reasons for not using palliative care.

**Discussion**

Our population-based study uncovered the frequency of the reasons given for why many people with illness types indicative of palliative care needs are not using palliative care services. The most indicated reasons were that 1) care received already sufficiently addressed the patient's palliative and supportive needs, 2) palliative care was not meaningful or not meaningful enough and 3) there was not enough time to initiate palliative care. In addition, this study revealed some striking differences between patient groups in the reasons given for not using these services: for older patients the care needs were more often said to be already sufficiently addressed than for younger people, and for patients with dementia it was more likely than for those with cancer or other illnesses that palliative care was considered as not meaningful.

*Strengths and limitations*

Our study is based on a representative sample of deaths in Flanders with a high response rate (61%). The retrospective design, with death as the sampling unit, is the most suitable design to describe the circumstances shortly before death for all dying people and hence to collect population-based and generalizable information on the use and non-use of palliative care<sup>13;23;24</sup>. The drawback of this methodology is that memory/recall bias may be possible in some cases, because there was a one- to two-month lag between death and the sending of the questionnaire. An underestimation of the use of specific palliative care services cannot be precluded, as the attending physician will not always have knowledge about the palliative care services previously involved in another setting. For overall estimation and comparisons we

believe this produces less of a problem. Our study focussed only on the perceptions of physicians about the reasons for not using palliative care, excluding the equally important perspectives of patients, family and other caregivers<sup>25</sup>.

#### *Comparison with other research*

We found that many people who were dying from illnesses indicative of palliative care needs had not used specialist palliative care services. On the one hand this might indicate that many patients die with unmet palliative care needs while on the other it corresponds with a coordinated palliative care model in which not all patients need specialist palliative care services because their treating physicians can manage palliative care problems where they are not too complex<sup>26</sup>. Our study indeed found that regular or general care already sufficiently meeting the patient's care needs was the most frequently reported reason given for not referring to palliative care services. Remarkably, this reason was more likely to be found in older people as compared with their younger counterparts. It remains a question, of course, whether physicians may overestimate their own competence or underestimate their patients' palliative care needs<sup>27;28</sup>.

Another striking finding in our study was that in one third of cases palliative care was perceived as not meaningful, especially considering that we limited our study to the population dying with illnesses indicative of palliative care need, as identified in the research by Rosenwax et al<sup>13</sup>. We found this reason particularly in cases of people dying with dementia. Nevertheless, people with dementia have been shown to have palliative care needs similar to those of cancer patients<sup>29-31</sup>. It has been consistently found that symptoms such as pain or spiritual care needs are under-recognized and undertreated in dementia patients<sup>31-33</sup>. Our results seem to suggest the persisting need for more awareness that specialized palliative care could be of great benefit to people with dementia and their families<sup>34</sup>.

The setting in which people are dying seems also to determine why some people are not using palliative care services. At home or in a nursing home regular care was much more likely to be perceived as sufficiently addressing palliative care needs than in a hospital. Our study also found that it was more likely that there was not enough time to initiate palliative care in a hospital setting than elsewhere. It is known that in the last months of life a significant proportion of people are hospitalized with very acute care needs, and physicians tend to focus on these acute, potentially reversible symptoms that have prompted hospitalization<sup>35</sup>. In contrast with Lynn and Adamson's model of palliative care, indicating that palliative care interventions may coexist with life-prolonging and curative treatment goals, this seems often not to be the case in practice<sup>36</sup>. Physicians' perceptions of palliative care as care to be provided when no more treatment is available, concomitant with their reluctance and/or inability to predict the correct time-to-death prognosis, might be a reason why there was - in their perception - not enough time to start palliative care<sup>37;38</sup>. Our study, in line with previous research<sup>6</sup>, also found that if a referral to specialist palliative care took place, this was often only shortly before death.

Although often mentioned in qualitative literature as a barrier to referral to specialist palliative care, our study shows that most physicians do not consider depriving people of hope as a reason for not referring their patients<sup>20</sup>. The problem of access or the availability of services, regularly mentioned in other studies, also did not seem to be an important reason why patients were not referred which perhaps reflects the fact that the study was performed in Belgium, where equal availability and access to palliative care services across the country is a legal requirement<sup>39</sup>.

### *Policy implications and conclusion*

While the WHO and other important organizations are pleading for equal access to palliative care services for all people with chronic life-limiting illnesses, our population-based study shows that even though availability of palliative care services was not a major problem, there were still many people who did not use these services. The reasons for not using palliative care found in our study inform future health policies regarding palliative care in at least two ways. Firstly, strategies to tackle palliative care needs within the population should not only focus on specialist palliative care services but also on evaluation, stimulation and the guaranteeing of adequate palliative care skills in regular caregivers. Secondly, there is still a need to promote awareness of the benefits of early palliative care, including its potential and meaningfulness in non-cancer conditions such as dementia.

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*Guarantor.* KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. This manuscript is an honest, accurate, and transparent account of the study being reported. There are no important aspects of the study that have been omitted. Any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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## **PART V**

### **GENERAL DISCUSSION AND CONCLUSIONS**





## **CHAPTER 8**

### **GENERAL DISCUSSION AND CONCLUSIONS**

## 8.1. Introduction

The broad aim guiding this dissertation was to understand the challenges of an early and timely palliative care approach, both generalist and specialist, for patients with cancer, organ failure and dementia. First, it explored the palliative care needs of patients with a life-limiting illness throughout their illness trajectory, from diagnosis onwards. Second, it explored the role of family physicians in the identification and handling of these palliative care needs throughout the illness trajectory of patients. Third, we investigated the extent and timing of referrals to specialist palliative care and reasons for not referring patients.

In this discussion section, I will first briefly summarize the main findings of this thesis (paragraph 8.2). Second I will address the strengths and weaknesses of the methods used in this work (paragraph 8.3). In paragraph 8.4 the findings are discussed in the light of the state-of-the-art in palliative care research and practice. Finally, a number of recommendations and implications for practice, policy and future research will be outlined (paragraph 8.5).

## 8.2. Summary of main findings

In this paragraph, the results of the previous chapters are summarized in three separate themes, following the three aims of this dissertation.

The first aim was to explore and evaluate palliative care needs experienced from diagnosis onwards by people with a life-limiting illness.

### *Experienced palliative care needs by patients with cancer, COPD, heart failure and dementia*

In Chapter 2, a qualitative semi-structured face-to-face interview study with 18 patients explored how patients with cancer, COPD, heart failure or dementia experience certain palliative care needs related to their condition during the whole course of their illness from diagnosis onwards. We found that patients expressed care needs during their illness course that fell within seven core domains of palliative care: physical, psychological, social, existential, financial, information and communication, coordination and continuity of care.

Multiple physical symptoms such as pain, breathlessness, dry mouth and cognitive impairment, depending on the illness, seemed to occur throughout the illness course, already starting from before the moment of diagnosis. Remarkably, some respondents did not define their experienced symptoms as problems for which they needed or sought care. Some perceived their physical symptoms, for example dyspnea and memory loss, as side effects inherent to their illness or as a part of getting older, about which not much can be done. Psychological needs were already pronounced early in the illness trajectory for many respondents. They were anxious about what to expect in the future, including in what setting they would be cared for, whether they would suffer and what would happen to their family

after they had died. Strongly diminishing social contact since diagnosis was a widely experienced problem and this was associated with feelings of loneliness and social isolation in all types of life-limiting illness trajectories. We also found that respondents not receiving specialist palliative care did not mention or raise the term ‘palliative’ and even the respondents with heart failure or dementia who we knew received specialist palliative care did not use the term palliative care; only those with cancer did.

The findings of the study provide insights into problems and care needs throughout the illness trajectory and seem to justify the proposal that a generalist or specialist palliative care approach might be relevant early in the illness course for all life-limiting illnesses.

### ***Palliative care needs throughout the cancer trajectory***

In Chapter 3, a cross-sectional survey study in 620 patients with cancer investigated the quality of life (based on physical, psychological, social, role, cognitive and existential functioning, physical symptoms, financial issues and spiritual issues) and the proportion of unmet care needs of patients with cancer at three different phases in the cancer trajectory. These three phases consisted of 1) when people receive (or have planned) treatments with a curative intent, 2) when people receive (or have planned) treatments with a life-prolonging intent and 3) the ‘most advanced’ phase, when people have no more curative or life-prolonging treatments and/or their life expectancy is less than six months.

Among the 620 patients who participated in the survey, 101 received treatments with a curative intent, 188 received treatments with a life-prolonging intent and 86 had no more disease modifying treatments and/or had a life expectancy of less than six months. The patient groups further into the trajectory reported statistically ( $P < 0.05$ ) and clinically significantly ( $\Delta \geq 10$ ) poorer functioning compared with earlier phases, indicating a poorer quality of life, even when controlled for the effects of sex, age or type of cancer, eg mean scores (on a scale from 0-100) for physical function were 91 in the European norm group, 76 in the curative group, 60 in the life-prolonging group, and 54 in the ‘most advanced’ group. A similar pattern was found for emotional functioning (respectively 83, 71, 58, 53). Symptoms were experienced at all three phases in the illness trajectories. Higher scores, implying more symptom burden, for fatigue, pain, dyspnea and appetite loss were found in groups further into the cancer trajectory ( $P < .05$ ) and fatigue, insomnia and constipation were clinically significantly worse in the curative group compared to the European reference group. Additionally, people in the life-prolonging group were less likely to have received help from a professional care giver than the ‘most advanced’ group for physical symptoms (69% vs 81%), emotional functioning (52% vs 74%) and social and role functioning (31% vs 50%) although there was no significant difference between the two groups in wanting more professional help for these domains.

This survey seemed to provide an empirical confirmation of a model of early palliative care needs<sup>1</sup>. Certainly those in a phase in which they were receiving life-prolonging treatments, even if they had a prognosis of more than six months experienced a deteriorated quality of life and they expressed substantial unmet care needs in the core domains of palliative care. Remarkably, even in the phase in which people were still receiving or planning curative

treatments many people experienced clinically significantly more problems compared with a European reference group. This seems to suggest that also for this ‘early’ group a palliative care approach could be meaningful. Our findings suggest that a palliative care approach might need to be initiated in standard oncological care early in the care trajectory, and palliative needs are likely to become more severe as the illness progresses.

The second aim was to explore the role of family physicians in identifying and handling generalist palliative care needs from diagnosis onwards.

***Barriers and facilitators in the timely identification of palliative care needs by the family physician***

In Chapter 4, a qualitative study with four focus groups with family physicians, two focus groups with community nurses and 18 interviews with patients with cancer, COPD, heart failure or dementia is reported. We addressed the research question: ‘What are the perceived barriers and facilitators affecting the early identification of palliative care needs in patients with cancer, organ failure or dementia from the perspective of family physicians, community nurses and patients?’. This study identified barriers and facilitators that relate to 1) the family physician’s knowledge, skills and communication styles, 2) the patient’s communication styles, 3) relationship and contact between family physician and patient, 4) perceptions regarding the role of a family physician, 5) collaboration with other caregivers and continuity of care, and 6) underlying fears and beliefs related to the prognosis.

A key finding of our study is that neither patients nor family physicians will introduce discussion of or conversations about non-acute care needs. We found that the family physician is (still) perceived as someone to appeal to for medication prescriptions, regular follow-up contacts (eg for measuring blood pressure) or acute situations (eg a cold). Many of the patients indicated that their family physician asked mostly about their acute care needs in acute situations when consulting the family physician and that they would not mention their non-acute care needs themselves. Some patients believed it is not the family physician’s role to deal with non-acute issues. Patients often viewed the specific manifestations of their disease (eg memory problems in dementia) as something to be addressed by a hospital specialist rather than the FP. Patients also stated they hold back because they perceive the FP as busy and are reluctant to bother them. Questioning about care needs including non-acute care needs proactively was considered as an important facilitator by our respondents.

Another important finding is that identification of palliative care needs by the family physician seems to be more problematic in the earlier stages than during the terminal phase. Family physicians stated they make enough time to visit patients (often out of hours), but admitted that this ‘privilege’ is mainly reserved for patients in the terminal stage.

The findings provide new and important insights into the reasons family physicians do not identify palliative care needs throughout the illness trajectory in a timely and successful manner and also offers facilitating ways to overcome these problems.

### ***The role of the family physician in early generalist palliative care***

In Chapter 5, we answered (with the same data collected from qualitative focus groups and interviews as in Chapter 4) the following research questions: ‘What do family physicians, community nurses and people with a life-limiting illness perceive as the role and the tasks of a family physician in tackling the palliative care needs of those with cancer, organ failure or dementia? Do the tasks attributed to the family physician in generalist palliative care differ according to the timing in the illness course?’ We gained insights into the perception on the roles and tasks for the family physician in tackling the ‘primary’ palliative care needs throughout the illness trajectory. We found various tasks that could be allocated to four overarching roles: the family physician as an available medical expert (e.g. clarifying diagnosis and implications), as a communicator (e.g. communicating terminal status to the patient and his or her family), as a collaborator (e.g. exchanging information, both medical and non-medical with the hospital physician), and as a life-long learner (e.g. following training on symptoms, treatments and communication). We noticed that the perceptions of some tasks changed with different phases of the illness, while others were applicable throughout the complete illness course. Hence the findings could be categorized into five broader stage-related contexts: 1) around diagnosis, 2) during treatment and follow up, 3) around acute episodes or exacerbations, 4) during the terminal phase and 5) throughout the complete illness course. Participants mostly had the same perception of the family physicians’ tasks, but not all our respondents agreed on the necessity of all tasks and particularly on their timing. Family physicians for example disagreed on the timing of conversations about advance care planning with the patient and the family and indicated how difficult it was to do this at earlier phases in the illness trajectory, despite the risk of postponing the discussions until it was too late. These findings help to elucidate the tasks and roles required of FPs to make integration of a palliative care approach into the care continuum possible.

The third aim was to investigate and describe the use of specialist palliative care services

### ***Extent and timing of referral to specialist palliative care services and treatment goals in the last three months of life.***

In Chapter 6, the Belgian sentinel network of general practitioners registered in 2009 and 2010 2,405 deaths of which 1,197 were from cancer, COPD, heart failure or involved severe dementia. We investigated how often patients with COPD, heart failure, dementia or cancer were referred to palliative care services, and how long before death are they referred. We also reported on the treatment goals for patients who were not referred to these services in the last three months of life.

The results of this nationwide showed that patients with COPD (20%) were referred considerably less frequently, and later, to palliative care services than were patients with heart failure (34%), cancer (60) or dementia (37%). Moreover, patients with COPD who were not referred to specialist palliative care services were less likely to have received treatment aimed

at comfort and palliation and were more likely to have received treatment aimed at cure and prolonging life than were other patients who were not referred. Even in the last week of life 40% of patients with COPD were not given treatment with comfort or palliative intent. Patients with COPD had a lower median number of days between referral and death (median of 10 days) than those with heart failure (12 days), dementia (14 days) and cancer (20 days).

