

Supporting patients and professionals in primary palliative care

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Cover: 'Intimiteit'. Gemaakt door mevrouw Rick voor de Poort, voormalig directeur van het Landelijk Steunpunt VTZ. 'Intimiteit' is één van de kunstwerken die gemaakt zijn door patiënten, naasten en vrijwilligers in het kader van een expositie getiteld 'de dood verbeeld' (2003). De kunstenaar zegt zelf het volgende over 'Intimiteit': "Dit is gemaakt in de periode na 2000, toen ik even niet meer kon werken en later niet meer zo hard hoefde. Terugkijkend voelt het als thuiskomen. Terwijl ik tegelijkertijd in een proces was beland van de balans opmaken, afscheid nemen en loslaten. Geleidelijk glooide een nieuwe horizon." ([www.galerie-austerlitz.nl](http://www.galerie-austerlitz.nl))

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# Supporting patients and professionals in primary palliative care

een wetenschappelijke proeve  
op het gebied van de Medische Wetenschappen

## **Proefschrift**

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# Contents

	<b>Page</b>
<b>Chapter 1</b> Introduction	7
<b>THEME I: BARRIERS IN DAILY PALLIATIVE CARE EXPERIENCED BY GPs</b>	
<b>Chapter 2</b> General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice <i>Palliative Medicine 2005; 19: 111 – 118</i>	21
<b>Chapter 3</b> Determinants of obstacles in primary palliative care <i>Submitted</i>	37
<b>THEME II: EXPERIENCES OF PATIENTS AND INFORMAL CARE PROVIDERS</b>	
<b>Chapter 4</b> Quality of primary palliative care: experiences of patients and their informal care providers <i>Submitted</i>	55
<b>Chapter 5</b> Living on borrowed time: experiences in palliative care <i>Patient Education &amp; Counseling 2007; 65 (3): 381 – 386</i>	69
<b>THEME III: PROSPECTIVE STUDIES ON THE NATIONAL PROGRAMME FOR QUALITY IMPROVEMENT IN PALLIATIVE CARE: PALLIATIVE CARE CONSULTATION TEAMS (PCC TEAMS)</b>	
<b>Chapter 6</b> Requests from professional care providers for consultation with palliative care consultation teams (PCC teams) <i>Supportive Care in Cancer 2005; 13: 920 – 928</i>	83
<b>Chapter 7</b> Consultation in palliative care: the relevance of clarification of problems <i>European Journal of Cancer 2007; 43: 316 – 322</i>	101
<b>Chapter 8</b> Expert advice given in palliative care consultation <i>Submitted</i>	115
<b>Chapter 9</b> General discussion	129
Summary	147
Samenvatting	155
Dankwoord	163
Over de auteur	168

# Chapter 1

## Introduction



## **Palliative care**

“To add life to days, when days cannot be added to life!” This familiar phrase, aptly expresses the idea underlying *palliative care* as defined by the World Health Organisation (WHO) for the second time in 2002. The WHO’s second definition of this relatively new concept runs as follows: *palliative care is 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*<sup>1</sup>. The WHO had first defined palliative care 12 years previously<sup>2</sup> <sup>a</sup>. In the intervening years, a shift in healthcare took place. Curative care (recovering from a potentially life-threatening illness) and palliative care (with the focus on quality of life and not on cure), with the latter following the failure of the former, were no longer sharply distinguished from each other, but became intertwined. Life prolongation in palliative care can now be contemplated alongside the primary goal of preserving or improving the quality of life. Even so, debates about the best treatment in the curative phase of a disease are now also fed by deliberations around the quality of life.

The notion of ‘palliation’ has been used for centuries; medicine has been palliative as well as curative in nature from its origins<sup>3,4</sup>. Despite the fact that the twin obligations of physicians - to cure disease and to relieve human suffering - stretch back into antiquity, little attention has been explicitly given to the problem of suffering in medical education, research or practice. This neglect is the widespread effect of the mind-body dichotomy in medical theory and practice<sup>5</sup>. Paying full attention to the needs and suffering of terminally-ill patients and their relatives did not fit into this realm of thought. Consequently, when curative treatment was ineffective, a patient would be told that “there is nothing more we can do for you”<sup>6-8</sup>. The term *palliative care* emerged for the first time in 1973. A hospital physician in Canada, Balfour Mount, introduced the concept<sup>9</sup> and in that same year the neologism also appeared in the Dutch medical literature<sup>10</sup>.

## **Palliative care in historical perspective**

Halfway through the twentieth century, there was evidence of an awaking medical interest in matters relating to the care of the dying<sup>11-14</sup>. The Swiss-American psychiatrist Elisabeth Kübler-Ross published her much-discussed book ‘On Death

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<sup>a</sup> In 1990 the WHO has presented its first definition of palliative care: *the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families*<sup>2</sup>.

and Dying' (1969), based on 500 interviews with dying patients<sup>15</sup>. Furthermore, Dame Cicely Saunders, nurse, social worker, and physician, and considered to be the founding mother of the hospice movement<sup>10,16</sup>, contributed enormously to the growing interest and public discussion about care for the dying. Largely through her efforts, St Christopher's Hospice opened its doors in London in 1967.

Close on a century before, *pre-* or *protohospices* were established in Dublin (Our Lady's Hospice for the Dying, 1879) and London (St Luke's Hospice, 1893). These hospices can be considered to be the forerunners of the hospice movement and the wider developments in the care for the dying<sup>12,17</sup>. They were more an outcome of religious endeavours rather than of medicine. There was no exchange of thought or involvement between the worlds of medicine and the hospice.

The very first hospices stem, however, from the 4<sup>th</sup> century; they were originally resting places for tired pilgrims. These homes developed into care-homes for weary travellers as well as people living in the locality<sup>10,18</sup>. After the Middle Ages, these homes disappeared. They were taken over by physicians who transformed them into hospitals<sup>10</sup>.

Thanks to such charismatic advocates as Elisabeth Kübler-Ross, Cicely Saunders, and other passionately-concerned healthcare workers, the principles of palliative care became embedded in modern medicine and palliative care developed towards modern medicine, rather than as an alternative to it. Five years after St Christopher's Hospice started up, there was an international hospice movement. Saunders' initiative was imitated worldwide, first in other places in the United Kingdom (UK), and in the 1970s in the United States, Australia, and Canada. European countries followed somewhat later<sup>10</sup>.

But despite these mutual approaches between modern medicine and palliative care, many countries ask themselves whether palliative care should be integrated into medicine, giving a new dimension to current practice, or whether palliative care should become a new discipline or medical specialty complementing the existing range of professional activities. This debate is still ongoing<sup>19,20</sup>. Palliative care is clearly emerging as a new area of healthcare in many countries, but until now only in some countries, with the UK taking the lead in 1987, it has become a new discipline<sup>12</sup>.

### **Palliative care: for whom?**

For a long time, palliative care was not bound to a specific group of patients. It was intended for all dying people irrespective of their underlying disease. However, nowadays, the term palliative care seems to be usually associated with cancer



patients. This link can also be said of the studies reported in this thesis. In spite of the broad basic assumption that palliative care is not confined to patients with cancer, we can conclude that very few projects within the Dutch national programme (see box 1 & 2) were specifically aimed at non-cancer patients<sup>21</sup> and that in our studies only a very small number of non-cancer patients participated.

When we consider the relationship between cancer and palliative care, their close association might seem logical. This might be so because the course of cancer partly has proved predictable, easing the recognition and planning for the needs of patients and their families<sup>22,23</sup>. Furthermore, despite a steady rise in the last few decades of the chances of a cure and the less frequent occurrence of some cancers with poor chances of survival (cancer of the stomach and lung cancer), cancer remains one of the major causes of death<sup>24-26</sup>. Cancer is currently the cause of 12 percent of all death worldwide. In approximately 15 years from now, the number of cancer death annually will increase to 10 million<sup>b</sup>. The number of patients living with cancer is expected to increase worldwide. Unless there are effective prevention campaigns, by 2020 there will probably be more than 30 million people living with cancer<sup>27</sup> <sup>c</sup>. Furthermore, the increased life expectancy, the ageing of the population in western Europe<sup>23,28-31</sup>, and some medical interferences concerning cancer (more and earlier diagnosis and better treatment possibilities with more people living longer with their disease<sup>32</sup>) are all factors contributing to the need for more palliative care.

In recent years there has been a noticeable tendency to extend the ideas of palliative care to other groups of patients. This extension is in accordance with the WHO's maxim, which states that every person with a progressive illness has the right to palliative care<sup>23,30</sup>. Research is less well advanced on meeting the palliative care needs of people suffering and dying from diseases other than cancer<sup>32</sup>. Nowadays, there are initiatives and research programmes for disease-related groups, including patients with dementia<sup>33,34</sup> or progressive neuromuscular diseases<sup>35</sup>, and target groups such as children<sup>36</sup>, immigrants<sup>37,38</sup> or the mentally handicapped<sup>39-42</sup>. These projects may stand apart, but sometimes they seek contact with existing structures or existing structures may expand their goals to non-cancer patients.

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<sup>b</sup> In 2002 there were about 6 million cancer death annually<sup>27</sup>. Concerning only the Western countries, cancer mortality is already exceeding 20 percent of all deaths<sup>43</sup>.

<sup>c</sup> Approximately 20 million people were living with cancer in 2002<sup>27</sup>.

## Palliative care in the Netherlands

The Netherlands was remarkably late in its development of palliative care. In the period in which the first hospices were opened in the UK, the discussions in the Netherlands concerning “a good death” were dominated by euthanasia. Our first high-care hospices opened their doors in 1991<sup>d</sup> and 1994<sup>e</sup> 43. The first almost-like-home house (bijna-thuis-huis/BTH<sup>f</sup>), was founded somewhat earlier in Nieuwkoop in 1988<sup>10</sup>; in 1993 the first palliative terminal-care unit in a Dutch nursing home was opened<sup>9</sup>. With respect to euthanasia, a state committee reported in 1985 that euthanasia was liable to prosecution, but if rigorous and meticulous demands were complied with, legal proceedings would not necessarily follow. The Act concerning euthanasia came into effect in 2002. From that time, euthanasia has no longer been liable to prosecution on condition that the physician concerned notifies the euthanasia and meets the requirements laid down by law. It seems that the development of palliative care has only grown to maturity since the euthanasia debate has died down. On the other hand, some voices are heard arguing that the real starting point of the development of palliative care was the establishment of the first nursing homes in the Netherlands, about halfway through the 1960s. Considerable experience and expertise in the care of the dying has been gained in these homes<sup>28,44,45</sup>.