In Chapter 7, a post-mortem survey study on the death certificates of 3,751 deaths in the first half of 2013 in Flanders, of which 1,917 were from a life-limiting illness was performed. We investigated how often patients with cancer, organ failure, dementia or other potentially life-limiting illnesses (such as HIV/AIDS) were referred to palliative care services, and how long before death these patients were referred.

Palliative care services were used in 21% of people with organ failure, 37% with dementia and 60% with cancer. Half of the patients who used palliative care were referred less than ten days before death. People with cancer were referred to any type of palliative care service earlier (median: 16 days before death) than those with organ failure (five days), dementia (eight days) or other illnesses (ten days).

The provision of specialist palliative care services in Belgium still largely favours patients with cancer. An increasing awareness of palliative care as an option for non-cancer patients, especially those with COPD is needed.

### ***Reasons for not referring people with a life-limiting illness to specialist palliative care services***

In Chapter 7, the post-mortem survey in physicians using a representative sample of official death certificates in Flanders also reported on the most frequent reasons for not referring people and how these reasons related to patient characteristics. We found that many people were not referred because physicians perceived the regular care provided to sufficiently address care needs (56%), especially in people more than 85 years old (64%), did not consider palliative care as meaningful (26%), especially in people with dementia (36%), or perceived that there was not enough time to initiate palliative care (24%), especially in hospital deaths (43%). Other reasons were less frequently indicated: the patient did not want palliative care (6%), the family did not want palliative care (4%), palliative care was not available (1.5%) or the physician did not want to deprive the patient and/or family of hope (0.5%). These findings suggest future health policies should not only focus on specialist palliative care services but also on evaluation, stimulation and the guaranteeing of adequate palliative care skills in regular caregivers. Additionally, there is still a need to promote awareness of the benefits of early palliative care, including its potential and meaningfulness in non-cancer conditions such as dementia.

### **8.3. Methodological considerations, strengths and limitations**

We used four types of studies to answer our research questions: one qualitative study, including focus groups and interviews, and three quantitative studies (a cross-sectional survey study, and two mortality follow-back studies, one via the Belgian Sentinel Network of General Practitioners, and a post-mortem study surveying physicians attending a representative sample of deaths). All four studies have their strengths and limitations.

#### **8.3.1. Qualitative focus groups with family physicians and community nurses and interview studies with patients**

Our qualitative study was innovative because we described the experiences and opinions of family physicians, community nurses and a wide range of patients on care needs and care provision at different stages of their illness and not at the stage of imminent death or advanced illness as has been done in most previous other studies on palliative care needs<sup>2-6</sup>. In contrast to questionnaire measurements, narrative interviews allow portrayal of the complex structure of lay concepts more adequately. Moreover, qualitative research leads to the recognition of phenomena and addresses issues that, up to this point, were neither considered nor expected by the researchers<sup>7:8</sup>. By using separate focus groups with family physicians and nurses and individual interviews with patients, all participants could speak more freely. This method is particularly preferred for gathering in-depth understanding of the complex mechanisms of a contested topic like palliative care and life-limiting illnesses<sup>9:10</sup>. Because of the multidisciplinary nature of palliative care and the importance of patient-centredness, we interviewed people with different perspectives and we analysed the data within a research team with multidisciplinary backgrounds. Our strategy of both data and investigator triangulation increases the validity of the findings<sup>11</sup>.

A number of considerations in this study have to be taken into account. First, we deliberately chose not to use the term ‘palliative’ at first during the interviews and focus groups, because their interpretation of palliative care might be, and can be expected to be, limited to terminal care<sup>12</sup>. Our goal was to explore care needs and recognition and handling these care needs within the perspective of the currently promoted model of early palliative care and to avoid focusing only on terminal stage care, unlike in most previous studies on this topic<sup>6:13-18</sup>. Second, we used a wide definition of palliative care needs, related to the WHO definition<sup>19</sup>, including physical, psychosocial, practical and existential/spiritual needs, that may be experienced from diagnosis onwards. This definition is of course open to discussion<sup>20</sup> and may evolve over time, but the perceived care needs and barriers and facilitators we found are relevant whether the care being received is perceived as ‘palliative’ or not. Third, our results are organized in reliable categories and we have tried to remain as close as possible to the phrasing used in the focus groups and interviews; however many issues discussed in each category are interrelated with other issues or categories and should therefore not be interpreted as isolated factors. Fourth, the results of the focus groups and interview study are based only on the experiences and opinions of small samples of family physicians, community nurses and patients. From this qualitative study, no conclusions can be drawn about the incidence of



palliative care needs or barriers in recognizing palliative care needs. However, the goal of this study was merely to explore these issues and qualitative research is the best possible method to do so. Finally, although we expect our findings to be applicable to family physicians in several countries, expectations and experiences of care in Belgium may be different from those in other countries, especially those with dissimilar primary care systems.

Certain methodological limitations of the study are acknowledged. Some effects of recall bias and possible psychological post-hoc adjustments of earlier experiences in their illness trajectory by patients cannot be ruled out. It should be taken into account that patients who agreed to participate in the interviews might have done so to express particular positive or negative experiences and might experience and cope with their care needs differently from others. Community nurses and family physicians who agreed to participate in the focus groups might have been more interested, and perhaps have more expertise, in this topic than do others. Furthermore, the addition of the perspectives of others for example hospital physicians could have provided additional insights, especially regarding the opinion and expectations of the role of the family physician. However, perceptions of the tasks and roles of the family physician are best explored in actors who regularly assist and cooperate with them, such as community and palliative care nurses and of those who are receiving care from them, namely the patients, and of course the family physicians themselves.

### **8.3.2. Cross-sectional survey study among patients with cancer**

The findings with regard to the quality of life, care provision and unmet care needs of patients with cancer at different time points in the illness trajectory in Chapter 3 are based on the cross-sectional survey study. A major strength of this study is the relatively good overall response rate and consequently the satisfying numbers from whom a response was received which made it possible to compare different groups of cancer patients according to the treatment phase and still have a reasonable statistical power. By using the same validated instrument for all patients we could have meaningful insights into differences between the three phase groups. Moreover, by using population based values of a European Normgroup (data from Sweden, Norway, the Netherlands and Germany) we had a reference point to which we could compare the means scores of our three groups, particularly relevant for the curative group, in order to make clinically relevant inferences<sup>21</sup>. Finally, by asking patients themselves we used the best way to map quality of life and unmet care needs<sup>22</sup>.

Several considerations and limitations must be stipulated when interpreting the results. First, a longitudinal design could have made it possible to describe an evolution of care needs in individual patients, but due to often long cancer trajectories and the possible uncertain nature of disease progression a longitudinal design is extremely challenging and resource intensive. Therefore, we believe the chosen cross sectional study in a population of cancer patients to be best suited for the purpose of this study<sup>23</sup>. Second, we included patients for the study as they came in for a consultation in the hospital. It may be that patients in a terminal situation who remained at home (e.g. with palliative home care) no longer came for consultations to the hospital and, hence, were underrepresented in our most advanced group (no more treatments or prognosis less than six months). However, research has found that a considerable proportion of cancer patients in Belgium are still admitted to hospital in the final weeks even if they go on

to die at home<sup>24</sup>. This might nevertheless imply that scores in the most advanced group in actual practice might be worse than those presented in our study. Third, this study only assesses palliative care needs of patients at a single university hospital (i.e. Ghent University). Because of this, one cannot be sure that the conclusions drawn about palliative care needs and the professional care they received apply to people in other geographic locations or at other hospitals. Moreover, there might even be variation in care needs and care provision in different wards (i.e. medical oncology, pneumology and gastro-enterology) due to different policies in the wards. By controlling for cancer type however, we might have overcome this limitation.

### **8.3.3. Mortality follow-back study via the Belgian Sentinel Network of General Practitioners**

The extent and timing of referrals and care goals for those who were not referred, described in Chapter 6, were found in the registration study via the Belgian Sentinel Network of General Practitioners. Strengths of this study are that we used an established representative family physician surveillance network with a long history of registration research<sup>25-27</sup> to identify a representative sample of patients who died in Belgium. We used the most appropriate design to make population-based estimates about who received palliative care and who did not<sup>28,29</sup>. Finally, contrary to other retrospective designs, we limited recall bias via weekly registrations, leaving little time between death and registration<sup>30,31</sup>.

This study also has several limitations. A possible weakness is that although family physicians are often the main treating and coordinating physicians of patients nearing the end of life, they may not always be fully aware of all treatment and care their patients receive in the last months of life, particularly in institutional settings. With a low number of patients with COPD and heart failure referred to specialist palliative care services statistical power for subanalyses for those patients (e.g. timing of referral) was relatively low. Finally, quality of care outcomes, such as care needs and quality of life, were not measured. We did have measures on symptoms, but only in the final week of life. It should be kept in mind that patterns of referral to specialist palliative care services are not necessarily a good basis on which to make inferences about the quality and appropriateness of the individual care needs of patients<sup>32</sup>. Our results can only serve as indicators for unequal referrals and treatment goals on a broad societal level which can provide indispensable public health information. Quality of care and quality of life outcomes such as patients' symptoms or needs and measuring patients' wishes for care would have made it possible to judge the individual appropriateness of care. However, these limitations are inherent to the design of this study in which physicians, and not patients, were the respondents.

### 8.3.4. Post-mortem survey using a representative sample of death certificates

This method was used in Chapter 7 to investigate the use of specialist palliative care services and the reasons for not using them in patients with a life-limiting illness in potential need of palliative care<sup>33</sup>. The retrospective design, with death as the sampling unit, irrespective of whether they receive care with an end-of-life intent or have been identified as terminally ill, is the most suitable design to describe the circumstances shortly before death for all dying people<sup>28</sup>. The retrospective design is an efficient means of collecting national/regional and generalizable information about the last months of life and about access to health care and hence to collect population-based and generalizable information on the use and non-use of palliative care for people suffering from different life-limiting illnesses<sup>28;29;33</sup>. This data collection has been proved to be a highly reliable method for describing end-of-life care and end-of-life decisions<sup>30;34;35</sup>. In 2013, the year from which we used the data comes, a very high response rate of 61% was received to the questionnaires sent to the physicians attending the deaths in the sample. We were allowed to make a non-response analysis, which assured us of the validity of the findings as the nonresponse analyses showed no major differences in terms of diagnostic and demographic characteristics between the deaths in the obtained and the non-responding samples. Reasons for not participating were predominantly practical in nature (e.g., the physician did not have the time to participate or was not able to because of patient identification issues), leading us to believe that systematic distortion of the final response sample is limited<sup>36</sup>.

Because of our large obtained sample it was possible to study associated factors and compare various subpopulations. In that way we could make meaningful comparisons between people with cancer, organ failure dementia and other illnesses who might benefit from palliative care. These illnesses were overrepresented in our sample because of the disproportionate stratification procedure. This stratification, based on the cause of death for which an end-of-life decision was more likely, was used to enhance the efficiency of the sampling procedure and to yield smaller confidence intervals around estimates. The data were weighted in the analyses to correct for stratification and to make results representative for all deaths.

There are also a number of weaknesses. First, physicians report on deaths that had occurred frequently one to two months before they filled in the questionnaire, thus making possible recall or memory bias one important limitation. The recommendation to consult patient records when completing the questionnaire may have minimized this problem. Second, the attending physicians might not always be aware of the care delivered in the final week or months of life, especially in patients referred to different settings in the final weeks or months. Therefore, an underestimation of the use of specific palliative care services cannot be precluded, as the attending physician will not always have knowledge about the palliative care services previously involved in another setting (e.g. a patient dying with palliative care in hospital previously receiving support from palliative home care services). However, it will impact on the estimation of the overall use of any specialist palliative care to a smaller degree. Third, the reliance on the attending physician as a proxy for reporting on the care of the patient compared with family members as proxies may be more suitable for the description of referral rates, timing of referral and reasons for not using palliative care intrinsic to the care, but less so to uncovering the reasons for not using palliative care emanating from the patient or the

family. Death certificates in Belgium do not allow for the identification of next of kin, unlike in the U.S.<sup>37</sup> and the U.K.<sup>38</sup>, so our design didn't allow questioning of the patient's family. Finally, we only have insights for Flanders and not for Brussels and the French-speaking Walloon region of Belgium.

#### **8.4. Discussion of the findings in the light of current challenges and state of affairs within palliative care research and practice**

##### **8.4.1. Palliative care may be appropriate at any stage of a life-limiting illness: initiating palliative care in a timely manner**

A key finding of this dissertation is that several care needs were experienced at different stages of the life-limiting illness, irrespective of the illness type or duration of the illness course (Chapter 2). In our study with cancer patients (Chapter 3) we found that particularly from the life-prolonging phase onwards symptoms and problems that are in the core domains of palliative care (physical, psychosocial and existential) are present. Many of these problems increase towards the most advanced phase, independent from sex, age or type of cancer. Importantly, patients in the curative phase had already experienced physical symptoms and had clinically significantly worse functioning than a European reference group. The care needs expressed by our respondents (both Chapter 2 & 3) coincide with the important principles and domains of palliative care according to the WHO and as identified in previous research (i.e. physical, psychological, social, existential/spiritual, information, financial, and continuity and coordination of care<sup>39-44</sup>).

These results on care needs can contribute to a clarification of what 'early' could mean in 'early palliative care'. The WHO definition merely states that it should be initiated early in the illness trajectory, in conjunction with other therapies that are intended to prolong life<sup>19;45</sup>. Others seem to have interpreted this in terms of the likelihood that death will occur rather soon (e.g. within 6 or 12 months using a 'surprise question')<sup>46</sup>. Yet others have implicitly suggested that early palliative care refers to care for those patients for whom disease is no longer responsive to curative treatment<sup>47</sup>, or for whom the disease is at an *advanced stage*<sup>48;49</sup>. The model of early palliative care built on the study by Temel et al<sup>48</sup> and on the many similar studies<sup>50;51</sup> based on it, is one in which a specialist palliative care team starts collaborating with the oncologists as soon as patients are diagnosed with advanced cancer. The WHO further propagates a needs-based rather than a prognosis-based model of palliative care. In that respect, based on our findings regarding the occurrence of palliative care needs, our study thus seems to suggest that 'early' might mean earlier than suggested in these previous studies<sup>48;52</sup>, possibly from diagnosis onwards. Our results provide a useful context for the recent resolution of the WHO<sup>45</sup> which emphasizes that palliative care should be integrated early within the continuum of care, possibly together with other disease modifying treatments, in order to address the needs of people with a life-limiting illness.

### 8.4.2. The important role of generalist palliative care

By showing the complexity of care needs throughout the illness trajectory of people with cancer, COPD, heart failure and dementia (Chapter 2 & 3), the question of ‘why’ palliative care should be possible from early on in and throughout the illness course can be changed to ‘how’ such a palliative care approach might be implemented. A multitude of types of care can probably address these care needs. However, a global consensus on what constitutes the implementation or integration of palliative care into the regular care of the patient is currently lacking<sup>53</sup>. Although most research up until now has focussed on integration of specialist palliative care teams into mostly oncology care in the hospital<sup>48;50</sup>, awareness is growing that specialist palliative care interventions for all patients diagnosed with a life-limiting illness is not feasible and would probably be too costly<sup>54-56</sup>. The only alternative then to avoid underserving patients in need is to decrease demand for specialist palliative care services by expanding the scope of generalists in the provision of palliative care and integrate a generalist palliative care approach into the regular care<sup>56-59</sup>.

We found (in Chapter 6 & 7) that many people who were dying from illnesses indicative of palliative care needs had not used specialist palliative care services. On the one hand this might indicate that many patients die with unmet palliative care needs while on the other it corresponds with a coordinated palliative care model in which not all patients need specialist palliative care services because their treating physicians can manage palliative care problems where they are not too complex and specialist palliative care services are not required<sup>56</sup>. One of the studies in this dissertation (Chapter 7) indeed found that regular or general care already meeting the patient’s care needs sufficiently was the most frequently reported reason given for not referring to palliative care services. This was the case for 56% of non-referred patients dying with a life-limiting illness. We found this reason to be more common for people who died at home (65%) than for those dying in the hospital (42%).

For most chronic seriously ill patients, the bulk of care is provided by family carers throughout the illness course and certain care needs will be met by them; other important aspects of care will be delivered by the caregivers in hospitals and in primary care<sup>24</sup>. In opinion pieces in influential journals family physicians are attributed a critical role in dealing with palliative care needs<sup>56;58;60;61</sup>. In these pieces it is stated that all physicians at undergraduate level should be taught a minimum set of palliative care skills. These should ensure that all family physicians have the knowledge and confidence to manage most common problems in palliative care. However, these definitions and opinions do not describe detailed and delineated tasks for the family physician in palliative care, especially not in the earlier phases of the illness trajectory. With this dissertation we contribute to an elucidation and delineation of the role of family physicians in the contemporary model of early palliative care. We described and discussed the perceived and expected tasks and roles of the family physicians as perceived by the family physicians themselves, community and palliative care nurses and patients (Chapter 5). The respondents attributed specific tasks and roles to the family physicians at various phases and throughout the illness trajectory, some already from diagnosis onwards. These tasks and roles reflected the palliative care principles of improving the quality of life by means of early identification and treatment of physical, psychosocial and spiritual

care needs<sup>19;45</sup>, such as clarifying diagnosis and implications, discussing the patient's prognosis and illness course, discussing test results and treatment decisions with other caregivers. It was notable however that not all our respondents agreed on the timing of some tasks. Family physicians for example disagreed on the timing of conversations about advance care planning with the patient and the family and said how difficult it was to do this at earlier phases in the illness trajectory, despite the risk of postponing the discussions until it was too late<sup>62;63</sup>. These results indicate that an early palliative care approach is - unsurprisingly - not yet generally applied in general daily practice. It was striking however that many patients indicated they would like to discuss their non-acute illness-related needs with their family physician, particularly if family physicians would have had more time. This suggests that patients are probably open to early palliative care interventions by the family physician (irrespective of whether this is formally called 'palliative' care).

Internationally, health care policy makers have been beginning initiatives in order to meet the palliative and other care needs of the growing group of patients suffering from a life-limiting illness in primary care<sup>46;64-66</sup>, for example, financial incentives for family physicians who coordinate patients with chronic diseases such as diabetes (e.g. in Belgium<sup>65</sup>) and heart failure (Australia<sup>66;67</sup>). Another initiative is a 'palliative care status' for patients with a life expectancy of more than 24 hours but less than three months to enable them to cover the costs of nurses, physiotherapists and family physicians (e.g. Belgium<sup>68</sup>). The Gold Standard Framework in the UK<sup>46</sup> or the development of other tools to identify patients with chronic conditions in need of palliative care (e.g. Spain<sup>64</sup>) are examples of palliative care approaches developed within primary care to identify and handle palliative care needs in the last months of life by the family physician. Most initiatives, however, focus on particular diseases (leaving out other life-limiting illnesses) and a specific time for beginning palliative care, which confirms the still predominant paradigm that palliative care needs are applied only to those who can clearly be identified as dying. Moreover, it illustrates how most health care systems are not tailored to the recommended early palliative care needs model where palliative care delivered by the family physician is available for all life-limiting diseases throughout the illness trajectory, starting from diagnosis.

This dissertation does not suggest that the family physician should take the responsibility for dealing with all dimensions of care needs, nor that specialist palliative care services should be involved with every patient. This dissertation shows important tasks and roles for the family physician in primary generalist palliative care in Belgium. However, by looking at the role of the family physician we also recognized the importance of other caregivers with whom family physicians collaborate or should collaborate (i.e. family physician as a collaborator, Chapter 5). The specialist palliative care teams provide a good example here. Family physicians might make referrals to more specialized services or could use these services as consultants<sup>69;70</sup>. Bearing in mind that involving specialist palliative care services may not necessarily be required or realistic for every patient with a chronic life-limiting disease and that patients are also frequently transferred between care settings (e.g. from home to hospital and the other way around)<sup>24</sup>, it is also particularly important that palliative care expertise and knowledge is cascaded to professional groups such as oncologists, respiratory physicians, neurologists, nurses etc.

Overall, our results (Chapter 5 & 8) imply that family physicians (and other regular caregivers) should have sufficient basic palliative care skills and attitudes. Some regular caregivers may develop expertise in all generalist domains and some specialist domains, so potentially each caregiver may find his or her own personalized set of palliative care skills and a threshold for referral to (or involvement of) a specialist palliative care service. By combining the skills of family physicians, hospital specialists, palliative care services and other caregivers such as nurses, the care of patients with life-limiting illnesses can be advanced.

*A palliative care approach by the family physician: just good care?*

Palliative care differs from many other specialties in that it is not defined by a given organ system or set of procedures, it tends to focus not only on patients but also their families and it is a multidisciplinary approach. Primary care and palliative care overlap, to some extent, in their holistic approach to care and lack of disease/organ-specificity. Patients with serious chronic illness such as cancer, organ failure or dementia are part of the daily practice of family physicians<sup>71</sup>.

The perceived roles of the family physician described in this doctoral thesis align with the CanMEDS Physician Competency Framework describing the abilities required to meet people's needs effectively<sup>72</sup> and with the principles of the European Academy of Teachers in General Practice i.e. communication, collaboration with other caregivers and training. Palliative care goes beyond the traditional medical model by focusing on psychosocial issues, existential/spiritual matters, medical decision-making, care planning and advance care planning and on the relief of suffering in all its dimensions. Importantly, this focus is held throughout the illness trajectory of all patients who can be expected to die in the short or long term from their disease. Our results thus suggest that to provide care for patients with a life-limiting illness family physicians need to combine the abilities required for good generalist care with the tasks and roles specific to the palliative patient population outlined in our study in Chapter 5. The overlap between the tasks and roles described in the family physician's definition and the roles described in our research on a palliative care approach by family physicians may however imply that a palliative care approach is no more than 'good primary care'. Nonetheless, this overlap does not necessarily mean there is a problem however, because a palliative care approach (at least when it is good integrated palliative care throughout the illness trajectory) should be an integral part of 'good primary care', with a specific focus on patients with a life-limiting illness.

**8.4.3. Barriers to identifying palliative care needs and initiating palliative care in a timely manner**

This dissertation points out difficulties in identifying palliative care needs by family physicians and reasons for a late shift to a palliative care approach and late referrals to specialist palliative care services. Our results are based on the experiences and perceptions of family physicians, community nurses and patients conducted in qualitative focus groups and interviews (Chapter 4) and on the perceptions of physicians in a post-mortem study on specialist palliative care use (Chapter 7). We found barriers at three levels: the health care

system level, the health care professionals' level and the patient/ family level. An important finding in our study was that identification by the family physician of palliative care needs seems to be more problematic in the earlier stages than in the terminal phase. Family physicians indicated that it was easier to discuss and identify palliative care needs in the last weeks of life when prognosis is clearer; family physicians make more time, do more home visits and more often involve nurses in that phase. Additionally, family physicians are often little involved when patients are under curative or life-prolonging treatment at a hospital. However, we also found that even at the very end various factors seem to hinder identification of palliative care needs by the family physician. These factors were similar to other reported barriers in end-of-life care<sup>6;63;73-76</sup>.

At the health care system level, the health care professionals' level and the patient/ family level, probably the most important barrier to timely recognition and initiation of a palliative care approach might be that initiation of palliative care is still too much prognosis-based instead of needs-based. The prevailing view on palliative care still follows a traditional dichotomous model of medical care, with curative or disease-modifying treatment offered initially and comfort care provided only when/if these measures are no longer appropriate. We want to argue that working with a prognosis-based model of palliative care (i.e. where palliative care is initiated when a certain limited remaining life-expectancy is prognosticated) will intrinsically imply several barriers to both generalist and specialist palliative care. A needs-based model may be better, albeit still not conclusive.

### ***Prognosis-based initiation***

At the health care system level legislation and financing makes it sometimes difficult to start palliative care early<sup>77</sup>. For example, in Belgium, the current reimbursement and eligibility criterion to be granted a 'palliative status' (to remove all out-of-pocket costs for formal home care) and a 'palliative lump sum' (to cover the costs of additional medicines and materials) from the health insurance is that the patient is expected to live for three more months or less. This does not only strengthen the 'old' idea of palliative care as terminal care, but it may impede a generalist palliative care approach from general caregivers and early referral to specialist palliative care services. Many patients will not receive generalist or specialist palliative care, or will only receive it late, because often physicians do not correctly judge the prognosis, mostly over-estimating the period of survival<sup>78-81</sup>. This is probably one of the factors explaining why we found that many patients in potential need of palliative care were not referred to specialist palliative care services, or referred very late, (Chapter 6 & 7) or why many family physicians felt more comfortable talking about palliative care issues at the very end of life (Chapter 4 & 5). Moreover, the inability to predict the correct time-to-death prognosis<sup>82;83</sup> might be a reason why there was not - in the perception of physicians - enough time to start palliative care. For a quarter of the patients whom were not referred to palliative care services, physicians indicated there was not enough time to initiate palliative care (Chapter 7). By the time they realized the patient might be 'eligible for' palliative care, the patient was 'suddenly' death.



Although comparison of referral rates with other countries is constrained by different study designs, estimation methods or inclusion criteria, there is a recent study in four European countries, using the same method based on representative epidemiological surveillance networks, which showed that specialist palliative care services were used to a similar or larger extent in Belgium (36% in non-cancer patients and 65% in cancer patients) as in Spain (respectively 34% and 62%), the Netherlands (respectively 19% and 37%) and Italy (respectively 19% and 63%)<sup>84</sup>. Our findings on specialist palliative care services indicated that referrals in Belgium mostly occur only one to three weeks before death: 20 days in cancer, 14 days in dementia, 12 days in heart failure and 10 days in COPD. This may indicate a much shorter time between referral to specialist palliative care services and death compared to other countries such as Australia (54 days in cancer patients)<sup>85</sup>, US (42 days in cancer patients)<sup>86</sup>. In the same European study as described above it shows that Belgium has shorter referral periods than other European countries (in all patients who died non-suddenly): Belgium (15 days), the Netherlands (21 days), Spain (26 days) and Italy (30 days)<sup>84</sup>. Even the average referral periods in those countries can be considered relatively late if the goals of palliative care have to be adequately achieved<sup>19;87</sup>. Again, the difference in referral period between Belgium and other countries might be a consequence of the Belgian limited prognosis-based policy regarding the palliative care status and lump sum (see above). The ‘earlier’ initiation of specialist palliative care in the other countries may simply be due to the fact that no time limit (e.g. Italy, Spain), or a longer prognosis period (e.g. US, i.e. six months) is set by national health services for access to palliative care or hospice care status or to specialist palliative care services. This would suggest the important influence of policy and organizational choices. Given that patients with cancer are referred to specialist palliative care services earlier than patients with organ failure or dementia (Chapter 6 & 7), a prognostic threshold seems to work better for cancer patients. Such a threshold does not accommodate diseases of organ failure or dementia, given their very different and more unpredictable trajectories<sup>88</sup> (Chapter 6 & 7).

In an attempt to improve physicians’ prognostic accuracy and improve the identification of people in need of palliative care, some authors have suggested that patients should be considered for palliative care involvement if clinicians would not be ‘surprised’ if the patient survived less than twelve months, i.e. ‘the surprise question’<sup>80;89</sup>. Recent studies have shown the feasibility of this surprise question and the high accuracy of survival prognosis<sup>90;91</sup>. In this respect, the three Federations of Palliative Care in Belgium are taking initiatives to implement this question in the development of a tool to help caregivers identifying patients qualifying for palliative care in all care settings<sup>92;93</sup>. This might be specialist palliative care or generalist palliative care, e.g. by reinforced interventions of family physicians and other caregivers in primary care (with increased reimbursement for the consultations). Although studies suggest that the number of patients who will receive palliative care by using this question might increase<sup>90;91</sup>, similar prognostic problems (especially in non-cancer patients) will still exist and many patients whose prognoses are incorrectly judged or who experience palliative care needs earlier in their illness trajectory may not receive a palliative care approach or will receive it too late<sup>90</sup>.

Prognostication is and will be a very important skill, especially for patients with a life-limiting illness<sup>89</sup>, because one of the key roles of physicians in palliative care is to initiate discussions on prognosis and goals of care<sup>94</sup>. It has never been easy - even with cancer - to predict when

someone is within six months or a year of dying. But prognostication as the, or the only, trigger to initiate a palliative care approach, will not be sufficient. Based on our studies about palliative care needs we can expect that many palliative care needs at earlier stages will be left unmet if physicians only use a trigger such as prognosis to start asking about or handling palliative care needs or to refer patients to specialist palliative care. Therefore, a shift towards a needs-based approach is required.

### *Needs-based initiation*

While the time of death may be uncertain for many patients with a life-limiting illness, our results and other research show that the care needs they face are not<sup>88;95</sup>. Threshold levels or criteria of unmet care needs generally make a lot more sense than survival thresholds since 1) there is widespread agreement that palliative care interventions should not be reserved for the very end of life and 2) the problems with prognosis, as described above. Thereby, more recent models of palliative care try to overcome this prognosis related structural barrier and recommend a ‘needs-based’ approach<sup>19</sup>. Although such an approach may overcome the prognosis barrier, it remains questionable whether it is the magic bullet to bring about the practice of early palliative care, considering the manifold factors that hamper the timely identification of care needs by health professionals which we found in this dissertation<sup>96;97</sup>. In our study on barriers in identifying palliative care needs by the family physician (Chapter 3) we identified key barriers which mainly relate to communication styles (the lack of pro-active communication by both family physician and patient), the perceived role of the family physician (still mainly seen as someone to appeal to in acute situations), and continuity of care (i.e. family physician are often not involved in disease related problems, but where specialists are). A key finding of our study is that patients will not introduce discussion of their non-acute care needs and also family physicians do not initiate such conversations, which is in line with previous research about end-of-life communication<sup>97;98</sup>. Similar barriers were identified in previous research for advance care planning and for provision of palliative care at later stages of the illness<sup>5;18;43;99-103</sup>. These problems do not only relate to family physicians. Other research shows that hospital physicians too often lack the skills, knowledge and communication styles to initiate and provide timely palliative care<sup>104</sup>.