In any event, the actual starting point for a rapid development of palliative care was a discussion in Parliament about the procedures of reporting within the framework of the law on euthanasia<sup>21</sup>. This debate was also a result of the television documentary ‘Death on request’, a documentary about euthanasia that led to much (inter)national criticism and discussion<sup>20</sup>. Members of Parliament supposed that requests for euthanasia were possibly correlated with a lack of development in pain relief and other aspects of palliative care. This debate formed the direct motivation for the programme ‘Palliative Care in the Terminal Phase’<sup>46</sup> (box 1). The first phases of this programme led to a financial impetus from the Ministry of Health for the further development of palliative care. Priority was given to the development of palliative care on the basis of existing structures; no boost was given to private initiatives.

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<sup>d</sup> Johannes Hospice, Vleuten<sup>43</sup>.

<sup>e</sup> Hospice Rozenheuvel, Rozendaal<sup>43</sup>.

<sup>f</sup> In the Netherlands we distinguish between (high-care) hospices and almost-like-home houses. Hospices have their own nursing staff. Medical responsibility rests with a GP, a hospice physician, a nursing home physician or a hospital physician. In a almost-like-home house the central team mainly consists of volunteers. They provide the main part of the daily care for the patient together with the family. The patients’ own GP is the responsible physician. Sometimes professional primary care nurses lend support for parts of care<sup>47</sup>.

<sup>9</sup> Antonius-IJsselmonde, Rotterdam<sup>43</sup>.

**Box 1. Palliative care in the Netherlands 1996 – 2003<sup>21,46,48,49</sup>**

1996: the Netherlands Organisation for Health Research and Development [ZonMw] was asked by the Ministry of Health, Welfare and Sport [VWS] to develop the programme 'Palliative Care in the Terminal Phase'. ZonMw proposed a programme in 3 phases:

1. Inventory of demands for, and supply of, palliative care in the terminal phase (executed in 1997 by Netherlands Institute for Health Services research [NIVEL], reported on in 1997).  
2. Exploration of future developments with regard to demand and supply considering societal and socioeconomic developments (executed from 1998 – 2000 by NIVEL, reported on in 2000).  
Considering the results (partly intermediate) of these two projects, phase 3 had to strive for integration and a structural incorporation of palliative care in the regular care. To this end the Ministry launched 4 trajectories within phase 3:

- A. Palliative care in residential- and nursing homes
- B. Integration of hospice care: executed by a project group working on the Integration of Hospice care [PIH], reported on in 2000 – 2002
- C. Close association of the organisations of volunteers in terminal care
- D. Establishment of regional Centres for the Development of palliative care [COPZ] (reported on by the COPZ review committee in 2001 - 2004) (see Box 2)

Six Centres for the Development of Palliative Care [COPZ] (box 2) were financed for a period of five years (1998–2003). A centre consists of a collaborative arrangement between a University Hospital and a regional Comprehensive Cancer Centre [IKC] with a close connection with professional(s) (groups) having affinity with palliative care patients, such as General Practitioners (GPs), district nurses, regional hospitals, nursing homes, and so forth. The studies presented in this thesis were carried out within a collaborative research programme of the COPZ.

**Box 2. Six centres for the Development of palliative care [COPZ] 1998 – 2003<sup>28,46</sup>**

A COPZ consisted of a collaborative arrangement between a University Hospital and a regional Comprehensive Cancer Centre [IKC] with a close connection to professional(s) (groups) having affinity with palliative care patients, for example GPs, district nurses, regional hospitals, nursing homes, and so forth. In the Netherlands there were 6 COPZ; they were formed around the universities of Amsterdam, Groningen, Maastricht, Nijmegen, Rotterdam and Utrecht.

Tasks of the COPZ:

- to become coordination centres taking into account all the organisations involved in palliative care in the region
- to launch PCC teams working in intra- as well as extramural setting
- to initiate undergraduate and postgraduate educational programmes
- to stimulate research into palliative care

**The aim of the research project**

The path chosen by the Dutch government intensified the need for research into the state-of-the-art seen through the eyes of important players in the field and those most concerned with palliative care; the patient and the informal care provider. These insights are necessary, because only with them can new initiatives be judged on their merits. One key feature of palliative care in the Netherlands is that, as far as possible, it should be provided by generalists in the patient's own

home<sup>47,48,50,51</sup>. Accordingly, in addition to our special interest in the patients, we paid attention to the GP, the central professional care provider for patients receiving palliative care at home.

An important element of the governmental programme on palliative care in the Netherlands was the establishment of the Palliative Care Consultation (PCC) teams throughout the country. In contrast with most other countries<sup>23,52-55</sup>, the Netherlands opted for a transmural palliative care consultation model: a team of professional care providers from different settings with expertise on palliative care giving advice and support to their healthcare colleagues when they encountered problems in daily practice. To policymakers this consultation model seemed promising, because of the assumption that the problems and barriers confronting professionals might be decreased through consultation. Dutch healthcare professionals were not, however, immediately enthusiastic. They were afraid this interference would harm the collaborative structures which, in their view, were working well, would aggravate bureaucracy, and might adversely affect the relationship between professional care provider and patient. Consequently, whether the PCC teams would be successful was considered highly debatable. Furthermore, no comprehensive picture was available of the barriers occurring in primary palliative care, the presumed preferred place<sup>23,56-59</sup>. Initially, therefore, it was impossible for the PCC teams to anticipate the nature of possible requests for consultation and the appropriate constitution of a PCC team. For these reasons, a study of the barriers experienced by GPs, as the presumed professional central caregiver in primary palliative care, and the monitoring of this new care concept became essential.

### **Outline of the thesis**

The thesis elaborates on three themes. First, two studies covered the barriers in daily palliative care experienced by GPs; the professionals invariably responsible for primary palliative care patients. Concentrating on those to whom palliative care primarily and finally is connected, the patients and their informal care providers, the second theme explores several aspects of their experiences in primary palliative care. The last theme concerned the PCC teams and the process initiated by a request for consultation and proceeding via the clarification of the request to the advice and support given.

### ***Theme 1: Barriers in daily palliative care experienced by GPs***

The first two chapters after this general introduction are concerned with the experiences of a central professional care provider in primary palliative care: the GP. Knowledge of the barriers GPs experience in their daily care could contribute to the development of effective activities for the improvement of palliative care. The results will therefore be put at the disposal of the PCC teams, considered to be one of the major quality improvement activities in the Netherlands.

In **chapter 2**, we present the results of a qualitative study of palliative care administered by GPs. Their tasks in daily palliative care and the barriers confronting them were investigated by means of focus groups. Based on the results of this study, we developed a questionnaire, which we used for a survey of more than 500 GPs. We collected information about the prevalence of the barriers clustered in five groups. We also explored the variation of the groups of barriers among GPs owing to differences in GP characteristics and differences in activities on expertise development variables. The results are reported in **chapter 3**.

### ***Theme 2: Experiences of patients and informal care providers***

The second theme of this thesis is concerned with patients and their informal care providers. Patients' views can differ from those of their healthcare professionals, and also from those of the family members caring for them<sup>23</sup>. To complement the picture of primary palliative care with the views of those receiving it, two studies reporting the personal views of their experiences are presented. It is important that the professionals, policymakers, and managers involved in care provision and the improvement of primary palliative care take to heart the experiences and judgments of the quality of care of patients and informal care providers.

In **chapter 4**, we describe a cross-sectional observational study in which we assessed the quality of primary palliative care from the perspective of the patient and informal care provider. The next chapter (**chapter 5**) features a qualitative case analysis regarding a palliative care patient and her husband who were living on borrowed time. We look at the way in which the patient and husband integrated this new reality into their lives and tried to find a new equilibrium.

### ***Theme 3: Monitoring of a national programme for quality improvement in palliative care: PCC teams***

Theme 3 features studies regarding aspects of palliative care consultation. We investigated the extent to which professionals requested assistance from PCC teams and the reasons underlying these requests (**chapter 6**). During the process

of consultation, the PCC team consultant clarifies the request for consultation by exchanging thoughts with the requesting care provider, perusal of the patient's file, and contact with the patient (for bedside consultation only). In the next chapter (**chapter 7**), we focus on this clarification process in order to identify the additional problems derived from clarification in palliative care consultation and to reveal the factors influencing the identification of additional problems.

In the last chapter within this theme (**chapter 8**), we close the circle of the consultation process. Here, we describe our study that focused on the extent and nature of the support and advice given by PCC team members to the requesting care providers and on the factors that influence the differences in the advice given.

This thesis concludes with a chapter (**chapter 9**) that discusses the main findings from all the studies. The results are placed in a wider perspective; the most relevant methodological limitations are considered; and recommendations are put forward for further research and for palliative care in general.

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## **THEME I**

### **BARRIERS IN DAILY PALLIATIVE CARE EXPERIENCED BY GPs**

## Chapter 2

### General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice

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## **Abstract**

**Background:** General practitioners (GPs) play a crucial part in palliative care. The quality of care can be improved by investigating and addressing barriers perceived by GPs in daily practice. The aim of this study was to investigate GPs' task perception and barriers involved in palliative care.

**Methods:** Qualitative focus group study. We gathered together a group of GPs representing a broad range of experience in palliative care. Content analysis was performed to derive a comprehensive view of tasks and barriers in daily palliative care.

**Results:** GPs described their palliative care tasks as satisfactory and varied, but burdensome. Palliative care tasks included somatic and psychosocial care. Opinions differed with respect to whether the coordination of care belonged to the primary GP tasks. Barriers were classified according to three levels: (1) personal: barriers related to knowledge, skills, emotions; (2) relational: barriers concerning communication and collaboration; (3) organisational: barriers related to the organisation of care and compartmentalisation in healthcare.

**Conclusions:** This study revealed a complex web of tasks and barriers. It may be possible to trace back a problem (lack of knowledge, for example) on the personal level to an isolated knowledge gap, but the problem may well have originated from communication or compartmentalisation problems. To maintain GPs' feeling of being at ease with palliative care requires helping them acquire the appropriate balance between technical and organisational interventions and a compassionate orientation to their terminally-ill patients.