It is notable that we found variation in which respondents voiced their problems and care needs (Chapter 2). Not all patients take the initiative to make their problems known<sup>105</sup>. Our patient respondents seemed to vary in the manner and extent to which they want professional caregivers to be involved and did not always define their problems as involving the need for professional care. Some research shows that many patients (not unlike healthcare professionals) equate palliative care with ‘giving up’ and therefore do not want to initiate talking about their non-physical care needs or starting up palliative care<sup>18;77;106</sup>. However in our study (Chapter 2) we did find patients who would have liked to have discussed their psychosocial and existential care needs (although not explicitly calling these palliative care needs) with their family physician if he or she had more time. In addition, other research has shown that many patients are willing to talk about these problems and that there is no negative

impact by discussing the prognosis of their disease, their wishes and preferences regarding treatment in the future etc.<sup>107</sup>.

Additionally, our results show a tendency in family physician–patient interactions to consider mainly medical issues and physical needs. Whilst this medical and physical care is vital, the other aspects of palliative care may be equally important to the patient and their family. A remarkable finding of our studies in Chapter 2 and 3 concerning the care needs of patients is that more attention needs to be paid particularly to deterioration in social functioning and role functioning (i.e. involvement in life situations related to work for pay, household, social life, family life and studies) due to the illness.

The barriers we found in our different studies in identifying the palliative care needs thus suggest that a needs-based approach can only successfully lead to an early and integrated palliative care approach if adequate multidimensional needs-assessment methods or techniques are implemented in regular practice (see further).

### ***What's in a name?***

It is noticeable that in our qualitative studies family physicians, nurses and patients do not usually refer explicitly to care provided throughout the illness course as palliative care but use the term ‘palliative’ only for care during the terminal phase (Chapter 2, 4 & 5). However, from a semantic and theoretical perspective, what they are describing covers exactly an early palliative care approach<sup>19;45</sup> as well as the described care needs that cover the different dimensions and domains in palliative care<sup>39-43</sup>. The reason for not using the term ‘palliative’ in this context could be that palliative care originates in ‘terminal’ care for patients with cancer and is still perceived as such. Therefore it is understood as care for an imminently dying patient at a time when no more treatment is available, rather than for a patient with an illness from which they are expected to die sooner or later. Also the term ‘palliative care’ is still often perceived as only a type of care or as a specialized discipline, rather than as an approach or ‘philosophy’ to care<sup>108</sup>.

Several studies in oncology hospital settings have suggested that the use of the term ‘palliative care’ may be a deterrent to the adoption of early palliative care and that ‘supportive care’ may be better. Supportive care is a term used in oncology settings to define the prevention and management of the adverse effects of cancer and its treatment. It alleviates symptoms of cancer, supports communication with patients about their disease and prognosis and eases emotional burden<sup>109</sup>. In essence, both names describe approximately the same practice of ‘total care’ with attention to physical, psychological and social care needs. In a study with medical oncologists and midlevel care providers, the name palliative care compared with supportive care was perceived more frequently as a barrier to referral, decreasing hope and causing distress to patients and their families<sup>110</sup>. As a follow-up to this study, the team changed the name of the unit. In a study of records of 4,701 patients with a first specialist palliative care consultation before and after the name change they found a 41% greater number of specialist palliative care consultations and a shorter duration from advanced cancer diagnosis to specialist palliative care consultation<sup>12</sup>. Using the term ‘supportive care’ instead of ‘palliative

care' for the earlier phases when the patient is still receiving disease modifying treatments would be in line with the original and traditional definitions of palliative care seen as terminal care. Most contemporary definitions, however, perceive a palliative care approach as applicable from diagnosis onwards possibly together with curative or life-prolonging treatments. We acknowledge that the definitions of supportive and palliative care are open to discussion<sup>20</sup> and may change over time, but our findings remain useful beyond semantic discussion as the perceived care needs or care processes exist even if people do not necessarily consider them to be 'palliative'. In any case, giving another name to a similar practice should not be an excuse not to talk with the patient about their care needs and the possible outcomes of their illness. There should be enough care provision to handle these needs.

#### **8.4.4. Patients with dementia and organ failure, especially those with COPD, are underserved in terms of palliative care**

Our study described in Chapter 2 reveals that even at early stages in the illness trajectory people with both cancer and a non-cancer condition experience palliative care needs. Previous research showed that COPD patients experience similar palliative care needs in their last months of life to patients with other chronic life-limiting diseases such as cancer<sup>111;112</sup>. We found high frequencies of pain, feelings of drowsiness and sadness and even higher frequencies of nervousness and difficulties breathing in the last week of life (Chapter 6), which suggests that referral to a palliative care service or at least changing treatment to include palliative or comfort intents may be of benefit to them<sup>88;113-115</sup>. Other recent studies, white papers and the WHO<sup>19</sup> are pointing in the same direction i.e. to the benefit of palliative care for other non-cancer patients<sup>116-118</sup> and have been pleading for palliative care for non-cancer patients for many years now. At the same time, the Belgian law on palliative care of 2002 gives equal rights to all patients to use palliative care services and regulates its equal availability across the country<sup>119</sup>.

However, palliative care needs seem to be more easily identified in cancer patients than in others (Chapter 4) and palliative care services still mainly serve cancer patients in comparison with others<sup>33;120-122</sup> (and Chapter 6 & 7). The historical focus of palliative care on cancer and the easier predictability of the cancer disease trajectory may explain the emphasis on cancer<sup>123</sup>. However, a remarkable finding of this dissertation is that patients with COPD, with disease symptoms and a trajectory comparable to heart failure and an unpredictable prognosis comparable to dementia, receive palliative care less often, both in terms of referral to specialist palliative care services and in terms of receiving generalist care aimed at comfort or palliation. A possible explanation is that many patients with COPD and their caregivers do not consider the disease to be life-limiting or to be suitable for palliative care<sup>124;125</sup>. Some of the patients we interviewed did not regard their symptoms as abnormal and perceived them as an inherent effect of their illness for which not much can be done. Similarly, family physicians in our focus group stated they do not associate COPD with death and dying, whereas this was the case for cancer. They will often not ask for professional help to improve their situation. This was also found in another qualitative study with COPD patients<sup>125</sup>. As a result, curative or life-prolonging treatments are more frequently continued until the last days of life in patients with

COPD at the expense of comfort-oriented care<sup>126</sup>. The high prevalence of curative and life-prolonging treatments and low prevalence of palliative treatments for this group suggests that medical disease management is prioritized when setting treatment aims<sup>122</sup>. Because organ failure patients might recover from acute episodes, life-prolonging measures may be appropriate right until death. Nonetheless, treatments with a palliative aim are appropriate alongside optimal chronic disease management and have been recommended for kidney failure<sup>127</sup>, heart failure<sup>128</sup> and COPD<sup>88;129</sup>. However, even when treatments are primarily palliative, the absence of noninvasive ventilation in many palliative care settings<sup>130</sup>, as opposed to in pulmonology wards<sup>131</sup>, may additionally lead physicians to consider referring patients with COPD to palliative care services less often.

Although they more regularly received treatment aimed at comfort and were more often referred to specialist palliative care in the last months of life than patients with COPD, approximately two third of patients dying with dementia were not referred to specialist palliative care services. In 36% of those patients the physician considered a palliative care service as not meaningful for the patient. This was significantly more than in cancer (23%) and organ failure (24%). This is striking considering people with dementia (and their carers) have been shown to have palliative care needs similar to those of cancer patients<sup>33;132-135</sup>. It has been frequently found that symptoms such as pain or spiritual care needs are under-recognized and undertreated in dementia patients<sup>76;134;136</sup>. Other research using focus groups with specialist family physicians and other caregivers showed that the caregivers perceive dementia as ‘not a disease - it’s just something that happens to people’, and ‘dementia is not terminal’<sup>137</sup>. Moreover, frail elderly and dementia patients, the group most likely to lose decision-making capacity, have been found to have fewer end-of-life and advance care planning discussions with their family physician than patients with cancer or organ failure<sup>122</sup>. Our qualitative study with patients with mild dementia showed that in this patient group care needs were often not expressed by patients, or family physicians did not explicitly ask about non-acute care needs. A possible explanation is that the stigma associated with dementia leads to a fatalist, uncomplaining attitude such as ‘nothing can be done anyway’. This could result in avoiding discussing the disease and physicians not referring these patients to palliative care services<sup>135</sup>. Moreover, family physicians feel uncomfortable discussing and planning end-of-life care with patients who are losing capacity and family physician do not consider it meaningful<sup>63;138</sup>.

## **8.5. Implications for practice, policy and research**

Our findings suggest that there is room for improvement in the extent, timing and content of provision of palliative care to patients suffering from life-limiting illnesses. The growing amount of people living with and dying from such illnesses requires us to consider the rising importance of (early) palliative care in our society. There are important challenges for caregivers, policy makers, and researchers regarding the initiation, provision, facilitation, and evaluation of both generalist and specialist palliative care. Based on the studies in this dissertation, these challenges are formulated below together with recommendations for

caregivers, policy makers, and researchers in recognizing and handling palliative care needs in a timely manner.

### 8.5.1. Challenges and recommendations for practice

Palliative care needs can be identified and handled by various caregivers such as a hospital specialist, nurses, and the family physician. The family physician might be ideally suited to take on an important role in palliative care. In many cases he or she is familiar with the medical background of the patient, the capacity of the family and the care context. Furthermore, our qualitative studies revealed that patients, nurses and family physicians indicate that there are important tasks and roles for the family physician in identifying and handling palliative care in a timely manner and that the family physician could be an ideal coordinator of palliative care for the patient (Chapter 5). However, many care needs are not, or are wrongly, identified and handled by the family physician<sup>139</sup> (and Chapter 4 & 5). According to the family physicians and community nurses interviewed in this dissertation an early initiation of a palliative care approach by the family physician is or should be possible, but this needs time, more skills and a change in attitude of both caregivers and patients (see below). For optimal provision of a palliative care approach, the role of the family physician should be strengthened and he or she should be stimulated to assess the palliative care needs of his or her patients, possible through monetary reimbursement (see policy recommendations) for the extra workload.

This dissertation offers a useful preliminary framework by means of its description of the tasks and roles of the family physician in palliative care throughout the illness trajectory (Chapter 5). This framework can contribute to the promotion and development of the integration of a timely palliative care approach into regular primary care. In Chapter 4 more specific facilitators to improve the timely identification of palliative care needs by the family physician were outlined. Below we offer and discuss our findings which could all be facilitating factors in implementing the early palliative care approach and should be considered in the formulation of policy in primary care and future guidelines for family physicians; we believe many of these facilitators may also apply to or profit other caregivers. These skills and recommendations should also be accounted for in training programmes for family physicians and other caregivers (see policy recommendations).

- Communication with patient
  - *Pro-active questioning and gentle exploration of care needs.* Family physicians should not reactively wait until the patient comes up with his or her care needs. Our study has shown that many patients will not introduce a discussion of their non-acute care needs. A more proactive approach, e.g. with the family physician taking initiatives to talk about social problems and whether the patient need extra help, may result in a better match with the patient's (and family members') existing care needs.
  - *Using short assessment scales.* Standardized assessment is purported to help providers better identify care needs and improve care<sup>140-142</sup>. However, reluctance to use such

assessment scales among physicians is often found<sup>143</sup>. In our focus groups some family physicians proposed to using short assessment scales for common palliative care needs such as pain and insomnia in order to follow up their patients gradually and to not overlook problems. It was important to them that these assessment scales should be very easy to use and would not take up much time.

- *Making time*. Patients stated that they would communicate more about their non-acute care needs if they had more time with their family physician to discuss them.
- *Building up a trusting relationship*. A long and trusting relationship seems to be a facilitating factor to enable patients to ask for a visit when needed and for family physicians to make spontaneous visits. By creating a trusting atmosphere people will more easily discuss their care needs. Family physicians mentioned that with every new visit they discover the patient's willingness to discuss more serious topics. This trusting relationship with the physician also is described as an important component of improving the quality of life and quality of palliative care in advanced cancer patients; physicians stated that the initial visits with a focus on symptom management were an important bridge to other, non-physical issues<sup>144</sup>.
- *Considering a palliative care approach for non-cancer patients*. Special efforts should be taken to talk about illness related symptoms, non-physical care needs, diagnosis, prognosis, care planning, death and dying as these are important palliative care issues that are less often discussed by family physicians in cases of patients with organ failure and dementia. Nonetheless, these factors have also been shown to be relevant for these patient populations<sup>115;117;145</sup>. Realizing that organ failure and dementia are life-limiting illnesses of which patients might eventually die from is a related important factor<sup>125;137</sup>. Furthermore, considering specialist palliative care services as an option for patients with organ failure or dementia as opposed to those with cancer will be of benefit for these patients<sup>146</sup>.
- *Taking into account individual and cultural differences*. On the one hand it is very important that the family physician takes the initiative to identify the palliative care needs of the patient (and does not wait reactively for the patient to come up with his or her care needs), but on the other hand this communication process should be tailored to the patient's (and family members') preferences. Other challenging features will be the combination of a treatment goal aimed at comfort in the combination with other preferred treatment goals (such as life-prolonging chemo therapy), the use of medications (such as antibiotics) as well as well as the use of advance care planning etc.<sup>147</sup>.

- Communication and collaboration with other caregivers

It is important for the family physician to work in a multidisciplinary manner and to involve other caregivers such as community nurses, social workers, physiotherapists, psychologists, pastors etc. Patients are frequently transferred between care settings: from their home to the hospital and the other way around, from their home to a nursing home, from a nursing home to the hospital etc<sup>24</sup>. However, communication and information exchange between care settings is often not, or not completely, passed on between care settings. Therefore, some perceived facilitating factors from our studies (Chapter 4 & 5) are summarized and discussed:

- *Communication notebook.* A shared notebook where the patient, the family, and all other caregivers visiting the patient at home can write their problems, care needs and questions was stated as a solution to pass on information and would improve the identification of care needs by the family physician, as other caregivers may see the patient more frequently. The family physician can then read through the recently experienced problems since he or she had last visited the patient.
- *Multidisciplinary meetings.* Especially the communication between settings is important and can be improved. A possible solution would be regular meetings involving the family physician and hospital specialists. In many hospitals multidisciplinary oncological consults (MOCs) are performed approximately weekly, but family physicians are often not invited, or if invited often are not present, because the travel is time consuming and the timing of the meetings is often not manageable within their office hours. A possible facilitating factor could be to organize these meetings via modern media. These opportunities should also be outlined and tested for non-cancer conditions.
- *Regular check-ups by the family physician.* Regular contact with the family physician is a facilitator to timely identification of care needs. However, sometimes patients do not see their family physician for a long time, especially when no acute care needs show up and they have regular visits to the hospital. A possible solution might be that the hospital specialist sends the family physicians for regular check-ups or for a blood test.
- *Shared medical file.* At a basic level, we suggest that when the hospital specialist passes on the medical information to the family physician this would also contain non-medical or non-physical information (for example about how the patient reacted to bad news). More sophisticatedly, this would mean that all authorized caregivers could access an on-line medical file containing medical, physical and non-physical information about the patient. This would help the family physician to have an overview of the care and care plans with the patient, but could also help hospital specialists when a patient is hospitalized with very acute care needs in deciding what interventions are still desirable<sup>24</sup>. In the last decade about eight countries have been testing and implementing such shared electronic medical records which seem of benefit to both medical professionals and patients. Finland was the first to establish such an e-health service<sup>148</sup>. Their file consists of health data generated, maintained and preserved by different health care service providers in primary and secondary care and offers an option for communication in the form of eConsultation between general practitioners and hospital specialists. It is important to note that before an implementation of such shared a medical file in Belgium is possible further ethical, legal and practical elaboration is needed.
- *Referring to specialist palliative care.* Where the specialist palliative care services fits into a given patient's care depends very much on the interplay between the patient's needs and the family physician's skill set<sup>56</sup>. From our study with cancer patients (Chapter 3) it can be expected, in general, that patients further into their illness trajectory will have more severe symptoms and worse functioning, and for many of them more intense care will be needed.



### **8.5.2. Challenges and recommendations for policy makers**

People with a life-limiting illness can live with that condition for many years, and during that time experience physical, psychosocial and existential needs related to the condition itself and its treatment. A possible strategy to address these care needs is by providing equal and easy access to specialist palliative care services for all people<sup>45</sup>. Our findings however suggest that - probably often for legitimate reasons - patients are often not referred to these services, or only close to death. Therefore, the evaluation, stimulation and the guaranteeing of adequate palliative care skills in regular caregivers is at least as important as access to specialist palliative care to tackle the challenges of early palliative care.

Advances in practice in terms of the timely initiation of a palliative care approach and timely referrals to specialist palliative care services, such as those likely to be achieved based on the recommendations for practice presented above, can probably only be achieved if they are accompanied by system-level and policy changes. In what follows we will describe and discuss three policy recommendations: raising awareness regarding palliative care, guaranteeing the relevant skills through training and education, and creating a favourable legal framework with incentives for a feasible palliative care model.

#### ***Raising awareness***

Our findings, in line with other studies which came to similar conclusions<sup>108;149</sup>, suggest that there may be a general knowledge deficit (both lay and professional) with respect to both what palliative care is in general and what added value a palliative approach can provide to patient care. Our results seem to suggest that especially for people with organ failure (especially COPD) and dementia a greater awareness is needed of the advantages and content of a palliative care approach (both generalist and specialist).

Moreover, many patients, families and health care professionals strongly associate palliative care with cancer and believe it is synonymous with end-of-life care<sup>108</sup> and relates to active dying rather than a philosophy of care ideally implemented throughout the illness trajectory of all patients with a life-limiting illness<sup>150-152</sup>. Patients might also benefit from 'awareness raising' as they still tend to view their family physician mainly as the person to turn to in acute situations and often do not see them during treatment phases<sup>61;153;154</sup> and are unaware of the things the family physician may be able to do to alleviate their various problems.

#### ***Training and education***

Family physicians, nurses and hospital specialists are regularly involved in the care and palliative care of patients with life-limiting illnesses. These caregivers should be sufficiently trained or educated and acquire basic palliative care skills and attitudes to provide generalist palliative care<sup>56;155</sup>. In our focus groups many physicians stated themselves that they are inadequately skilled and trained in palliative care and also nurses mentioned that family physicians often do not know what is possible and what is available concerning palliative care. Family physicians do realize that training and a positive attitude toward palliative care can make an important difference to the quality of life and quality of care of their patients.

The basis for such training would be the management of pain and other common symptoms, and attention to psychosocial and spiritual issues. The hindering and facilitating factors provided in this dissertation should be taken into account when developing such training. Important aspects of this training should be:

- basic symptom management
- knowledge of care options (including specialist palliative care services)
- knowledge of illness trajectories and accompanying treatment understanding
- communication skills and techniques for difficult conversations about diagnosis, prognosis, existential and spiritual issues<sup>156</sup>
- skills in providing psychosocial and existential/spiritual care
- decision-making skills
- advance care planning skills
- clinical exposure to patients with a life-limiting illness<sup>157</sup>.

A recently published white paper of the European Association for Palliative Care (EAPC) outlined the top 10 core competencies that health- and social care professionals involved in palliative care should possess<sup>158</sup> and there is some overlap with those aspects outlined here.

These palliative care skills should be included in the goals of all medicine and nursing training. Moreover, these skills should be available to practicing physicians in the form of continuous professional development training, offered by scientific associations or universities. For those whose work is mainly focussed on palliative care a specialist level of training should be available.

### ***Legal framework and incentives for a feasible palliative care model***

Even with awareness raising and training, some barriers (e.g. physicians do not have enough time for care or are only poorly reimbursed) can only be solved at health care system level. In Belgium, there are low financial thresholds for all patients concerning all types of specialist palliative care. Specialist services are distributed evenly over the country and are available free of charge<sup>93;159</sup>. The Belgian law (2002) makes palliative care a basic right for all patients near death<sup>68</sup>. The problem of access or the availability of palliative care services, frequently mentioned in other studies<sup>102;160;161</sup>, does not seem to be an important factor for being referred or not to specialist palliative care services in Flanders (Chapter 7). Growing evidence and the recognition that palliative care can improve the patient's quality of life and quality of care has led to increased demand for palliative care services and palliative care specialists<sup>162-165</sup>. So, although specialist palliative care is quite well developed in Belgium, policy makers should continue to invest in these services. Especially considering the recommendations to refer patients to specialist palliative care earlier in their illness trajectory and to also non-cancer patients, enough human capital in specialist palliative care services should be available.

However, at present, the conditions for reimbursement of palliative care and access to specialist palliative care still depend on a terminal and short prognosis<sup>45</sup> (see also Chapter 8.4).

This policy ignores the earlier needs of many individuals, and is not tailored to the contemporary models of palliative care with an emphasis on an early palliative care approach provided by both generalist and specialist caregivers<sup>19;45</sup>. Being diagnosed as several weeks or months from death must no longer be the (only) trigger for providing (specialist or generalist) palliative care because it will mean that too many people with life-limiting illnesses who experience palliative care needs will not have had access to care that could enhance both their living and their dying.

Although this early ‘needs-based’ model of palliative care<sup>19</sup> is recommended, the manifold factors that hamper the timely identification and addressing of early palliative care needs by health professionals (see above) should be kept in mind<sup>96;97</sup>. The palliative care model should be multidisciplinary, with an important role for the family physician and tailored to the individual patient (patient preferences, family wishes, health status, social support etc.). Listening and responding to the wishes of patients and families, assessing and relieving care needs and coordinating care within and across different settings all take time. Approaches to practice and financial incentives should take into account the amount of time that will be required to implement a palliative approach to chronic disease management. This means that in general practice, but also in oncology, respiratory or other hospital wards and in nursing homes, there should be adequate palliative care infrastructure as part of the global service with key tasks of screening patients to identify specific care needs, and the provision of palliative care interventions (generalist and specialist) as part of routine/standard care. For example, reimbursement structures could provide incentives for advance care planning and generalist and specialist palliative care consultations early in the course of illness<sup>166;167</sup>. These initiatives would not automatically lead to high health care costs. Some studies showed that early involvement of palliative care results in less expensive treatments at the end of life. In America for example, The Aetna Compassionate Care Program of early nurse-managed palliative care and advanced care planning alongside usual care has decreased hospital lengths of stay and admissions while decreasing costs at the end of life by 22%<sup>168</sup>.

### **8.5.3. Challenges and recommendations for future research**

In this dissertation we performed qualitative interviews to provide insights into the various palliative care needs throughout the illness trajectories of different life-limiting illnesses. We performed a survey to quantify these care needs in patients with cancer only. Future quantitative research is recommended in which the findings from our qualitative interviews are verified among a larger group of patients in patients with COPD, heart failure, dementia and other non-cancer illnesses. Moreover, insights into the treatment aims and care provision at earlier phases than the last three months (as done Chapter 6) in non-cancer illnesses would be of interest, especially considering the importance of an early palliative care approach in all patients suffering from life-limiting illnesses.

All studies concerning generalist palliative care in this dissertation are based on the primary care perspective (i.e. nurses, family physicians and patients at home). Although we already used a ‘triangulation’ of various perspectives, it is important to investigate elements of the care continuum from hospital specialist perspectives too, as many of these patients will visit

hospitals during their illness trajectory. This would enable a more complete picture to be obtained of the continuum of care.

Previous studies reinforce the view that a palliative care approach can be integrated into care in all care settings. However, in virtually all cases studied the palliative care services were delivered by people who were highly skilled and specialized in palliative care. Most studies were performed in oncology settings in the hospital. These models still use a rather more prognostic-based than a needs-based trigger to offer palliative care to patients. To overcome the problems with prognoses-based models, instruments that assess palliative care needs in order to initiate and determine the care provided should be further developed and tested<sup>169;170</sup>. Moreover, such a model of integration in which it is only specialist palliative care provided by specialist teams working together with oncologists might be insufficient and unfeasible. Many patients will be diagnosed with a chronic life-limiting illness other than cancer and many of them will stay a long time at home. The challenge will be to develop and evaluate a model in which the regular caregivers (including those outside oncology and hospital settings) have the necessary skills for assessing and addressing palliative care needs early in the disease trajectory. It will be important to find out which patients can be well-managed by non-palliative care caregivers, which might benefit from a brief consultation, and which would best be served by co-management with specialist palliative caregivers or by referral to a specialist service. Some trigger time-points or trigger care needs can be explored and investigated to better guide caregivers in the care for their patients. Future research needs to evaluate the extent to which such models can improve the quality of life and quality of care of patients in earlier phases of their disease and throughout their disease trajectory. Additionally, the cost-effectiveness of such models should be evaluated. In the current environment of rising health care costs and concerns about the sustainability of funded health care, policy makers might benefit from information concerning the costs and benefits of care for patients with chronic life-limiting illnesses.

## 8.6. Conclusion

This doctoral thesis reveals that people with cancer, COPD and heart failure as well as dementia experience various problems and care needs (physical, practical, psychological, social, existential and financial, as well as needs for information and communication) for which a palliative care approach might already be relevant early in the illness course. Our study with cancer patients provides an empirical confirmation of a model of early palliative care needs<sup>1</sup> by showing that from the curative phase onwards symptoms and problems that are core domains of palliative care are present and increase towards the most advanced phase.

In this thesis however we found multiple reasons of why family physicians do not recognize these care needs in a timely manner. Key barriers and facilitators identified relate to communication styles, the perceived role of the family physician and continuity of care. We gained insights into the perception of the roles and tasks of the family physician in handling the 'primary' palliative care needs throughout the illness trajectory. These tasks could be allocated to four overarching roles: the family physician as an available medical expert, as a communicator, as a collaborator and as a life-long learner.

Additionally this thesis shows that the current provision of specialist palliative care services in Belgium still largely favours patients with cancer. Those with COPD are especially less likely to receive palliative care than those with other chronic life-limiting diseases, both in terms of referral to specialist palliative care services and in terms of receiving generalist care aimed at comfort. Many people were not referred because physicians perceived that the regular care they were receiving sufficiently addressed their care needs especially in older people, or did not consider palliative care as meaningful especially in people with dementia, or because they believed that there was not enough time to initiate palliative care, especially in hospital deaths.

A multidisciplinary palliative approach with an important role for the family physician seems ideally suited to all people with a life-limiting illness and should not be confined only to those actually dying. The challenge will be to integrate such an approach into the care continuum. In practice this will ideally mean that comprehensive assessments of care needs need to be performed by regular caregivers throughout the trajectory, starting from diagnosis. The findings in this dissertation can be used as an important framework to support, promote and develop an integration of a palliative care approach into the care continuum.

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**SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN**





## INLEIDING

Vandaag de dag heerst nog steeds de perceptie dat palliatieve zorg gelijk is aan zorg aan het levenseinde meestal verleend aan mensen met kanker. Er is ook nog steeds de perceptie dat palliatieve zorg een specialisme op zichzelf is, verleend door zorgverleners of teams die gespecialiseerd zijn in palliatieve zorg. Met de toenemende vergrijzing en het groeiend aantal chronische patiënten is dat model van palliatieve zorg niet langer houdbaar (zowel financieel als praktisch). Als we de kwaliteit van zorg, en bijgevolg de kwaliteit van leven, voor mensen met een levensverkortende of levensbedreigende aandoening willen garanderen, zou palliatieve zorg ook als een algemene vaardigheid, een benadering van zorg, beschouwd moeten worden. Elke zorgverlener die in contact komt met deze patiënten zou moeten beschikken over een basispakket palliatieve zorgvaardigheden en palliatieve zorgkennis, en zou een palliatieve zorgattitude aan de dag moeten leggen. In dit doctoraat verwijzen voor deze zorg naar ‘generalistische palliatieve zorg’. Omdat veel patiënten tijdens het grootste deel van hun ziekte-traject thuis verblijven, is een belangrijke rol voor huisartsen weggelegd. Wanneer echter de zorgnoden complexer worden, kan beroep gedaan worden op gespecialiseerde palliatieve zorgservices. De hulpverleners in deze services zijn speciaal opgeleid en ontwikkelden een expertise in palliatieve zorg. In dit doctoraat wordt hiervoor verwezen naar de term ‘gespecialiseerde palliatieve zorg’.

De Wereldgezondheidsorganisatie (WGO) publiceerde recent (2014) een resolutie over de integratie van palliatieve zorg in de reguliere zorg. In deze resolutie wordt het belang van een palliatieve zorgbenadering doorheen het hele ziekteverloop, reeds vroeg startend in het ziekte-traject van een levensverkortende (of levensbedreigende) aandoening benadrukt. Invloedrijke studies tonen aan dat het vroeger integreren van gespecialiseerde palliatieve zorg in standaard oncologische zorg de kwaliteit van leven en de kwaliteit van zorg verbetert voor gevorderde kankerpatiënten.

Er is echter nog weinig geweten over de palliatieve zorgnoden doorheen het ziekte-traject, de herkenning en de (generalistische) aanpak van deze zorgnoden vanaf diagnose. De meeste studies beperken zich enkel tot de inzet van gespecialiseerde palliatieve zorgservices (en niet de palliatieve zorgbenaderingen verleend door reguliere hulpverleners zoals de oncoloog of huisarts zelf), leggen de focus meestal op kanker (en niet op andere levensverkortende aandoeningen die gebaat zouden zijn bij palliatieve zorg, zoals orgaanfalen of dementie), en focussen enkel op de gevorderde fases van de ziekte (en kijken niet naar mogelijke positieve effecten voor mensen in vroegere fases van hun ziekte).