## Introduction

For a long time general practitioners (GPs) in the Netherlands, as in many other countries, have played a pivotal part in palliative care<sup>1</sup>. GPs have valued this role<sup>2</sup> and there has been broad agreement that palliative care is an important task. This perception is in line with the needs and wishes of terminally-ill patients, most of whom want to spend the last phase of their lives in their own homes. Furthermore, national healthcare policy in the Netherlands has encouraged terminal care in the home of the patient (See Box 1 for information about the context of primary care in the Netherlands).

### Box 1. The context of primary care in the Netherlands

In the Netherlands, healthcare is organized in two echelons. The first consists of primary (community) care; the second of hospital care<sup>3</sup>. Dutch healthcare is characterized by its strong emphasis on primary care. General Practitioners (GPs) play a pivotal part in primary care. Usually, they are the first professional group attending patients with health complaints. The tasks of GPs are a mixture of cure, care, and prevention. Another important part of primary care is homecare. This encompasses nursing care as well as domiciliary care. The need for primary care is increasing, for a number of reasons: the ageing of the population, more small families and singles, the reduction of the length of stay in hospital. In addition to professional care providers, a patient's family and friends also perform nursing and homecare tasks. This voluntary 'informal care' is an important part of the care for sick persons. The costs of homecare and GP care account for over one quarter of the total health care budget in the Netherlands<sup>4</sup>.

Since the end of the 1980s, the role of GPs in palliative homecare has come under discussion. There has been criticism of the content and organisation of care<sup>5,6</sup>. This criticism has been focused on inadequate collaboration, poor accessibility, continuity gaps, and a lack of knowledge and skills concerning pain management and medical technical equipment. Specialist teams and outpatient clinics have been suggested as possible alternatives<sup>1,7</sup>. Such a vision, were it justified, would constitute a threat to the pivotal role of GPs in terminal homecare. At the beginning of the 1990s, palliative care seems to have come to maturity<sup>8</sup>. Many new initiatives were undertaken and in the mid 1990s the Dutch government initiated a stimulation programme (See Box 2)<sup>9</sup>.

The principle underlying this programme was that palliative care should be provided as far as possible by care providers working in regular nonprivate facilities<sup>10</sup>. One element of the programme was the initiation of six Centres for the Development of Palliative Care [COPZ]: each centre comprises an alliance of at least a medical faculty and a university hospital, usually in collaboration with inpatient and outpatient care providers, and a Comprehensive Cancer Centre [IKC] in the district concerned.

### **Box 2. The Dutch palliative care programme<sup>9</sup>**

In 1998 the Dutch Government initiated a five-year stimulation programme in order to improve the quality of palliative care. The programme comprised three main aspects:

- Attention to the structure and organisation of palliative care within the boundaries of regular healthcare
- Stimulation of the promotion of competence of providers of healthcare for terminal patients
- Promotion of insight into the developments in supply and demand of palliative care.

Part of this programme was the establishment of six Centres for the Development of Palliative Care [COPZ]. Universities, university hospitals, comprehensive cancer centres and other relevant institutions collaborated in these centres: they were situated in Amsterdam, Groningen, Maastricht, Nijmegen, Rotterdam, and Utrecht. The assignment of the COPZ was to improve the quality of palliative care for terminally-ill patients by means of research, education, network development, and care innovation.

The Centres were mandated to stimulate and guide the development of palliative care by means of consultation, education and research projects. GPs became involved in many discussions concerning the context and content of future palliative care. As a result, at the beginning of 2000, one of the six COPZ considered it worthwhile investigating whether the role of the GP in daily palliative care had changed as a result of the changes in (palliative) healthcare. Subsequently, they considered it important to improve their understanding of the problems GPs encountered in their work in palliative care. The enhanced understanding thereby acquired could contribute to the development of effective activities for the improvement of palliative care. At that time little research had been devoted to this topic. The studies available in the literature concerned cancer care in general<sup>11-13</sup>, or had only investigated the usual practice and problems of professionals with regard to isolated aspects of palliative care, for example symptom management<sup>14,15</sup>. Other studies were directed at GPs' educational needs, or the learning effects of specific GP educational provision<sup>16,17</sup>.

To fill the gap in palliative care research, we set up a qualitative study aiming to identify GPs' opinions of their tasks in palliative care and the barriers encountered in performing these tasks, thereby enabling the construction of a comprehensive view of both of these aspects.

## **Method**

### *Sample selection*

All GPs from one district (n > 200) were initially sent a letter of invitation. Those willing to participate constituted a group with a wide range of experience and knowledge of palliative care and attitudes towards it. We did not offer any incentives to the GPs to persuade them to participate.

*Data collection*

Focus group interviews were carried out with three groups of GPs, each of which met for about three hours. The size of the groups varied from four to eleven. Through unforeseen circumstances, 12 GPs failed to attend the interview. The interviews took place in the period from March to May 2000 at a central location for all GPs: the Comprehensive Cancer Centre in the district.

The method utilising focus group interviews capitalises on the interaction within a group to elicit rich, experiential data<sup>18</sup>. The most important underlying principle is that the temporary social structure stimulates and facilitates the provision of information<sup>19</sup>. The group process enabled the GPs to explore and clarify their views in ways that would be less easily accessible in, for example, a one-to-one interview<sup>20</sup>. Our participants discussed the tasks and barriers encountered in providing palliative care. To facilitate the interviews and to ensure that the same issues were discussed in all of them, an interview guide with open-ended questions was compiled (Table 1).

**Table 1. Interview guide**

*Task perception*

1. Which tasks do you have in mind for GPs in palliative care?
2. Which tasks may other professionals have in mind for GPs?
3. Which tasks do you have in mind for other professionals?

*Barriers*

1. Where does daily practice conflict with your task perception?
2. What could be the reasons for this?
3. Which other barriers do you see in general palliative care?
4. What could be the reasons for these?

Experienced GPs associated with the regional GP vocational training institute acted as discussion leaders. They facilitated group discussion by asking clarifying questions and providing guidance. Whenever it seemed appropriate, the discussion leaders joined the discussion.

All the meetings were audio taped with the participants' consent. During the interviews, two or three members of the research team were present. They did not participate in the discussion, but took notes in case the audiotape installation failed.

*Data analysis*

All the recorded interviews were transcribed for analysis. Systematic content analysis<sup>21</sup> was performed by just two of the authors in the interests of reliability. Emerging themes were developed by repeated study of the transcripts and the

attribution of codes to text segments. Rather than impose a framework a priori, it was allowed to evolve from the interview data; it was then gradually refined by grouping related categories<sup>22</sup>. Finally, the definitive framework comprising a comprehensive view of tasks and problematic issues in daily palliative care was obtained.

## Results

### Subjects

Twenty-two GPs each attended one of the three meetings. Some of them were already acquainted with one another. The interviewees varied according to such characteristics as age, gender, practice and experience in palliative care (Table 2).

**Table 2. Characteristics of participating GPs (N=22)**

Characteristic					Missing	Total
Gender	Male 15	Female 7	-	-	-	22
Age	< 40 1	40 – 50 6	50 – 60 7	≥ 60 3	5	22
Form of practice	Solo 3	Duo 8	Group 6	Healthcare Centre 1	4	22
Working years	< 1 -	1 – 6 2	6 – 11 2	≥ 11 15	3	22
Part-time factor	< 40% -	40 – 80% 10	≥ 80% 9	-	3	22
Yearly amount of patients in palliative phase	≤ 2 1	3 – 6 12	6 – 10 5	≥ 10 1	3	22
Setting GP practice	Rural 1	Urbanised countryside 11	Small or medium- sized town -	Big city 9	1	22

### Tasks

The GPs' opinions of their tasks comprised two segments: perception and performance.

**PERCEPTION.** Without exception, every GP described working in palliative care as a responsible, difficult, but rewarding job. It is never the same; one has to go by one's feelings in this complex, typical GP work. One GP expressed it thus:

*Work without any palliative care would be very frugal care; palliative care is the epitome of a GP's work.*



Palliative care combines the crucial aspects of general practice: medical care as well as supportive care. A close relationship with the patient and patient's family is usually established in the palliative phase.

**PERFORMANCE.** GPs carry out a mixture of somatic, psychosocial, and coordinating tasks.

*There are two very important aspects to being a GP. You are a doctor, there to kill the pain, carry out diagnostics every now and then, cope with the moments of decision, and coordinate the care. And there is the other part of being a doctor: the psychosocial support of a family that you may well have known for a long time.*

The GP's care is directed towards the patients and their families, although the GP's role for the family is less extensive. With regard to the patient, the intensity and extent of the GP's tasks depend on several aspects: the complexity of the situation, the characteristics of the patient, and the extent to which the patient and the GP have a history in common.

To care for patients in the last phase of life and their families, GPs have to use their communication and cooperation skills as well as their medical knowledge. They must recognise the opportunities for optimising care as well as have the ability to consult experts at the right moment. These tasks, nowadays performed in increasingly complex situations where patients are relocated from the hospital to their homes at a much earlier stage, are demanding in terms of time and energy.

*You are not going to the patient for a visit of 10 minutes. Sometimes it is possible,..... but yes, to organise things, have some contact with the family, the home nurses and their substitutes.*

In the course of the focus groups, GPs discussed whether some tasks in palliative care could be delegated.

*I want to give the best of myself to it. The way we used to be taught, that a GP was a family doctor, of course it was not brought up in the discussion that you were the coordinator in such a situation. During my years of experience in terminal care, I have indeed developed some doubts about continuing the coordination of care as part of my job.*

Among the participating GPs, there was no consensus about dispensing with the coordinating tasks. On the one hand, some argued that coordination does not belong to the primary GP tasks and ought therefore to be delegated. On the other

hand, the vital importance of comprehensive palliative care was emphasised. The GPs did not know of anybody who could take over some of the tasks and still allow them to maintain continuity of care.

*Palliative care is such a challenge for us, so that if no other solution is possible, we will do it on top of our other tasks. It is not that we would make a mess of it because no one else was available; I would give it the time, but if we can delegate some tasks, we should.*

### *Barriers experienced in daily palliative care*

Following a thorough analysis of our qualitative data, we classified the barriers according to the following levels (Table 3):

- 1) Personal level: Barriers experienced by the GP at the level of competence, emotions or time.
- 2) Relational level: Barriers regarding relationships between GPs and others. Two main themes emerged: communication, and coordination & collaboration.
- 3) Organisational level: Barriers originating from the character, the composition and the functioning of organisations that often play an indispensable part within palliative care. The subcategories within this level are bureaucracy, the organisation of care, and the compartmentalisation of regional and national healthcare.