Dit proefschrift belicht daarom drie in deze context relevante thema's:

1. Palliatieve zorgnoden vanaf diagnose bij mensen met een levensverkortende aandoening;
2. De rol van de huisarts in het herkennen en aanpakken van algemene palliatieve zorgnoden vanaf diagnose;
3. Het gebruik van gespecialiseerde palliatieve zorgservices bij mensen met een levensverkortende aandoening.

**ONDERZOEKSVRAGEN**

In dit proefschrift hebben we getracht volgende onderzoeksvragen te beantwoorden:

- 1) Hoe ervaren patiënten met kanker, chronisch obstructief longlijden (COPD), hartfalen of dementie palliatieve zorgnoden die gerelateerd zijn aan hun ziekte gedurende het volledige traject van hun ziekte, startend vanaf diagnose? (hoofdstuk 2)
- 2) Wat is de levenskwaliteit (gebaseerd op lichamelijk, psychologisch, sociaal, rol en cognitief functioneren, lichamelijke symptomen, financiële problemen en spirituele problemen) en welke zijn de onbeantwoorde zorgnoden van patiënten met kanker die zich op drie verschillende tijdstipmomenten in het kankertraject bevinden: de fase waarin mensen behandelingen krijgen (of gepland hebben) met een curatieve intentie, de fase waarin mensen behandelingen krijgen (of gepland hebben) met een levensverlengende intentie en de ‘meest gevorderde fase’ waarin mensen geen curatieve of levensverlengende behandelingen meer krijgen of gepland hebben en/of hun levensverwachting minder is dan zes maanden? (hoofdstuk 3)
- 3) Wat zijn de belemmerende en bevorderende factoren bij de vroege en tijdige herkenning van palliatieve zorgnoden bij mensen met kanker, COPD, hartfalen of dementie vanuit het perspectief van huisartsen, thuisverpleegkundigen en patiënten? (hoofdstuk 4)
- 4) Wat zien huisartsen, thuisverpleegkundigen en patiënten als de taken en rollen van een huisarts in het aanpakken van palliatieve zorgnoden doorheen het volledige ziekte-traject van mensen met kanker, orgaanfalen of dementie? Verschillen deze taken van de huisarts in algemene palliatieve zorg naargelang het tijdstip of fase in het ziekte-traject? (hoofdstuk 5)
- 5) Hoe vaak worden mensen met kanker, orgaanfalen (bijv. COPD en hartfalen) of dementie doorverwezen naar gespecialiseerde palliatieve zorgservices? Hoeveel dagen voor het overlijden worden deze mensen doorverwezen? Welke socio-demografische gegevens zijn gerelateerd aan doorverwijzing en timing van doorverwijzing naar palliatieve zorgservices in deze vier ziektegroepen? (hoofdstuk 6 en 7)
- 6) Wat zijn de behandeldoelen in de laatste drie maanden voor overlijden van mensen die niet waren doorverwezen naar deze palliatieve zorgservices? (hoofdstuk 6)
- 7) Wat zijn de meest voorkomende redenen om mensen niet naar palliatieve zorgservices door te verwijzen? Zijn deze redenen gerelateerd aan bepaalde patiënten kenmerken? (hoofdstuk 7)

## **METHODES**

### **Kwalitatieve interview- en focus groep studie (hoofdstuk 2, 4 en 5)**

In 2012 werd een kwalitatief onderzoek uitgevoerd om dieper in te kunnen gaan op de palliatieve zorgnoden, de herkenning en aanpak van deze zorgnoden doorheen het ziekte-traject van mensen met kanker, COPD, hartfalen en dementie in de eerstelijnszorg. Hiervoor gebruikten we semigestructureerde interviews met patiënten, en aparte focus groepen met thuisverpleegkundigen en huisartsen.

We interviewden 18 volwassen patiënten: zes met kanker, zes met milde dementie, drie met COPD en drie met hartfalen. Er werd de patiënten gevraagd naar hun behoeften op diverse palliatieve basisdomeinen: (1) lichamelijke, (2) psychologische, (3) sociale, (4) levensbeschouwelijke, (5) informatie en (6) praktische noden. Verder werd bij die patiënten ook gepeild naar hoe hun huisarts tewerk ging om deze zorgnoden te weten te komen, of hij ze al dan niet te weten kwam en welke factoren hieraan ten grondslag lagen. Verder vroegen de onderzoekers ook aan de respondenten wat zij beschouwden als de taak van de huisarts om deze noden aan te pakken.

Om de belemmerende en bevorderende factoren voor het herkennen van palliatieve zorgnoden na te gaan, gebruikten we naast het perspectief van patiënten –op basis van hierboven vermelde interviews- ook de perspectieven van huisartsen en thuisverpleegkundigen. Daarvoor werden 20 huisartsen bevraagd in 4 focusgroepen en 12 thuisverpleegkundigen (waaronder ook 3 palliatieve thuisverpleegkundigen) in 2 focusgroepen. Dezelfde onderwerpen als in de interviews uitgevoerd met patiënten werden aangehaald en bediscussieerd in de focusgroepen.

Aan hetzelfde panel van huisartsen, thuisverpleegkundigen en 18 patiënten werd de vraag naar de taken en de rol van de huisarts in palliatieve zorg doorheen het ziekte-traject voorgelegd.

### **Vragenlijststudie bij mensen met kanker (hoofdstuk 3)**

In 2014 vulden 620 patiënten met kanker die op consultatie kwamen in het Universitair Ziekenhuis in Gent een vragenlijst in die hun zorgnoden en de zorg die ze ontvingen mat. Deze vragenlijst werd door de patiënt zelf ingevuld en teruggestuurd naar de onderzoekers. De behandelende artsen vulden enkele klinische gegevens over de patiënt in op een korte vragenlijst, zoals de plaats van primaire tumor, prognose, fase van de ziekte. Deze vragenlijsten ingevuld door patiënt en arts konden aan de hand van een patiëntenziekenhuiscode aan elkaar gekoppeld worden zodat de dataset op een anonieme manier verwerkt kon worden. Door deze koppelingen konden we de patiënten opdelen in drie groepen, naargelang de fase van de ziekte: (1) curatieve fase, (2) levensverlengende fase en (3) geen levensverlengende behandelingen meer of minder-dan-zes-maandenprognose. De mensen die in remissie of follow-up waren, werden voor de analyses van deze studie weggelaten.

We evalueerden klinische en statistische verschillen tussen de drie groepen. Een steekproef uit de algemene populatie werd noodzakelijk geacht om een referentiepunt te hebben waarmee we

onze drie groepen konden vergelijken. Dit is vooral belangrijk om de scores van onze eerste groep, de curatieve groep, klinisch te evalueren aan de hand van vergelijken met een algemene populatie.

### **Registratiestudie via huisartsenpraktijken (hoofdstuk 6)**

Met behulp van een retrospectieve mortaliteitsstudie bij huisartsen probeerden we een beter zicht te krijgen op de zorg in de laatste drie maanden voor het overlijden in België. Hiervoor deden we beroep op de reeds bestaande Huisartsenpeilpraktijken. Dit netwerk is opgericht in 1979 en heeft onder meer als doel de aanpak en opvolging in de huisartspraktijk van bepaalde gezondheidsproblemen te onderzoeken. Over de jaren heen heeft het zich als een gevestigde waarde weten te positioneren om gezondheidsgerelateerde epidemiologische gegevens (waaronder zorg aan het levenseinde) op een betrouwbare manier te vergaren. De deelnemende huisartsen zijn representatief voor alle Belgische huisartsen voor wat betreft leeftijd en geslacht, en met een goede spreiding over het hele land. Het netwerk valt onder de coördinatie van het Wetenschappelijk Instituut Volksgezondheid.

Deze huisartsen werd gevraagd om alle sterfgevallen (ouder dan 1 jaar bij overlijden) uit hun praktijk wekelijks te registreren. Naast algemene gegevens van de patiënten zoals leeftijd en geslacht bevroeg een gestandaardiseerd registratieformulier een aantal aspecten over de zorg die de patiënt verkreeg in de laatste maanden van zijn of haar leven, waaronder ook de inzet van gespecialiseerde palliatieve zorgservices en de behandeldoelen in de laatste maanden. Wij gebruikten data van 2405 overlijdens, waarvan 1197 van kanker, COPD, hartfalen of dementie, verzameld in 2009 en 2010.

De studie kreeg de naam SENTI-MELC studie, wat staat voor ‘Sentinel Network of General Practitioners Monitoring End-of-Life Care Study’.

### **Vragenlijst studie bij artsen gebruik makend van overlijdenscertificaten (hoofdstuk 7)**

In deze studie werd naar de attesterende artsen van een representatieve steekproef (n=6188) van overlijdenscertificaten in Vlaanderen een vragenlijst opgestuurd over de zorg en de medische besluitvoering aan het levenseinde van de betrokken overledenen. In deze korte schriftelijke vragenlijst waren ook vragen over de doorverwijzing naar gespecialiseerde palliatieve zorg en redenen voor niet doorverwijzing opgenomen.

De gehanteerde methode is zeer betrouwbaar en werd reeds in vele landen gebruikt, zoals ook Nederland waar deze methode voor het eerst is aangewend. Het is de vierde maal dat deze methode in Vlaanderen wordt gebruikt.

## **BELANGRIJKSTE BEVINDINGEN**

De resultaten en antwoorden op de onderzoeksvragen zijn samengevat onder de drie relevante thema's van dit proefschrift.

### **Palliatieve zorgnoden vanaf diagnose bij mensen met een levensverkortende aandoening**

*De ervaren palliatieve zorgnoden door patiënten met kanker, COPD, hartfalen en dementie (hoofdstuk 2)*

Aan de hand van een kwalitatieve interviewstudie met 18 patiënten vonden we dat patiënten tijdens hun ziekte-traject zorgnoden ervaren die onder te brengen zijn in zeven domeinen inherent aan palliatieve zorg: lichamelijk, psychologisch, sociaal, levensbeschouwelijk, financieel, informatie en communicatie en coördinatie en continuïteit van zorg.

Meerdere lichamelijke symptomen zoals pijn, kortademigheid, droge mond en cognitieve stoornissen werden, afhankelijk van de ziekte, ervaren door de patiënten. Vaak traden die symptomen op doorheen het ziekteverloop, zelfs al voor diagnose. Opmerkelijk was dat sommige respondenten deze symptomen niet definieerden als problemen waarvoor ze hulp zouden zoeken. Zo zagen sommigen bepaalde lichamelijke symptomen, zoals kortademigheid en geheugenverlies, als bijwerkingen van hun ziekte of als deel van het ouder worden, waar toch niet veel aan gedaan kan worden. Gevoelens van angst of depressie deden zich ook voor vanaf het begin van het ziekte-traject. Patiënten waren angstig over wat de toekomst zou brengen: Op welke plaats zullen zij uiteindelijk verzorgd worden? Zullen zij lijden? En wat zal er met hun familie gebeuren na hun overlijden? Bij veel patiënten met een levensverkortende ziekte verdween hun sociaal netwerk, met eenzaamheid en sociale isolatie tot gevolg. We vonden ook dat de respondenten die geen gespecialiseerde palliatieve zorg kregen het woord "palliatief" niet gebruikten of vermeldden. Zelfs de mensen met hartfalen en dementie waarvan wij als onderzoekers wisten dat ze gespecialiseerde palliatieve thuiszorg kregen, gebruikten deze term niet. Enkel deze met kanker deden dat wel.

Deze bevindingen bieden inzicht in de problemen en zorgnoden doorheen het ziekte-traject, reeds vanaf diagnose. Deze zorgnoden vallen allemaal binnen de zeven domeinen die de kern uitmaken van een palliatieve zorgbenadering. Kortom, palliatieve zorg, gedefinieerd als een benadering die ingaat op verschillende specifieke domeinen van noden, kan relevant zijn vanaf het begin van het ziekte-traject voor veel patiënten met een levensverkortende aandoening.

*Palliatieve zorgnoden doorheen het kankertraject (hoofdstuk 3)*

We voerden een kwantitatieve vragenlijststudie uit bij 620 patiënten. Van deze groep patiënten waren er 101 patiënten die behandelingen kregen met een curatief behandelingsdoel, 188 met een levensverlengend doel en 86 hadden geen curatieve of levensverlengende behandelingen meer en/of hadden een prognose van minder dan zes maanden. De overige 245 patiënten waren in follow-up of remissie en werden in deze studie niet opgenomen. Uit de analyses bleek dat er in alle drie de groepen gelijkaardige moeilijkheden optraden die indicatief zijn voor een

palliatieve zorgbenadering: moeite met emotioneel en sociaal functioneren, fysiek functioneren, allerlei lichamelijke symptomen, lage levenskwaliteit enzovoort. Palliatieve zorgnoden waren weliswaar groter in de ‘meest gevorderde’ groep dan in de curatieve groep. Zo vonden we bijvoorbeeld dat de gemiddelde scores (op een schaal van 0-100, waarbij een hogere score beter functioneren aangeeft) voor lichamelijk functioneren 91 was in een populatiegebaseerde steekproef in Europa (die we als vergelijkingsgroep gebruikten), 76 in de curatieve groep, 60 in de levensverlengende groep en 51 in de ‘meest gevorderde’ groep. Een gelijkaardig patroon werd ook gevonden voor emotioneel functioneren (respectievelijk 83, 71, 58, 53). Lichamelijke symptomen werden ook in alle drie de groepen teruggevonden. Hogere scores, wat wijst op hogere symptoomlast, werden gevonden in de groepen in latere fases in het ziekte-traject voor vermoeidheid, pijn, kortademigheid en verminderde eetlust vergeleken met eerste groep. Vermoeidheid, slapeloosheid en constipatie waren klinisch significant slechter in de curatieve groep dan in de Europese vergelijkingsgroep.

Aanvullend vonden we ook dat mensen in de levensverlengende groep minder kans hadden om hulp te krijgen van een professionele hulpverlener dan de mensen in de ‘meest gevorderde’ groep voor lichamelijke symptomen (69% vs. 81%), emotioneel functioneren (52% vs. 74%) en sociaal en rol functioneren (31% vs. 50%), hoewel er geen verschil was tussen deze twee groepen in de mate waarin zij meer professionele hulp wensten voor deze domeinen.

Deze surveystudie lijkt een empirische bevestiging van het theoretische model van vroeg optredende en geleidelijk toenemende palliatieve zorgnoden. Zeker de mensen die levensverlengende behandelingen kregen, ook met een prognose van meer dan zes maand, rapporteerden een verminderde kwaliteit van leven en uitten substantiële onbeantwoorde zorgnoden binnen de domeinen van palliatieve zorg. Opvallend is echter ook dat in de fase waarin mensen nog curatieve behandelingen kregen, velen van hen klinisch significant meer problemen aangaven in vergelijking met een Europese vergelijkingsgroep.