**PERSONAL LEVEL.** GPs state that competence is a necessary condition in palliative care. They reported several inadequacies concerning both knowledge and skills.

There may be a lack of knowledge in the area of symptom and symptom control and of the existing resources for help. However, GPs are also often ill acquainted with the activities of other care professionals. Another knowledge gap may consist of not knowing about the possibilities of a specific medical or nursing technical treatment in the home situation.

*Sometimes there are situations where you constantly feel: I just don't get all of this!*

GPs acknowledged that they lack not only knowledge, but also certain skills needed to perform a particular medical treatment.

*Just very practical things you run into. People who absolutely do not want to go back to the hospital ..... and they suddenly have retention of the bladder ..... and then you do not manage to insert the catheter.*

GPs experience difficulties in maintaining and delivering up-to-date and adequate knowledge and expertise. Their explanation of this covers several aspects. On a yearly basis, a GP cares for only a few, on average four to six, patients in the palliative phase. These patients can experience an enormous range of different symptoms. Furthermore, GPs sometimes concentrate too much on particular aspects of palliative care at the unintentional expense of overlooking other aspects.

*I am inclined to think, yes, that's it for this patient, I am going to support him - and then I forget the medical- technical part.*

With regard to emotions, GPs found it annoying if other professional workers involved failed to display shared responsibility. Furthermore, GPs have experienced friction between the onerous and labour-intensive coordinating tasks and their assumed primary role of providing treatment and support.

*We take care of everything .... and then maybe the homecare organisation says that something is possible, while in fact suddenly it is not, so it all falls on our shoulders, and we just have to do it all.*

As mentioned above, GPs see themselves as care coordinators. A necessary condition for this task is adequate time. As a result of several barriers on the various levels, palliative care is very time-consuming. GPs do not always have enough time to fulfil their coordinating tasks, so that other parts of their job, for instance supporting the relatives of the patient, are carried out unsatisfactorily.

*Sometimes I have my hands full with the medical-technical aspects and with the spiritual terminal care, as far as it takes shape, and it often conflicts with stupid organisational things, so that you have to fall behind, or everything lands on my plate at the very last moment. .... you know what I mean, Friday afternoon, 3.30!*

**RELATIONAL LEVEL.** Two themes emerged at this level: communication, and coordination & collaboration. Problems in the domain of communication relate to the interaction between the GP and the patient/relative and communication with other healthcare professionals.

It is difficult for GPs to assess whether or not their patients have informed them about all their problems and needs. Furthermore, problematic situations can occur

if patients and relatives are not quite straightforward with each other, through not wanting to admit to each other how much grief they bear.

*For example, at this moment I have a 64-year-old man with a metastasized carcinoma of the prostate..... What I see is that she (his wife, MG), who is 58, is tremendously sad about it and is suffering, too. But it is so difficult, you want to give her attention too, but because he is sitting there, or lying there, it is so difficult to know how far to go ..... In the situation at home it is difficult to handle ..... Inviting her for a visit on her own is onerous, because they have the idea that the one is concealing something from the other partner. But I think I have a guiding rule; I have to be approachable.*

Sometimes, relatives' wishes differ from those of the patient, or the relatives may differ among themselves about certain matters. Another barrier is the relatives' non-expert knowledge.

*Then there are the children, one has spoken to the other and the other has spoken to someone else, and they disagree. So, you have two more practice-visits to align them. That is not to be sneezed at!. .... and her neighbour has cancer of the prostate too and he got this from his doctor, all that kind of stuff!*

Often, there are many professionals involved in palliative care. When a patient is discharged from the hospital, handing over all responsibilities to the GP is not always simple and logical. Hospital doctors may on occasion infringe on GPs' territory.

*The hospital doctors sometimes have difficulties in setting their own limitations. They sometimes start to act as a GP.*

In the case of the involvement of multiple primary care professionals in the palliative phase, not every professional concerned is fully acquainted with the situation of specific patients and their relatives. Even so, a lack of awareness of the activities of other professionals involved is often an obstacle, because of non-optimal communication, coordination, or collaboration.

*What I find annoying is if suddenly, for example, the patient has a stomach catheter and I think oh you should not have done this. ....So I think, such a choice has to be made in consultation.*

Sometimes, the lack of collaboration becomes obvious when a GP wants to discuss the treatment of the patient with another physician from the hospital. Most of the other professionals do not have a clear overall picture of the patient and the patient's situation. The GP then has to build a plan by merging the bits and pieces received from several individual specialists.

*You can get a situation, that is my experience, where one hospital has 10 haematologists or 10 oncologists and if you made a clear agreement with one, the other will brightly pass over it and they could not care less, or they do not know, but ...*

**ORGANISATIONAL LEVEL.** The problems encountered at this level concern the involvement of many people and several different authorities. In addition, rules and regulations (whether written or unwritten) can cause problems. These can be divided into problems concerning bureaucracy, the organisation of care, and the compartmentalisation of regional and national healthcare.

Delay is often considerable before extra care for the patient can be obtained, in spite of the fact that it is absolutely necessary. GPs argued that this delay is caused by bureaucracy and the lack of specialised personnel. The consequences are increased physical and mental burdens placed on family care providers and a more arduous task for the GP.

Arranging and connecting technical machinery is often hindered by bureaucratic procedures, or by the number of people involved.

*A morphine pump really has to be obtained. Immediately, you are confronted with the amount of work accompanying its organisation; the 'Indication Office' has to be involved, as does the specialised homecare team; the pump has to be requested ... and then the patient concerned dies just before the pump arrives.*

With respect to the organisation of care, GPs criticised the continuous changes in the homecare professional workforce. Continuity is impossible, and none of the workers involved is well acquainted with the patients and patients' families.

*I have got the idea that since the austerity policy (of homecare organisations, MG), they firmly put everything onto schedules, so that the feelings of powerlessness have increased.*

Compartmentalisation causes problems for GPs. Many technical tasks, for instance an ascites puncture or the insertion of a drip, can be done in the patient's home. Nevertheless, it seems to be well nigh impossible for skilled hospital

workers to perform such tasks in the home. As a result, very sick or terminally-ill people have to be transferred to undergo a relatively straightforward intervention.

*It is terrible when someone has to be transferred to the hospital again. Ah, that is pain; that is worry!*

**Table 3. Classification of barriers**

Personal level	Relational level	Organisational level
Competence	Communication: <ul style="list-style-type: none"> <li>• GP and patient/relative</li> <li>• GP and other healthcare professionals</li> </ul>	Bureaucracy
Emotions		Organisation of care
Time	Coordination & collaboration	Compartmentalisation of regional and national healthcare

### Discussion and conclusions

GPs described their palliative care tasks as satisfactory and varied, but burdensome. There was little agreement as to whether handing over the coordinating role to another professional would spoil the continuity of care. Palliative care was perceived as typical GP work, considered one of the best parts of the job rather than a source of burnout symptoms. GPs consistently aim to provide high quality care for their patients, but as a result of personal, relational and organisational barriers, fulfilling their tasks according to their own high standards sometimes becomes difficult.

The focus group interviews were effective in eliciting the participants' view of the world in which they operate. The enthusiasm and willingness of the participating GPs stimulated in-depth discussions and enhanced insights into both tasks and barriers. Theoretical saturation is assumed to have been achieved, because during the third group discussion scarcely any new themes were revealed.

The group composition may have presented a limitation. Most (n=15) of the GPs had 11 or more years experience, so GPs with little experience were underrepresented in our groups. This also applies to GPs coming from healthcare centres and solo practices; most of our GPs work in duo or group practices. In the Netherlands the number of solo practices is in decline<sup>4</sup>. We may have gathered a group of GPs with a special interest in palliative care. On the other hand, we assume, on the basis of our study as well as on previous research<sup>2</sup>, that palliative care is interesting and satisfying for most GPs. We therefore presume that our respondents may differ more from their non-responding colleagues with respect to whether or not they are research oriented, and whether or not they wish to exert

an influence on future developments in palliative care by discussing their daily practice.

Since the year 2000, there has been a growth in research concerning GPs and palliative care. With regard to their tasks in this field, the GPs in our study did not report the experience of change or a desire to strive for it. A possible exception concerns the subject of coordination. In general, the GPs stated that they coordinate the palliative care. However, they debated whether this is a GP task. These findings are not consistent with the results of some other studies. Both Field and Cuisnier found that most GPs perceived their role as the coordination of care<sup>23,24</sup>, but on the other hand Van den Muijsenbergh has recently contended that GPs have reconciled themselves to a situation in which the community nurse usually organises palliative care and the GP is a point of reference for problems<sup>25</sup>. What will be the case in future is as yet unclear, but thorough discussion with all the parties involved (including nurses) of the (dis)advantages of palliative care in the home is of importance if a correct, but flexible allocation of tasks is to be achieved.

Several authors have identified barriers in palliative care. However, these have referred to isolated aspects. In general, the treatment of symptoms in palliative care has been evaluated negatively<sup>14,26</sup>; furthermore, two recent surveys in England point towards symptom control as a major educational need from palliative care professionals<sup>27,28</sup>. These findings correspond to some extent with the lack of competence expressed by the GPs in our study with respect to symptoms and symptom control. However, certain comments merit further discussion. Blaming GPs for unresolved problems is not always justified. Patients are sometimes reluctant to tell GPs about their symptoms<sup>29</sup>; they may prefer to put up with uncomfortable symptoms rather than undergo irksome treatment<sup>25</sup>. Furthermore, Van den Muijsenbergh concluded that both the patients and the GPs in her study assumed that several symptoms were not capable of being resolved<sup>25</sup>. These findings are consistent with the difference found between the presence of problems and the need for care in relation to these specific problems<sup>30</sup>. Finally, as Barclay and colleagues state: "GPs cannot be expected to be familiar with the smaller print of all the medical specialities that they encounter in their work. A good GP knows what (s)he does not know, but also knows where to find the answer"<sup>31</sup>.

Caring for patients in the palliative phase accounts for a significant part of the workload for GPs. National explorative research estimates an expected increase of 20% (between 1997 and 2015) in adults with non-acute disorders being cared for and dying in their own homes<sup>32</sup>. In our study, GPs stated that, partly because of

the barriers, palliative care is very time-consuming and that consequently other parts of the job, such as supporting the relatives, cannot be carried out satisfactorily. This issue is an important one, because research has revealed that 25% of the patients are only prepared to discuss their emotions with a doctor when the latter begins such a conversation<sup>33</sup>. Lay carers also expect attention from the GP; they also leave the doctor to take the initiative<sup>34</sup>.

Our findings have uncovered a complex web of barriers hindering GPs' performance of their tasks according to their own standards. Tasks and barriers also seem to be inextricably interwoven rather than separate entities. Certain barriers come into play in accordance with the way in which GPs perceive and perform their tasks. The barriers themselves are closely connected. It may be possible to trace back a problem (lack of knowledge, for example) on the personal level to an isolated knowledge gap, but the problem may well have originated from communication or the compartmentalisation problems.

The principle feature of the concept of palliative care is the provision of comprehensive care for the patient and the patient's family by several professionals acting together. From this perspective, these connections between tasks and barriers seem logical. Palliative care is in itself multidimensional, multiprofessional and complex; disentangling the web and resolving barriers must be approached from this perspective. Furthermore, quantitative insights into the occurrence and differences in level regarding barriers on the various aspects are needed to design tailor-made and effective action. Our study has revealed the domains and component items which can be included in a questionnaire for future research.

There are no standard solutions for the complex problems arising in palliative care, so there is a need to build bridges across the various approaches to quality improvement<sup>35</sup>. One step can be taken by multidisciplinary palliative care consultation teams who can offer GPs the opportunity to acquire knowledge, practical help, and possibly emotional support in caring for specific patients at home.

Modern western culture assumes that dying at home, surrounded by family and friends, is an important feature of a 'good death'<sup>36</sup>. To achieve such a situation and to maintain GPs' feelings of being at ease with palliative care requires the building of several more bridges to make the task of GPs easier and to help them acquire the balance between technical and organisational interventions and a compassionate orientation to their dying patients.



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## Chapter 3

### Determinants of obstacles in primary palliative care

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## **Abstract**

**Introduction:** In order to facilitate GPs in their work and increase the possibilities for patients to remain at home, it is important to find out which obstacles hinder primary palliative care. From previous research we learned about GPs' experienced obstacles. In this survey we aimed to identify the prevalence of obstacles and its determinants.

**Methods:** The prevalence of obstacles and its determinants were identified by a questionnaire. Obstacles were grouped as follows: communication, organisation & coordination of care, knowledge & expertise, integrated care, time for relatives. The potential determinants were GP characteristics and expertise development activities.

**Results:** GPs experienced considerable obstacles in all palliative care aspects. The most prevalent obstacles were: problems with bureaucratic procedures, the time necessary to arrange homecare technology and the difficulties accompanied with the wish or necessity to obtain extra care. 'Number of years of experience', 'region', 'practice setting' and '(multidisciplinary) case discussions' were significant determinants in two or more scale- or item scores.

**Discussion:** In general, more years of GP experience and the participation in (multidisciplinary) case discussions was associated with less perceived obstacles. Based on these results policymakers and practitioners can plan and set priorities in handling the obstacles, choose the (additional) expertise needed in the future and realise the preferred expertise advancement activities.

## Introduction

General practitioners (GPs) increasingly encounter patients requiring palliative care. Medical developments, an ageing population, and a primary-care oriented government policy all contribute to the growing need for palliative care in primary practice<sup>1,2</sup>. GPs value this care provision highly<sup>3</sup>, some even describe it as the epitome of their work<sup>4</sup>. They have usually had a longstanding relationship with their patients and have a good knowledge of the family context. At the same time, palliative care can be described as complex care in terms of both content and organisation; consequently, GPs perceive many obstacles in daily practice<sup>4-7</sup>.

Good primary palliative care is essential, since it allows patients to remain at home as long as possible. It is known that most patients wish to do so and would eventually prefer to die at home among family and friends<sup>8-13</sup>. Nevertheless, as in many industrialised countries with a strong hospital sector, many patients in the Netherlands still die in hospital despite the emphasis on and preference for primary palliative care<sup>8,14,15</sup>. In the year 2003, a third of all Dutch deceased died in hospital, a quarter at home, one fifth in a nursing home and one fifth in homes for the elderly<sup>16</sup>. Transferring patients contrary to their wishes to another, more institutionalised place of care can lead to their disappointment and frustration and also to that of relatives and primary care professionals such as GPs.

There are several ways to support GPs in their primary palliative care, for example by means of the development of good practice frameworks like the Gold Standards Framework (GSF)<sup>17</sup> or the Liverpool Care Pathway (LCP)<sup>18</sup>. In the Netherlands a sizable palliative care developmental programme was launched in the last decade (see Box 1 and 2 for information about the context of primary care in the Netherlands and for information about the developmental programme). Part of this programme was the establishment of Palliative Care Consultation teams (PCC teams) all over the country: teams of experienced professional care providers from different settings giving advice and support to their healthcare colleagues when they encountered problems in daily practice. Knowledge of barriers could contribute to an effective PCC team service provision as well as to the development of other quality improvement activities in palliative care. In order to support GPs in their care of these patients and increase the opportunities for patients to remain at home whenever they so wish, it is important to identify the obstacles that hinder palliative care in daily practice. Several authors<sup>19,20</sup> report the importance of identifying the barriers which have to be eliminated if clinical practice is to be improved; they also recommend that interventions be related to these barriers<sup>21,22</sup>.

### **Box 1. The context of primary care in the Netherlands**

In the Netherlands, healthcare is organised in two echelons. The first consists of primary (community) care; the second of hospital care<sup>14</sup>. Dutch healthcare is characterised by its strong emphasis on primary care. General Practitioners (GPs) play a pivotal part in primary care. Usually, they are the first professional group attending patients with health complaints. The tasks of GPs are a mixture of cure, care, and prevention. Another important part of primary care is homecare. This encompasses nursing care as well as domiciliary care. The need for primary care is increasing, for a number of reasons: the ageing of the population, more small families and singles, the reduction of the length of stay in hospital. In addition to professional care providers, a patient's family and friends also perform nursing and homecare tasks. This voluntary 'informal care' is an important part of the care for sick persons. The costs of homecare and GP care account for over one quarter of the total healthcare budget in the Netherlands<sup>1</sup>.

From a previous qualitative study using focus groups, we learned that GPs experienced barriers on three different levels, namely: personal, relational, and organisational<sup>4</sup>. However, we still do not know the prevalence of the obstacles and neither do we have information on the determinants of the obstacles. So, with reference to this focus group study, we carried out a survey of the obstacles in palliative care as perceived by GPs. In order to give practitioners and policymakers extra grip on planning and setting priorities and choosing the right ways for improvement, insight in influencing factors concerning the obstacles is needed. It is hypothesised that GP characteristics and expertise development activities will influence the occurrence of several barriers. Therefore, the present article describes the results of this survey that aimed to identify the frequency of the various obstacles and its determinants.

### **Box 2. The Dutch palliative care programme**

In 1998 the Dutch Government initiated a five-year stimulation programme in order to improve the quality of palliative care. The programme comprised three main aspects:

- Attention to the structure and organisation of palliative care within the boundaries of regular healthcare
- Stimulation of the promotion of competence of providers of healthcare for terminal patients
- Promotion of insight into the developments in supply and demand of palliative care.

Part of this programme was the establishment of six Centres for the Development of Palliative Care (COPZ). Universities, university hospitals, comprehensive cancer centres and other relevant institutions collaborated in these centres: they were situated in Amsterdam, Groningen, Maastricht, Nijmegen, Rotterdam, and Utrecht. The assignment of the COPZs was to improve the quality of palliative care for terminal patients by means of research, education, consultation, network development, and care innovation.

## **Method**

### *Study design and participants*

A survey was conducted in three regions in the Netherlands. All the GPs practising in these regions (220, 167, and 127 respectively) received written questionnaires together with a covering letter explaining the aims of the study and a stamped addressed return envelope. Reminder letters were sent after one month.

### Variables

The dependent variables in our survey were the perceived obstacles in palliative care. After a rigorous procedure consisting of a qualitative focus group study, a pilot study (n=10 GPs) of the first version of the questionnaire, and preliminary analyses to determine the relevance of items and the underlying factor structure, the perceived obstacles featured in our survey were grouped as follows:

- Communication scale (5 items, Cronbach's  $\alpha$  0.73)
- Organisation and coordination of care scale (4 items, Cronbach's  $\alpha$  0.66)
- Knowledge and expertise scale (5 items, Cronbach's  $\alpha$  0.63)
- Integrated care<sup>a</sup> items (7)
- Time-for-relatives item (1).

Answers could be given on a five-point Likert scale ranged from 'totally disagree' to 'totally agree'. Most items were formulated negatively; originally, only seven of the 22 items were formulated positively, for instance as 'it is easy to.....'. At the end of the questionnaire there was room to add further comments.

The survey of GPs in our study population was arranged according to the following possible determinants:

- *Expertise development.* We ascertained whether GPs had undertaken any activities to develop their expertise in palliative care, had attended any specific educational meetings, (multidisciplinary) case discussions, consultation, or had read the current literature (yes/no).
- *GP characteristics.* We ascertained and classified the number of years of experience (< 1, 1–5, 6–10, > 10), the annual number of palliative care patients ( $\leq$  2, 3–5, 6–9,  $\geq$  10), region (Nijmegen, Arnhem, Gelderse Valley), and we dichotomised gender, practice setting (country or rural town versus (big) city), and practice type (solo practice versus duo- or group practice). We also gathered data on the region, gender, and practice setting of the non-responders.

### Analysis

Descriptive analyses were made of the characteristics of the respondents and non-respondents, the items on expertise development, and the questionnaire scores for the perceived obstacles in palliative care (tables 2, 3, and 4). We reversed the rank responses of the positively phrased questions in the obstacles questionnaire so that responses with a similar meaning have a similar magnitude.

<sup>a</sup> Integrated care: care attuned to the needs of the patient, provided on the basis of the cooperation and coordination of general and specialist care providers, with shared overall responsibility, and the specification of delegated responsibilities<sup>23</sup>.

Non-response bias was assessed by comparing the respondents and non-responders on three publicly-available GP characteristics; gender, region, and the setting of the practice (table 1).

To determine the variation associated with the perceived obstacles in palliative care, a General Linear Model univariate analysis was used to compare scale and item scores by GP characteristics and expertise information. The level of significance was set at  $p < 0.05$ . All statistical procedures were performed with the SPSS 12.0 programme.