### **De rol van de huisarts in het herkennen en aanpakken van algemene palliatieve zorgnoden vanaf diagnose**

*Belemmerende en bevorderende factoren voor het tijdig herkennen van palliatieve zorgnoden door de huisarts (hoofdstuk 4)*

Aan de hand van 18 interviews met patiënten (kanker, COPD, hartfalen en dementie), vier focusgroepen met huisartsen en twee focusgroepen met thuisverpleegkundigen gingen we de belemmerende en bevorderende factoren na bij het tijdig en vroeg herkennen van palliatieve zorgnoden. Deze factoren konden ingedeeld worden in zes thema's: (1) de kennis, vaardigheden en communicatiestijl van de huisarts, (2) de communicatiestijl van de patiënt, (3) de relatie tussen huisarts en patiënt, (4) percepties ten aanzien van de rol van de huisarts, (5) samenwerking tussen zorgverleners en continuïteit van zorg en (6) onderliggende angst en overtuigingen met betrekking tot de prognose.

Een belangrijke bevinding van deze studie is dat noch patiënten, noch huisartsen een gesprek startten over niet-acute zorgnoden. We vonden tevens dat de huisarts (nog steeds) aanzien

wordt als degene die men enkel inschakelt voor het uitschrijven van medicatievoorschriften, voor regelmatige onderzoeken (bijv. opvolgen en meten bloeddruk) of in acute situaties (bijv. een verkoudheid). Sommige patiënten vonden dat bepaalde manifestaties van hun ziekte (bijv. geheugenverlies bij dementie) eerder door de ziekenhuisspecialist moet aangepakt en opgevolgd worden dan door de huisarts. Patiënten gaven ook aan dat ze vaak hun zorgnoden niet delen met de huisarts omdat hij het te druk heeft en ze hem/haar niet willen storten. Proactief bevragen van zorgnoden, ook de niet-acute noden, werd als een belangrijke bevorderende factor gezien door onze respondenten.

Een andere belangrijke bevinding is dat het herkennen van palliatieve zorgnoden door de huisarts meer problematisch was in de vroegere fases van het ziekteverloop dan de terminale fase. Huisartsen gaven aan dat ze wel genoeg tijd maken om patiënten te bezoeken (vaak buiten de uren), maar gaven toe dat dit ‘privilege’ vooral weggelegd is voor patiënten in de terminale fase.

Deze bevindingen tonen nieuwe en belangrijke inzichten in de redenen waarom huisartsen palliatieve zorgnoden niet of niet op tijd herkennen en bieden ook bevorderende factoren om deze problemen te overwinnen.

### *De rol van de huisarts in vroege generalistische palliatieve zorg (hoofdstuk 5)*

Na de analyse van de interviews met patiënten en focusgroepen met huisartsen en verpleegkundigen (zie hierboven) kwamen het onderzoeksteam tot vier grote ‘overkoepelende’ rollen voor de huisarts: die van ‘beschikbare medisch expert en crisismanager’ (die bijvoorbeeld de diagnose en de implicaties uitlegt), ‘communicator’ (die bijvoorbeeld de terminale status aan de patiënt en diens familie mededeelt), ‘teamspeler’ (die bijvoorbeeld informatie, zowel medisch als niet medisch, uitwisselt met de ziekenhuisarts) en ‘levenslange leerling’ (die bijvoorbeeld een cursus volgt over symptomen, behandelingen en communicatie). Die rollen evolueerden echter met de voortgang van de ziekte en veranderden soms naargelang de fase van de ziekte. De taken konden gecategoriseerd worden in vijf bredere fase-gerelateerde contexten: (1) rond diagnose, (2) gedurende behandelingen en follow-up, (3) rond acute episodes of opstoten, (4) gedurende de terminale fase en (5) gedurende het hele ziekteverloop. De respondenten hadden meestal eenzelfde visie over de taken die weggelegd zijn voor de huisarts, maar niet alle respondenten waren het eens over het belang en vooral over de timing van alle taken. Huisartsen waren het bijvoorbeeld niet allemaal eens over de timing van voorafgaande zorgplanninggesprekken met de patiënt en de familie. Ze gaven aan hoe moeilijk dit was in de vroegere fases van het ziekteverloop, ondanks het risico om deze gesprekken uit te stellen tot het misschien te laat is.

Het is opvallend dat als de respondenten de term palliatieve zorg gebruikten, ze in feite verwezen naar zorgtaken in de terminale fase. Alle groepen gaven echter ook taken aan in de vroege fases van het ziekteproces die eveneens inherent toebehoren aan palliatieve zorg. Alleen werden ze door de deelnemers niet als palliatieve zorgtaken benoemd.



Deze omschrijvingen van de taken en rollen voor de huisarts dragen bij aan een theoretisch en praktisch kader om de integratie van een generalistische palliatieve zorgbenadering in het zorgtraject mogelijk te maken.

### **Het gebruik van gespecialiseerde palliatieve zorgservices bij mensen met een levensverkortende aandoening**

*De frequentie en timing van doorverwijzing naar gespecialiseerde palliatieve zorgservices en behandeldoelen in de laatste drie maand voor overlijden (hoofdstuk 6)*

Aan de hand van een vragenlijsstudie bij huisartsen (via de Huisartsenpeilpraktijken) kregen we informatie over 2405 overlijdens, waarvan 1197 ten gevolge van kanker, COPD of hartfalen of bij wie er ernstige dementie was vastgesteld. Uit de registratie blijkt dat 60% van de kankerpatiënten wordt doorverwezen naar gespecialiseerde palliatieve zorg. Dat is een stuk meer dan patiënten met dementie (37%), hartfalen (34%) of COPD (20%). Verder lijken patiënten met hartfalen en COPD later te worden doorverwezen dan kankerpatiënten. De helft van de doorverwijzingen van mensen met kanker gebeurt 20 dagen voor hun overlijden of later. Bij dementie, hartfalen en COPD liggen die cijfers respectievelijk op 14, 12 of 10 dagen voor hun overlijden.

In de groep van de patiënten die niet worden doorverwezen, krijgen mensen met hartfalen en COPD tijdens de laatste drie maanden voor hun overlijden nog vaak behandeldoelen met een curatief of levensverlengend doel. Heel vaak zelfs tot in de laatste week voor het overlijden. Zo krijgt 40% van alle COPD-patiënten nog tijdens de laatste week een therapie gericht op levensverlenging.

In de eerste helft van 2013 voerden we een vragenlijststudie uit bij artsen gelinkt aan overlijdenscertificaten van 3751 overlijdens in Vlaanderen. Van deze overlijdens waren er 1917 met een levensverkortende aandoening. Uit de resultaten blijkt dat een doorverwijzing naar een gespecialiseerde palliatieve zorgservice gebeurde voor 21% van de mensen met hartfalen, 37% met dementie en 60% met kanker. De helft van de patiënten die doorverwezen werden waren slechts doorverwezen minder dan 10 dagen voor overlijden. Mensen met kanker werden eerder doorverwezen (16 dagen voor overlijden) dan deze met orgaanfalen (5 dagen) of dementie (8 dagen).

Gespecialiseerde palliatieve zorgservices blijken in Vlaanderen en België nog steeds het meest weggelegd voor mensen met kanker. Een toenemende bewustwording dat palliatieve zorg een optie is voor niet-kanker patiënten lijkt nodig, voornamelijk voor mensen met COPD.

*Redenen waarom mensen met een levensverkortende ziekte niet doorverwezen worden naar gespecialiseerde palliatieve zorgservices (hoofdstuk 7)*

Met behulp van de vragenlijststudie bij de certificerende artsen onderzochten we waarom mensen die stierven aan een levensverkortende ziekte niet werden doorverwezen naar gespecialiseerde palliatieve zorgservices. Uit deze studie kwam als belangrijkste reden naar

voren dat volgens de arts (1) de zorg al voldoende tegemoetkwam aan de palliatieve en 'supportieve' zorgnoden van de patiënt (56%), vooral bij mensen ouder dan 85 jaar (64%), (2) palliatieve zorg niet of onvoldoende zinvol was voor deze patiënt (26%), vooral bij mensen met dementie (36%) en (3) er onvoldoende tijd was om nog palliatieve zorg in te schakelen (24%), vooral bij mensen die stierven in het ziekenhuis (43%). Andere redenen die minder aangeduid waren: de patiënt wilde geen palliatieve zorg (6%), de familie wilde geen palliatieve zorg (4%), palliatieve zorg was niet beschikbaar (1,5%) of de arts wou de hoop van de patiënt en/of familie niet wegnemen (0,5%).

Deze bevindingen duiden aan dat het gezondheidsbeleid in de toekomst niet enkel moet focussen op de gespecialiseerde palliatieve zorgservices, maar ook op het evalueren, stimuleren en garanderen van adequate palliatieve zorgvaardigheden bij reguliere zorgverstrekkers. Aanvullend is het nodig om de voordelen van vroege palliatieve zorg, zoals de zinvolheid hiervan bij niet-kankercondities te promoten, zeker voor mensen met dementie.

## **DISCUSSIE EN AANBEVELINGEN**

Hoofdstuk 8 van de doctoraats thesis beschrijft de sterktes evenals de beperkingen van de vier onderzoeksmethodes die gebruikt zijn. In hoofdstuk 8 zijn ook de belangrijkste resultaten van alle studies samengevat en geïnterpreteerd en worden aanbevelingen voor zowel praktijk, beleid en verder onderzoek gegeven. Hieronder worden enkele belangrijke discussiepunten en aanbevelingen voor praktijk en beleid kort beschreven worden.

### **Palliatieve zorg kan geschikt zijn in alle fases van een levensverkortende aandoening en moet tijdig worden gestart**

Veel personen met kanker, COPD, hartfalen en dementie ervaren palliatieve zorgnoden. Wij vonden dat problemen en zorgnoden ervaren worden gedurende het volledige ziekte-traject, vanaf de diagnose – en soms zelfs voordien als de persoon al ziekte ervaart maar nog geen diagnose ontving- tot in de terminale fase. De behoeften zijn deels gerelateerd aan de ziekte, deels aan het individu. Ze spelen zich af op het lichamelijke, psychologische, sociale, existentiële en financiële vlak. Bovendien is er voor velen ook behoefte aan extra informatie en communicatie. Dat zijn allemaal domeinen die de kern uitmaken van een palliatieve zorgbenadering en waar zo'n benadering op kan inspelen. Deze resultaten kunnen bijdragen aan de verheldering en verduidelijking van het begrip 'vroeg' in 'vroege palliatieve zorg'. Deze term wordt in verschillende definities van organisaties en onderzoekers gebruikt, maar heeft vaak een andere invulling: samengaand met curatieve en levensverlengende behandelingen, vanaf diagnose van een gevorderde kanker, vanaf dat de arts niet verrast zou zijn dat de patiënt binnen het jaar zou overlijden ('surprise question'), als er geen behandelingen meer mogelijk zijn enzovoort. Onze resultaten tonen aan dat 'vroeg' vroeger zou kunnen zijn dan werd voorgesteld in eerdere studies, mogelijks reeds vanaf diagnose van een levensverkortende ziekte.

## De belangrijke rol van generalistische palliatieve zorg

Door de complexiteit van zorgnoden doorheen het ziekte-traject aan te tonen bij mensen met kanker, COPD, hartfalen en dementie verschuift de vraag van ‘waarom’ een palliatieve zorgbenadering al vroeg zou moeten mogelijk zijn naar ‘hoe’ zo een palliatieve zorgbenadering vroeg geïmplementeerd kan worden. Een gespecialiseerde palliatieve zorg interventie voor alle mensen die gediagnosticeerd zijn met een levensverkortende ziekte is in de praktijk niet haalbaar en zou wellicht ook te kostelijk zijn. Om ervoor te zorgen dat mensen de nodige zorg krijgen, is het nodig om reguliere zorgverleners meer verantwoordelijkheid te geven in het verlenen van palliatieve zorg en om een generalistische palliatieve zorgbenadering te stimuleren in deze reguliere zorg.

In definities over huisartsgeneeskunde en opiniestukken over palliatieve zorg wordt aan huisartsen vaak een belangrijke rol toegeschreven in palliatieve zorg. Deze definities en opiniestukken geven echter geen gedetailleerde en afgelijnde omschrijving van wat de taken voor een huisarts in palliatieve zorg dan zijn, zeker niet in fases vóór de terminale fase van het ziekte-traject. In dit doctoraat vonden we taken en rollen voor de huisarts, toegeschreven door zowel patiënten, thuisverpleegkundigen en huisartsen die de principes van palliatieve zorg reflecteren. Toch tonen onze resultaten aan dat een vroege palliatieve zorgbenadering –niet erg verrassend- nog niet algemeen wordt toegepast in de dagelijkse praktijk.

In dit proefschrift opperen we niet dat de huisarts alle verantwoordelijkheid op zich moet nemen voor alle dimensies van palliatieve zorg, noch dat de gespecialiseerde palliatieve zorgservices betrokken moeten zijn bij elke patiënt met een levensverkortende ziekte. Dit proefschrift geeft wel enkele belangrijke taken en rollen weer voor de huisarts in eerstelijns generalistische palliatieve zorg in Vlaanderen en toont het belang aan van multidisciplinaire samenwerking. De samenwerking met gespecialiseerde palliatieve zorgteams is hiervan een mooi voorbeeld. Huisartsen kunnen mensen doorverwijzen naar deze teams of kunnen deze teams consulteren bij een specifieke vraag. In gedachte houdend dat niet elke patiënt behoefte heeft aan een gespecialiseerde palliatieve zorgservice en dat patiënten vaak overgeplaatst worden tussen verschillende settings (bijv. van thuis naar het ziekenhuis en terug), is het van groot belang dat ook kennis en expertise over palliatieve zorg doorgegeven wordt naar professionele groepen zoals oncologen, longartsen, neurologen, verpleegkundigen enzovoort. Door de vaardigheden van huisartsen, ziekenhuisartsen, palliatieve zorgservices en andere zorgverleners zoals verpleegkundigen samen te brengen kunnen we de zorg van patiënten met een levensverkortende ziekte verbeteren.

### *Is palliatieve zorg dan gewoon goede zorg?*

De rollen die de huisartsen toegewezen krijgen in deze studie vinden we ook terug in de overkoepelende rollen, definities en principes van de algemene huisartspraktijk, zoals bijvoorbeeld omschreven door de ‘CanMEDS 2015 Physician Competency Framework’ en door de ‘European Academy of Teachers in General Practice’. Onze resultaten suggereren dat voor de zorg van mensen met een levensverkortende aandoening huisartsen hun vaardigheden nodig voor goede algemene zorg moeten combineren met taken en rollen specifiek voor deze

patiëntenpopulatie zoals voorgesteld in hoofdstuk 5. Gezien de competenties van huisartsen in palliatieve situaties grotendeels gelijklopen met hun algemene competenties, is er op dat vlak geen beletsel om palliatieve zorg te integreren in de algemene huisartsenpraktijk.

### **Belemmeringen om tijdig palliatieve zorgnoden te herkennen en tijdig palliatieve zorg op te starten**

Dit doctoraat wijst op de moeilijkheden in het herkennen van palliatieve zorgnoden door de huisarts, redenen voor een late start van een palliatieve zorgbenadering en late doorverwijzing naar gespecialiseerde palliatieve zorgservices. Deze moeilijkheden bevinden zich op drie niveaus: op niveau van de gezondheidszorg, op niveau van de zorgverlener en op niveau van de patiënt en/of de familie. Een belangrijke bevinding in onze studies is dat de herkenning van palliatieve zorgnoden meer problematisch is in de vroegere fases van de ziekte dan in de terminale fase. Hoewel er ook in de terminale fase nog veel barrières gevonden werden. Het grootste probleem om tijdig een palliatieve zorgbenadering te starten ligt waarschijnlijk in het feit dat het initiëren van een dergelijke benadering nog steeds te veel gebaseerd is op prognose in plaats van op de zorgnoden van de patiënt.

Palliatieve zorg wordt nog steeds te vaak gezien als een verlengstuk van de reguliere geneeskunde, een extensie, een aanhangsel dat alleen van toepassing is bij de epiloog van het leven. Er wordt pas palliatieve zorg opgestart op het ogenblik dat ‘alle andere medische opties zijn opgebruikt’, waardoor voor mensen pas heel laat of zelfs geen palliatieve zorgbenadering (generalistisch of specialistisch) opgestart wordt. Met dit doctoraat willen wij aantonen dat gebruik maken van een prognose-gebaseerd model van palliatieve zorg (d.i. palliatieve zorg wordt opgestart zodra een bepaalde gelimiteerde levensverwachting wordt voorspeld) intrinsiek bepaalde belemmeringen impliceert voor generalistische en gespecialiseerde palliatieve zorg. De dreiging van het nakende overlijden is verre van een ideaal beslissingscriterium voor het al of niet opstarten van palliatieve zorg. Een prognose maken over het tijdstip van overlijden is immers bijzonder moeilijk en vaak komt de dood toch nog onverwacht. Bijgevolg krijgen veel patiënten nooit of alleszins te laat palliatieve zorg. Een model gebaseerd op de individuele zorgnoden van de patiënt zou beter zijn, hoewel ook daar bepaalde barrières weggewerkt moeten worden. Dit betekent concreet dat palliatieve zorg ook een plaats heeft als de patiënt nog volop curatief of levensverlengend behandeld wordt.

#### *What's in a name?*

Het is opmerkelijk dat in onze kwalitatieve studies de huisartsen, thuisverpleegkundigen en patiënten niet expliciet het woord ‘palliatieve zorg’ gebruiken wanneer ze praten over de verleende zorg gedurende het ziekte-traject, maar enkel de term ‘palliatief’ gebruiken voor de zorg in de terminale fase. Toch beschrijven de respondenten, vanuit een semantisch en theoretisch perspectief, precies de dimensies en domeinen van een palliatieve zorgbenadering. De reden waarom ze de term ‘palliatief’ niet gebruiken in deze context zou kunnen zijn omdat palliatieve zorg zijn oorsprong vindt in ‘terminale’ zorg voor patiënten die stervende zijn en

wanneer voor deze patiënten geen andere behandelingen meer mogelijk zijn, eerder dan voor een patiënt met een ziekte waaraan hij of zij verwacht wordt vroeg of laat te sterven. De term ‘palliatief’ is ook vaak enkel gelinkt aan een type van zorg of aan een gespecialiseerde discipline, eerder dan als een benadering van zorg.

Verschillende studies in oncologische ziekenhuissettingen stelden dat de term ‘palliatieve zorg’ mensen afschrikt en dat daardoor vaak geen vroege palliatieve zorg opgestart wordt. ‘Supportieve zorg’ zou volgens deze studies een betere term zijn. Deze laatste term is al van toepassing in oncologische settingen. In essentie beschrijven beide termen ongeveer dezelfde praktijk van ‘totale zorg’ met aandacht voor het lichamelijke, psychologische en sociale noden. Een andere studie toonde aan dat wanneer de palliatieve dienst van naam veranderd was (van palliatieve zorg naar supportieve zorg) er 41% meer consultaties waren van het palliatieve zorgteam en dat er minder tijd tussen de diagnose en de eerste consultatie was.

Het gebruiken van de term ‘supportief’ in plaats van ‘palliatief’ voor de eerdere fases van het ziekte-traject zou er voor zorgen dat de term ‘palliatieve zorg’ terug meer overeenkomt met de oorspronkelijke en traditionele definities van palliatieve zorg gezien als terminale zorg. Echter, de meeste definities vandaag zien een palliatieve zorgbenadering als een benadering die van toepassing kan zijn vanaf diagnose mogelijks samengaand met curatieve en levensverlengende behandelingen. Wij erkennen dat de definities van supportieve en palliatieve zorg open zijn voor discussie en dat deze kunnen veranderen overheen de tijd. Echter, los van deze semantische discussie blijven onze bevindingen nuttig omdat de ervaren zorgnoden of zorgprocessen blijven bestaan ook als mensen deze niet bestempelen als ‘palliatief’. In elk geval mag een andere naam geven aan een gelijkaardige praktijk geen excuus zijn om niet met de patiënt over zijn of haar verschillende zorgnoden te praten en de mogelijke uitkomsten van zijn of haar ziekte.

## **UITDAGINGEN EN AANBEVELINGEN VOOR PRAKTIJK EN BELEID**

Onze bevindingen tonen aan dat er nog ruimte is voor verbetering wat betreft het herkennen van palliatieve zorgnoden en het starten en integreren van een palliatieve zorgbenadering in de reguliere zorg. Het groeiend aantal mensen die leven met en sterven aan levensverkortende aandoeningen zorgt ervoor dat we het stijgende belang van (vroege) palliatieve zorg in onze samenleving in overweging moeten nemen. Er zijn belangrijke uitdagingen voor zorgverleners, beleidsmakers en onderzoekers met betrekking tot het initiëren, voorzien, bevorderen en evalueren van zowel generalistische als gespecialiseerde palliatieve zorg. Hieronder worden enkele belangrijke aanbevelingen voor praktijk en beleid kort beschreven.

### **Uitdagingen en aanbevelingen voor de praktijk**

Gebaseerd op onze resultaten in hoofdstuk 4 en 5 kunnen we hieronder enkele bevorderende factoren opsommen om een vroege palliatieve zorgbenadering te implementeren. Deze zaken kunnen ook mee opgenomen worden in toekomstige beleidsaanbevelingen en richtlijnen voor

huisartsen; wij zijn ervan overtuigd dat veel van deze factoren ook van toepassing zijn op of nuttig zijn voor andere hulpverleners.

- Communicatie met de patiënt

- *Pro-actief bevragen en voorzichtig exploreren van de zorgnoden*, bijvoorbeeld de huisarts die het initiatief neemt om te praten over de sociale problemen en bevrägt of de patiënt hiervoor meer hulp wil.
- *Gebruiken van korte assessment schalen*, bijvoorbeeld een korte en makkelijke checklist voor pijn en slapeeloosheid om zo de patiënt te kunnen opvolgen en om geen problemen over het hoofd te zien.
- *Tijd maken*, er zullen dan meer niet-acute zorgnoden besproken kunnen worden.
- *Een vertrouwensband creëren*, meerdere bezoeken (ook huisbezoeken) zijn nodig om een band op te bouwen en om in volgende bezoeken over andere 'meer serieuze' topics te kunnen praten.
- *Een palliatieve zorgbenadering als een optie zien voor niet-kanker patiënten*.

- Communicatie en samenwerking met andere zorgverleners

Voor de huisarts is het belangrijk om op een multidisciplinaire manier te werken en om andere zorgverleners, zoals verpleegkundigen, sociaal werkers, kinesisten, psychologen, pastors te betrekken bij de zorg voor de patiënt. Patiënten worden heel vaak overgeplaatst tussen zorgsettings: van thuis naar het ziekenhuis en terug, van thuis naar het woonzorgcentrum, van het woonzorgcentrum naar het ziekenhuis enzovoort. De communicatie en de informatieoverdracht tussen deze settings gebeurt vaak niet of slechts gedeeltelijk. Hieronder beschrijven we daarom kort enkele bevorderende factoren:

- *Communicatieschriftje*, een gedeeld schriftje waarin zowel patiënt, familie als alle andere zorgverleners die de patiënt thuis zien de problemen, zorgnoden en vragen kunnen opschrijven en dit ook gebruiken als communicatiemiddel.
- *Multidisciplinaire meeting*, regelmatige meetings (eventueel via moderne media) tussen de verschillende hulpverleners.
- *Regelmatige controle door de huisarts*, de ziekenhuisarts zou ervoor kunnen zorgen dat de huisarts gedurende het hele ziekte-traject betrokken blijft bij de zorg, door bijvoorbeeld de patiënt regelmatig te laten opvolgen door de huisarts.
- *Gedeelde medische gegevens*, een elektronisch bestand waarin alle zorgverleners de medische en niet-medische (zoals reactie op een slecht nieuwsgesprek bijvoorbeeld) informatie over de patiënt kan vinden en aanvullen.
- *Doorverwijzen naar gespecialiseerde palliatieve zorg*, wanneer de zorgnoden te complex worden voor de reguliere hulpverlener kan er beroep gedaan worden op gespecialiseerde palliatieve zorgteams.

## **Uitdagingen en aanbevelingen voor het beleid**

Mensen met een levensverkortende ziekte kunnen nog vele jaren met deze aandoening leven, maar kunnen gedurende deze periode verschillende lichamelijke, psychosociale en levensbeschouwelijke zorgnoden ervaren. Een mogelijke strategie om deze zorgnoden op te vangen is een makkelijkere toegang bieden tot gespecialiseerde palliatieve zorgservices voor iedereen. Onze bevindingen tonen echter aan dat patiënten – vaak wellicht terecht- niet worden doorverwezen naar deze services en ook dat een groot deel dat wel wordt doorverwezen slechts heel kort voor het overlijden wordt doorverwezen. Om vroege palliatieve zorg te integreren is het is daarom tenminste even belangrijk om zowel de palliatieve zorgvaardigheden in reguliere zorgverstrekkers te evalueren, stimuleren en garanderen als deze van de gespecialiseerde palliatieve zorgservices.

Verbeteringen in de praktijk in termen van het vroeger beginnen met een palliatieve zorgbenadering en tijdige doorverwijzing naar gespecialiseerde palliatieve zorgservices (zoals de praktijkaanbevelingen hierboven beschreven), kunnen wellicht enkel worden bereikt als ze ook samengaan met enkele veranderingen op structureel en beleidsniveau. Hieronder vatten we kort drie beleidsaanbevelingen samen:

- 1) De resultaten in dit proefschrift bevestigen eens te meer dat sensibilisering van hulpverleners, patiënten en de brede bevolking voor palliatieve zorg belangrijk blijft.
- 2) Reguliere hulpverleners die regelmatig in contact (zullen) komen met mensen met een levensverkortende aandoening zouden voldoende opgeleid moeten zijn om adequate palliatieve zorgvaardigheden en palliatieve zorgattitudes te bezitten (basis symptoommanagement, kennis van opties van zorg zoals bijvoorbeeld gespecialiseerde palliatieve zorgservices, kennis van ziektrajecten, communicatievaardigheden, voorafgaande zorplanningsvaardigheden enzovoort).
- 3) Er is nood aan een wettelijk kader en *incentives* voor een haalbaar palliatief zorgmodel dat vroeg geïntegreerd kan worden in de reguliere zorg, alsook voldoende middelen voor het inschakelen van gespecialiseerde palliatieve zorgservices wanneer de noden te complex worden.

# **CURRICULUM VITAE AND LIST OF PUBLICATIONS OF KIM BEERNAERT**





## **CURRICULUM VITAE**

Kim Beernaert (°1986) is an experimental psychologist and junior researcher working at the End-of-Life Care Research Group of the Vrije Universiteit Brussel (VUB) & Ghent University. She obtained her Master's degree in experimental and theoretical psychology in 2009 (UGent). After that she finished the specific teacher training (SLO) at Ghent University and worked as a teacher in high school. She started her scientific career on early palliative care in family practice in April 2011. Her study was part of the "Flanders study to improve End-of-Life Care and Evaluation Tools" (FLIECE project), which was supported by a grant from IWT (SBO IWT nr 100036). Today she still works as a researcher at the End-of-Life Care Research Group and is involved in a subsequent study of this PhD on early palliative care needs in people with cancer and in the study on the Care Programme for the Last days of Life for older people.

## LIST OF PUBLICATIONS

### Articles in international peer-reviewed journals

**Beernaert, K.**, Deliens, L., De Vleminck, A., Devroey, D., Pardon, K., Van den Block, L & Cohen, J. Is there a need for early palliative care in patients with life-limiting illnesses? Interview study with patients about experienced care needs from diagnosis onwards. *American Journal of Hospice & Palliative Medicine*, (in press) [SCI impact factor (2013): 1.347]

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## **Other publications and chapters in books**

**Beernaert, K.,** Cohen, J., Deliëns, L., Devroey, D., Vanthomme K., Pardon, K. & Van den Block, L. Doorverwijzing naar palliatieve zorg voor COPD en andere levensbedreigende aandoeningen: een nationale studie. *NVTPZ* 2013 (3/4).

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**Beernaert, K. &** Cohen, J. Gespecialiseerde palliatieve zorg inschakelen: wanneer en bij wie? (hoofdstuk 8 uit: Cohen J, Smets T, Pardon K, Deliëns L. Palliatieve zorg, meer dan stervensbegeleiding. Nood aan integratie en verbreding. Tiel, LannooCampus, 2015, 232p (ISBN:9789401425612))

## **Oral presentations given at international and national conferences and seminars**

Tijdig starten van palliatieve zorg en voorafgaande zorgplanning in de thuissetting. Presentation given at the FLIECE congress on improving palliative care, Brussels (Belgium), January 2015.

Early identification of palliative care needs. Presentation given at the EACH conference on communication in health care, Amsterdam (The Netherlands), September, 2014.

Tasks and roles of the family physician. Presentation given at the 20<sup>th</sup> Congress of Palliative care, Montreal (Canada), September, 2014.

Early identification of palliative care needs. Presentation given at the 20<sup>th</sup> Congress of Palliative care, Montreal (Canada), September, 2014.

Timely recognition and tackling of palliative care needs [Tijdig herkennen en aanpakken van palliatieve zorgnoden]. Presentation given at a family physicians meeting, Wetteren (Belgium), December, 2013

Why do family physicians not always identify palliative care needs and how can this be ameliorated? A qualitative study with family physicians, community nurses and patients. Presentation given at external seminar of the End-of-Life Care Research Group, Jette (Belgium), April, 2013

Differences in referrals to palliative care services between patients with cancer, organ failure and dementia. Presentation given at the International Collaborative on End-of-Life Care Research (ICER) meeting, Amsterdam (The Netherlands), September, 2012

Differences in extent and timing of referrals to palliative care services between patients with cancer, organ failure and dementia. Presentation given at the 7<sup>th</sup> World Research Congress of the European Association for Palliative Care (EAPC), Trondheim (Norway), June, 2012

Timely recognition of care needs by the general practitioner. Presentation given at the International Collaborative on End-of-Life Care Research (ICER) meeting, Brussels (Belgium), December, 2011