**Table 1. Assessment non-response bias**

	Gender	Region	Practice setting
Chi-Square	1.890	1.638	6.835
df	1	2	4
Asymp. Sig	0.169	0.441	0.145

$p \leq 0.01$

## Results

### *Study sample and non-responders (tables 1 and 2)*

Of the 514 questionnaires mailed to the GPs in our study, 320 questionnaires were returned, an overall response rate of 62.3%. The respondents were from 31 to 62 years of age, with a median of 46 years. Most (71.6%) of them were men. A substantial proportion (49.7%) worked in a duo- or group practice; GPs from the two sorts of practice setting were equally represented. More than half of the respondents had worked as a GP for more than 10 years and nearly half of the GPs reported an annual number of about 3–5 palliative care patients.

**Table 2. Characteristics of (non-)respondents<sup>1</sup>**

respondents (N=320)			Non-respondents (N=194)	
<b>Gender</b>				
Women	89	(27.8%)	40	(20.6%)
Men	229	(71.6%)	150	(77.3%)
Missing	2	(0.6%)	4	(2.1%)
<b>Region</b>				
Nijmegen	144	(45.0%)	76	(39.2%)
Arnhem	104	(32.5%)	63	(32.5%)
Gelderse Valley	72	(22.5%)	55	(28.4%)
<b>Practice setting</b>				
Country/rural town	165	(51.5%)	102	(52.6%)
(Big) city	149	(46.6%)	78	(40.2%)
Missing	6	(1.9%)	14	(7.2%)
<b>Practice type</b>				
Solo	90	(28.1%)		
Duo/group	159	(49.7%)		
Missing	71	(22.2%)		



Table 2 continued. Characteristics of (non-)respondents<sup>1</sup>

Number of years of experience		
< 1	2	(0.6%)
1 - 5	27	(8.4%)
6 - 10	62	(19.4%)
> 10	184	(57.5%)
Missing	45	(14.1%)
Yearly number of palliative care patients		
≤ 2	39	(12.2%)
3 - 5	141	(44.1%)
6 - 9	67	(20.9%)
≥ 10	21	(6.6%)
Missing	52	(16.3%)

Ad. <sup>1</sup>: Concerning the non-respondents, only the variables gender, region and practice setting were gathered.

An analysis of the non-responders showed that they did not differ significantly from the respondents regarding gender, region, or the setting of the practice.

### *Perceived obstacles in primary palliative care (table 3)*

Table 3 shows the distribution of GPs who registered their agreement (or disagreement) with the items on the presence of specific obstacles in palliative care. With regard to *communication* with patients and relatives, over 50% of the respondents experienced difficulties in situations featuring mutual disagreement among relatives and the handling of relatives' hidden agendas. Talking about a patient's problems and needs when the patient does not initiate the discussion was not considered particularly troublesome. With regard to the *organisation and coordination of care*, more than 80% of the responding GPs reported problems with bureaucratic procedures within organisations. Arranging homecare technology also seemed to be a source of problems. GPs' opinions were divided on the other two topics in this scale. The main problem regarding *knowledge and expertise* was the GPs' lack of sufficient expertise to enable them to deal with homecare technology themselves. However, the percentage of GPs who did not experience this as problematic was only slightly lower. GPs were most positive about their knowledge concerning possible treatment options; opinions differed when it came to gaining knowledge about the performance of homecare technology. Concerning *integrated care*, GPs reported obtaining extra care for the patient as the most problematic topic. The consecutive involvement of hospital staff and less than full knowledge of other professional care providers' activities involving the patient was seen as the least difficult problem. GPs' opinions differed with respect to the other three topics. Nearly a quarter of the GPs thought that the *time and attention they gave to the relatives* was insufficient.

**Table 3. Perceived obstacles in general palliative care (N=320)\***

<b>Parts</b>	<b>Item</b>	<b>% (strongly) agree</b>	<b>% (strongly) neutral</b>	<b>% (strongly) disagree</b>
<b>Communication with patients and relatives</b>	I find it difficult to handle relatives' hidden agenda	58.8	29.7	11.5
	I have difficulties with a situation in which mutual disagreement within the relatives exist	56.6	23.7	19.6
	I have difficulties if a patient assumes that I automatically know about his problems	49.1	25.9	25.0
	I have difficulties with talking to a patient and his relatives, when they do not want to admit to each other how much grief they bear	35.6	19.9	44.5
	Discussing problems and needs of a patient costs me a lot of trouble when the patient does not start talking about them himself	12.6	18.0	69.4
<b>Organisation &amp; coordination of care</b>	I have troubles with bureaucratic procedures within organisations	83.9	10.7	5.4
	Arranging homecare technology <sup>b</sup> costs me too much time	61.1	20.6	18.4
	It is difficult organising homecare technology	37.5	34.7	27.8
	I need to invest too much time in coordinating tasks	28.6	43.2	28.3
<b>Knowledge &amp; expertise</b>	I lack expertise to perform homecare technology myself	42.3	20.2	37.5
	It is not easy to gain knowledge about the performance of homecare technology	30.2	31.1	38.7
	I am short of knowledge concerning the possibilities within health- and social care	22.1	31.2	46.7
	It is not easy to gain knowledge about treatment possibilities**	20.3	32.4	47.3
	I am short of knowledge concerning possible treatment options**	14.6	34.9	50.5
<b>Integrated care</b>	Obtaining extra care for the patient is difficult**	56.3	20.3	23.4
	I have troubles with changes in the homecare professional workforce	44.8	23.5	31.7
	The transfer (of patient data) from the medical specialist to me is not going well**	35.7	34.7	29.6
	There are no clear appointments about who is the principal doctor in attendance during the palliative phase	33.4	32.5	34.1
	I am not fully acquainted with the possibilities of other health- and social caregivers	28.8	36.1	35.1
	I am not fully acquainted with the activities performed by other health- and social caregivers concerned with my patients	16.5	28.8	54.7
	I have difficulties with consecutive involvement of hospital staff when patient is discharged	10.8	25.4	63.8
<b>Time-for-relatives</b>	<b>In my view I cannot give enough time and attention to the relatives**</b>	<b>23.5</b>	<b>23.8</b>	<b>52.7</b>

Ad. \*: Missing (between 3 – 9 per question) excluded

Ad. \*\*: Reversal of items

<sup>b</sup> Home care technology covers the whole scale from diagnostics, therapeutic aids and procedures. Examples are: a drip or pump for medication or blood, drip feed, oxygen, ascitespuncture

*Expertise development (table 4)*

Nearly all the respondents had read some articles concerning palliative care during the previous year. Consultation with (expert) colleagues in palliative care was also a fairly common resource for expertise development. Attending specific educational courses ranked lower, but nevertheless half the GPs had participated in specific palliative care education.

**Table 4. Expertise development items and scores**

Activities	Yes (%)	No (%)	Missing (%)
Did you read articles about palliative care during the last year?	89.0	9.1	1.9
Did you get advice for palliative questions from one or more regular consultants in the region?	66.6	31.2	2.2
Did you participate in (multidisciplinary) case discussion?	58.4	39.7	1.9
Did you attend an educational meeting regarding palliative care or terminal care during the last year? E.g. course, workshop, conference or network meeting)	52.2	45.9	1.9

*Determinants of perceived obstacles*

Gender, consultation, and reading the literature did not have any influence on the quantity of obstacles perceived in palliative care. The other GP characteristics and expertise variables were significant contributors to one or more of the three scales or eight separate item scores.

More years of experience as a GP and attending specific educational meetings were associated with the experience of fewer obstacles in *communication* with patients and relatives. Having a larger number of palliative care patients per year was related to fewer obstacles in *knowledge and expertise*. Similarly, participation in (multidisciplinary) case discussions was associated with fewer obstacles on the knowledge and expertise scales. Table 5 also shows that GPs working in two regions and also in the cities reported more obstacles concerning knowledge and expertise and with regard to obtaining extra care for the patient. None of the independent variables in our model was related to the obstacles within the *organisation and coordination of care* scale. With regard to *integrated care*, participating in (multidisciplinary) case discussions and number of working years were also associated with the reporting of obstacles. This association was however contrary to what was expected; participating in (multidisciplinary) case discussions was related to more problems associated with 'changes in homecare professional workforce' and 'consecutive involvement of hospital staff after discharge'.

Table 5. Determinants of differences in perceived obstacles

<b>Communication scale</b>				
<b>Contributing Variables</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
Number of years of experience	< 1	-3.5	11.0	ns
	1 tm 5	-2.0	12.8	0.00
	6 tm 10	-1.2	13.8	0.01
	> 10		15.0	
Specific educational meetings	No	-0.8	14.0	0.04
	yes		14.8	
<b>Organisation &amp; coordination of care scale</b>				
<b>No contributing variables.</b>				
<b>Knowledge &amp; expertise scale</b>				
<b>Contributing Variables</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
Yearly number of palliative care patients	≤ 2	-2.8	14.0	0.00
	3 tm 5	-1.1	16.2	0.05
	6 tm 9	-1.4	16.2	0.03
	≥ 10		17.5	
Region	Nijmegen	-0.9	15.7	0.03
	Arnhem	-0.9	15.8	0.02
	Gelderse Valley		16.5	
Practice setting	country/ rural town	0.9	16.4	0.01
	(big) city		15.3	
(Multidisciplinary) case discussions	no	-1.5	14.8	0.00
	yes		16.7	
<b>Integrated care</b>				
<b>Changes in homecare professional workforce</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
(Multidisciplinary) case discussions	no	0.23	3.0	0.05
	yes		2.7	
<b>Transfer (of patient data) from medical specialist</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
Number of years of experience	< 1	-0.51	2.5	ns
	1 tm 5	-0.12	2.9	ns
	6 tm 10	-0.38	2.6	0.00
	> 10		3.0	
<b>Consecutive involvement of hospital staff after discharge</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
(Multidisciplinary) case discussions	no	0.26	3.7	0.01
	yes		3.5	
<b>Obtaining extra care</b>				
<b>Contributing Variables</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
Region	Nijmegen	-0.7	2.4	0.00
	Arnhem	-0.5	2.6	0.00
	Gelderse Valley		3.0	
Practice setting	country/ rural town	0.2	2.7	0.03
	(big) city		2.5	

Table 5 continued. Determinants of differences in perceived obstacles

<b>Integrated care (continued)</b>				
<b>Acquainted with the possibilities of other caregivers</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
Number of years of experience	< 1	-1.2	2.0	0.05
	1 to 5	-0.3	2.9	ns
	6 to 10	-0.2	3.0	ns
	> 10		3.2	
<b>Acquainted with activities by other caregivers</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
(Multidisciplinary) case discussions	no	-0.3	3.2	0.00
	yes		3.5	
<b>Time-for-relatives</b>				
<b>Give enough time and attention to the relatives</b>				
<b>Contributing Variable</b>		<b>B</b>	<b>Mean</b>	<b>Significance</b>
(Multidisciplinary) case discussions	no	-0.4	3.1	0.00
	yes		3.5	

## Discussion

GPs encounter formidable obstacles in all aspects of palliative care. The most frequent obstacles are problems with bureaucratic procedures within organisations, the time required to arrange homecare technology, and the difficulties accompanying the wish or the necessity to obtain extra care for the patient.

More years of experience as a GP and participation in (multidisciplinary) case discussions in general is associated with fewer perceived obstacles. Several previous studies have shown that education sometimes has small or no effect at all<sup>24-26</sup>; our association, however is not only at the level of ready knowledge, but more in terms of the better handling of problematic and complex situations. Furthermore, the positive relations mostly came from the participation in case discussions, a very specific form of education because of the high level of interaction between the participants and the fact that the topic directly comes out of daily practice. In general terms, the mean differences on the obstacle scales and items related to GP characteristics and expertise on the obstacles experienced are relatively small. It might be interesting to examine whether other factors such as organisational aspects (adding specialised nurses to the primary palliative care team, for example) or legislation and regulation have any influence on the obstacles experienced.

The practice has become established in our healthcare system for healthcare professionals from different institutions to collaborate on complicated care issues<sup>27,28</sup>. Such collaboration could lead to a decrease in the number of obstacles

encountered. In one region we found fewer obstacles, possibly as the result of such arrangements. Furthermore, the mutual disagreement about some obstacles might also be attributable to these (multidisciplinary, integrated) care arrangements. This should be kept in mind when using the results of our study for (the prioritising of) improvements in daily practice. Further exploration and specification of this problematic topic is needed; the method of approach should relate to whatever (groups of) professionals have already developed and the methods they have chosen for the improvement process.

The GP characteristics and expertise development activities of GPs had no significant influence on the organisation and coordination of care problems. This result seems to be logical for, say, the use of homecare technology; this is infrequently used, so the necessary skills are difficult to develop, even for experienced GPs. The same argument applies to bureaucratic procedures within organisations. Procedures are often very complex and they change as legal or financial scope differs in the course of time. Decreasing these obstacles seems to ask for other interventions. Focusing on organisation and coordination of care obstacles however is important given their magnitude.

A limitation of our survey is that it displays only the GPs' perspective of potential obstacles in the daily practice of palliative care. Professionals from other disciplines, and the patient and patient's family, may have different views about obstacles. In primary palliative care the patient is often surrounded by a multitude of different, frequently changing professionals and volunteers. Notwithstanding the very important role in primary practice of, for instance, district nurses, usually GPs constitute the main stable, continuing factor. If primary care remains the preferred place to be in the last phase of life and GPs continue to play a pivotal part in palliative care, keen observation of the problems experienced is important for future developments. Developments in primary care (like the increase of GPs' out-of-hours-organisations and the boundaries concerning informal care<sup>29,30</sup>) and the existence of the huge barriers like we found demand for a broad debate concerning the (near) future of primary palliative care and the ways in which this focus on primary care remains feasible.

The results of this study provide a basis for policymakers and practitioners to plan and set priorities in handling the obstacles, choosing the (additional) expertise needed in the future, and achieving the preferred expertise advancement activities. Practice-oriented education, given by GPs experienced in palliative care on demand and at the bedside, combines a number of obstacle-decreasing factors. The provision of such support might be one of the actions capable of

leading to a situation in which more patients remain at home to be cared for by GPs who are sufficiently equipped and supplemented by specialist backup.

Another way of coping with the obstacles experienced might be the establishment of institutionalised consultation services. Following our survey, more than 20 Palliative Care Consultation teams (PCC teams) were set up to operate throughout the Netherlands, replacing the non-institutionalised *ad hoc* arrangements current at the time of our survey. A recent study has shown that half of all requests for consultation with PCC teams come from GPs, who fairly frequently request advice concerning organisational problems (such as the use/availability of material and equipment)<sup>31</sup>. Our survey refers to the consultation activities in the period preceding the establishment of these teams. The results reported in this PCC team study seem to be positive, although a repeated or complementary survey might yield more clarity concerning the possible contribution of PCC teams in the eradication of obstacles. Within the foreseeable future, we will be able to report about this survey.

A thoroughly considered palliative care action programme for the coming years, accompanied by support in the sphere of (temporary) staff and finances, will improve palliative care in general. This would have a positive effect on the GPs who consider palliative care as the epitome of their work as well as the patients and their families who want to end their lives at home in a humane and personal way.

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## **THEME II**

### **EXPERIENCES OF PATIENTS AND INFORMAL CARE PROVIDERS**

## Chapter 4

### Quality of primary palliative care: experiences of patients and their informal care providers

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## **Abstract**

**Objective:** To describe the quality of primary palliative care from the perspective of the patient and the patient's informal care provider.

**Design:** Observational study

**Setting:** Primary palliative care

**Participants:** 32 patients and 27 informal care providers selected by 34 general practitioners (GPs)

**Main Outcome Measure(s):** The Quality of Palliative Care – Questionnaire (QPC - Q): 16 items to be scored on a 5-point rating scale.

**Results:** Both patients and informal care providers were positive about their experiences with the concrete aspects of care. Both groups rated the GP at the highest rank; the patient can always appeal to the GP. Both groups criticized the delay in acquiring care or material/equipment for care owing to the rules and procedures of organisations. In general, the opinions of the informal care providers were more critical.

**Conclusions:** Patients in primary palliative care and their informal care providers are of the opinion that the level of palliative care in primary practice is fairly good. Despite this overall positive judgement, both critical comments and positive findings are important input for the planning of improvements. Much can be done to support informal care providers in their difficult and often exhausting task. Professional energy must also be invested in the clarification of the differences in the judgements of the patients and the informal care providers. Such clarification may lead to a more stable basis for patients to end their lives at home and for relatives to care for them without feeling completely overburdened.

## Introduction

This paper describes the primary palliative care from the perspectives of palliative care patients and their informal care providers. Usually, palliative care patients prefer to stay in their own homes and end their lives there<sup>1-6</sup>. During the last few decades, national healthcare policy in the Netherlands, as in many other countries, has encouraged the location of palliative and terminal care in primary care<sup>7</sup>. This focus on primary care requires an increase in the competence, expertise, and skills of the professional care providers working in this first echelon: general practitioners (GPs) and district nurses<sup>8,9</sup>. However, despite this policy and the expected increase in palliative care patients cared for and dying in their own homes<sup>9</sup>, most primary care professionals will only see a limited number of palliative care patients per year<sup>10,11</sup>. This limitation forms an obstacle for the building up of palliative care expertise.

Palliative care at home also places an increased care-giving responsibility on the family and friends of sick patients. On average, each Dutch terminal patient is supported by two informal care providers, often the partner or child(ren)<sup>12</sup>. Most informal care providers are very motivated; at the same time, they are often overburdened<sup>13</sup>. Professionals must therefore also pay attention to the problems and needs of informal care providers<sup>12,14,15</sup>.

In order to support both the patients and their informal carers, it is important for primary care professionals to understand the physical and emotional situation and the experiences of all concerned with the care given and received. At the time we conducted our study, this topic has rarely been studied in primary care; most research has been of palliative care patients in a hospital or hospice. The research that has been conducted in primary care has usually concerned specific topics such as experiences with out-of-hours care<sup>16-18</sup> or hospital/hospice at-home services<sup>19-21</sup> or have used informal care providers as proxies for the patient's own evaluation<sup>22,23</sup>.

Research regarding palliative care patients encounters all kind of difficulties<sup>24,25</sup>, such as problems in recruiting patients and patients having difficulty in completing questionnaires or interviews because of their weakness. We conducted a study to assess the quality of primary palliative care from the perspective of the patient and the patient's informal care provider; we also evaluated the recruitment and surveying of these patients.

## **Methods**

### *Design*

An observational study was undertaken in the period 2001-2003 as part of a larger study of healthcare status, quality of life, and healthcare utilisation among primary palliative care patients and their informal care providers; the study has been partly reported elsewhere<sup>26</sup>. The study was one element in a national programme aimed at improving the quality of palliative care. In this study, we collected qualitative and quantitative data from palliative care patients in primary care and, if present, from an important informal care provider.

### *Subjects*

*GPs.* At the start of the study, all eligible GPs in an eastern part of the Netherlands (n = 269) were approached to arouse their interest in the study. All the GPs were telephoned by a researcher (ED, NH, MG). Whenever they wished, we visited their practices to give further explanation and to encourage them to participate. Ninety-six GPs finally agreed to do so. Every two months we contacted them or a member of their surgery staff to remind them of the study and ask for potentially suitable patients.

*Patients.* Inclusion criteria were: (I) patients had to be  $\geq 18$  years of age; (II) their life expectancy was 6 months or less according to the GP; (III) they may still be receiving treatment, radiotherapy or chemotherapy, for example, to control their symptoms, but they must be aware of the fact that the treatment intentions are palliative; and (IV) the patients had to give informed consent. The medical ethics committee of the University Medical Centre approved the study design.

When patients were indicated as possible participants, the GPs gave them an information leaflet and a reply card. Only when patients had returned this card to the research team were we able to contact them to give them further information about the study or make an appointment for a timely home visit. On the basis of the number of GPs in our region and the number of palliative care patients a GP normally cares for per year, combined with the expected difficulties in such a study, our intended sample size was 100 patients.

### *Quality of Palliative Care – Questionnaire (QPC–Q)*

Since satisfaction questionnaires are often too abstract and too global for patients in the last phase of their lives, we developed the Quality of Palliative Care – Questionnaire (QPC–Q) ourselves. This questionnaire was based on a literature study and the clinical palliative care experience of the researchers. In addition, 5

experienced GPs reviewed the instructions, formulation (clear and unambiguous), and completeness of the first version of the QPC-Q. The result was a 16-item questionnaire with a 5-point scale concerning specific aspects of palliative care. Every item has a possible range from 1 (totally disagree) to 5 (totally agree); high scores mean better quality of care experienced by the patient or the informal care provider.

### *Data collection*

Patients were visited at home by a researcher (KJ, ED, MG). They filled in the questionnaire and were interviewed about their disease history, sociodemographic variables, health characteristics, and healthcare utilisation. When patients were too weak to fill in the list alone, the researcher read out the questionnaire items. When informal care providers were present and participating in the study, they completed the questionnaire on their own. The informal care providers were interviewed with respect to their health characteristics and experience in caring. All the data were entered into a computerised database that provides data for several studies<sup>26</sup>.

### *Data management and analysis*

The analyses were performed using SPSS 12.0.1. for Windows. We used frequencies and proportions to study the characteristics of patients and informal care providers. With regard to the QPC-Q, we calculated group means. In order to find out whether the members of the pairs (patients - their informal care providers) differ from each other as groups in their assessment of the quality of palliative care, we used the non-parametric Wilcoxon signed ranks test; a type I (alpha) error level of 0.05 (two-tailed) was used to indicate a statistically-significant difference.

## **Results**

### *GPs*

At the beginning of the study, 96 GPs agreed to participate (36%). During the study, 21 GPs (22%) withdrew their participation through loss of interest, retirement, lack of time, or having a disease themselves. At the end of the study, 75 GPs were still participating; however only 34 identified one or more patients.

*Patients and informal care providers (table 1, 2 & 3)*

In total, 54 patients were registered for the study. Of these, there were 13 the researcher did not interview. Some patients refused to participate, others were too ill at the moment of the home interview, and some had already died in the period prior to the interview. Of the remaining 41 patients, 32 completed all the research parts necessary for this study.

We collected data from 24 pairs of ‘patient – informal care provider’; not all the pairs were spouses. For 8 of the 32 patients, we were unable to interview an informal care provider; there was no one (anymore), the informal care provider did not want to participate, or they were ill themselves. In addition, we interviewed 3 informal care providers whose patients participated in the study, but who were unable to fill in the necessary research parts because of their own illness.

Most patients were women and less than 70 years of age. One quarter of all patients suffered from breast cancer; lung- and colon cancer were also diagnosed fairly often. Patients valued their overall quality of life between 4.7 and 8 (average 6.4), on a scale from 0–10 (table 1).

**Table 1. Characteristics of patients (n=32)**

<b>Gender</b>	<b>N</b>	<b>%</b>
Women	22	68.8%
Men	10	31.3%
<b>Age</b>		
< 70	25	78.1%
≥ 70	7	21.9%
Missing	-	-
<b>Diagnosis</b>		
Breast cancer	8	25.0%
Lung cancer	5	15.6%
Colon cancer	4	12.5%
Pancreas cancer	3	9.4%
Other	12	37.5%
<b>Prognosis</b>		
> 1 month	21	65.6%
Unknown	5	15.6%
Missing	6	18.8%
<b>McGill Quality of Life score*</b>	<b>Mean</b>	<b>Min - max</b>
Physical symptoms	3.9	0 – 10
Physical well-being	5.1	0 – 10
Psychological well-being	7.1	1.5 – 10
Existential well-being	6.9	3.8 – 10
Support	8.5	5 – 10
Overall score	6.4	4.7 – 8

Ad : McGill comprises 5 sub-measures (physical symptoms, physical well-being, psychological well-being, existential well-being, support). The mean score on all sub-measures have a possible range from ‘0’ (worst situation) to ‘10’ (best situation).



On average, patients suffered from 14 different symptoms (ranging from 5–26). Among the symptoms that bothered them the most were lack of energy, feeling sad, pain, shortness of breath, and difficulty with sleeping. Most patients had had contact with their GP during the previous 2 weeks; 40 percent of them contacted a clinical specialist in that period and a third of them received help from a district nurse. Only a few patients received some help from an organisation of volunteers (table 3).

**Table 2. Care consumption by patients in primary palliative care (n=32)**

<b>Care consumption items over last 2 weeks</b>	<b>Yes</b>	<b>%</b>	<b>No</b>	<b>%</b>
Did you have contact with your GP?	28	87.5	4	12.5
Did you have contact with any clinical specialist?	13	40.6	19	59.4
Did you obtain help from a district nurse?	11	34.4	21	65.6
Did you obtain (additional) paid home help?	8	25.0	24	75.0
Did you obtain any medical- or nursing devices in you home?	7	21.9	25	78.1
Did a family member resign from his/her job or take care leave to care for you	5	15.6	27	84.4
Have you temporarily been admitted to a hospital, nursery home or hospice?	4	12.5	28	87.5
Did you use a taxi because of your illness?	3	9.4	29	90.6
Have you been taken to hospital by an ambulance?	2	6.3	30	93.8
Did you obtain help from an organisation of volunteers?	2	6.3	30	93.8

The informal care providers were most often the patient's partner. There were somewhat more male than female informal care providers. Nearly 40 percent of the informal care providers scored  $\geq 16$  on the CES-D depression scale, indicating potential depression. The mean scores on state-anxiety as well as trait-anxiety can be interpreted as moderate. Informal care providers scored just under the score that can be assumed to be a clinical indicator of tiredness (table 2).

**Table 3. Characteristics of informal care providers (n=27)**

	<b>N</b>	<b>%</b>
<b>Gender</b>		
Women	12	44.4%
Men	15	55.6%
<b>Age</b>		
< 70	20	74.1%
≥ 70	3	11.1%
Missing	4	14.8
<b>Relation informal care provider to patient</b>		
Partner	23	85.2%
Children (in law)	4	14.8%
<b>CES-D (depression)<sup>*</sup></b>		
Score < 16	17	63.0%
Score ≥ 16	10	37.0%
	<b>Mean</b>	<b>Min - max</b>
Overall score	15.3	2 - 36
<b>STAI (anxiety)<sup>**</sup></b>		
	<b>Mean</b>	<b>Min - max</b>
State-anxiety	42.8	24 – 68
Trait-anxiety	41.3	24 - 64
<b>CIS (individual strength)<sup>***</sup></b>		
Subjective feeling of tiredness	29.4	8 – 56
Concentration	17.1	5 – 29
Motivation	15.3	4 – 28
Activity	8.9	3 – 21
Overall score	70.7	20 - 128

Ad : CES-D (Centre for Epidemiologic Studies - Depression) comprises 20 items. Every item has a possible range from 0 (seldom or never) to 3 (almost or always); high scores mean more feelings of depression. People scoring ≥16 can be seen as 'possible cases'

Ad<sup>\*\*</sup> : STAI (State-Trait Anxiety Index) comprises 2 sub-measures (state-anxiety and trait-anxiety). Both sub-measures have a possible range from 20 to 80; high scores mean more anxiety and low scores mean less.

Ad<sup>\*\*\*</sup> : CIS (Checklist Individual Strength) comprises 4 sub-measures (subjective feeling of tiredness (8 items), concentration (5 items), motivation (4 items), activity (3 items)). Every item has a possible range from 1 to 7; high scores mean less feelings of individual strength.

### *Experienced quality of care (table 4)*

Both patients and informal care providers were positive about their experiences with concrete aspects of care. Both ranked the GP the highest; the patient could always make an appeal to him/her. The time taken by professional care providers for the patient was also judged positively. Both groups criticised the bureaucracy, in particular the delay in acquiring care or material/equipment for care owing to the rules and procedures of organisations. The opinions of the informal care providers were in general more critical. However, when comparing the patient – informal care provider pairs, only three of the differences in score were found to be significant.

**Table 4. Quality of care in primary palliative care**

Ranking patients (n=32) quality of care-items	P-mean (group)	Ranking informal care providers (n=27) quality of care-items*	N-mean (group)
I can always make an appeal to my GP***	4.52	I can always make an appeal to my GP***	4.48
My district nurse can always be called on	4.43	My professional care providers take time for me	4.19
My professional care providers are prompt and sufficiently acquainted with (changes in) my situation	4.39	My professional care providers pay attention to my feelings	4.12
My professional care providers make me feel comfortable during care and treatment***	4.37	One of my professional care providers is my focal point in the event of questions and/or problems	4.12
Whenever I need (extra) care, I will have it***	4.37	I am being cared for by a fixed group of professional care providers	4.09
One of my professional care providers is my focal point in the event of questions and/or problems	4.34	I am sufficiently involved in decisions in care and treatment	4.08
My professional care providers listen to my wishes	4.32	My professional care providers listen to my wishes	4.04
When I need care or material/equipment for care, these can soon be arranged	4.32	When I need care or material/equipment for care, these can soon be arranged	4.04
My professional care providers take care of the necessary arrangements and material/equipment so as to make me as comfortable as possible	4.32	My professional care providers make me feel comfortable during care and treatment***	4.00
My professional care providers take time for me	4.31	My professional care providers are sufficiently acquainted with care given by other disciplines	4.00
I am sufficiently involved in decisions in care and treatment	4.29	My professional care providers take account of the needs, difficulties, and possibilities of my family and friends	3.92
My professional care providers take account of the needs, difficulties and possibilities of my family and friends	4.29	My professional care providers are timely and sufficiently acquainted with (changes in) my situation	3.92
My professional care providers pay attention to my feelings	4.19	My professional care providers take care of the necessary arrangements and material/equipment so as to make me as comfortable as possible	3.91
I am being cared for by a fixed group of professional care providers	4.17	My district nurse can always be called on	3.87
My professional care providers are sufficiently acquainted with care given by other disciplines	4.04	Whenever I need (extra) care, I will have it***	3.76
Acquiring care or material/equipment for care is often delayed owing to the rules and procedures of organisations**	3.39	Acquiring care or material/equipment for care is often** delayed due to rules and procedures of organisations	3.40

Ad : in the questionnaire for the carers, the statements are formulated so as to refer to the patient

Ad \*\*: for the purposes of uniformity in the scores, for this statement the scores are reversed

Ad \*\*\*: in the significant differences between pairs of patients and their informal care providers for these three items, the carers' scores are significantly lower than those of the patients

The sequence of QPC-Q items in table 4 is based on the mean scores for the group of patients or of the informal care providers. The differences in sequence between these two groups are striking. The most conspicuous differences were the ranking of the items concerning the district nurse (patients ranked their care second best, informal care providers 14<sup>th</sup>), receiving extra care whenever necessary (patients 5<sup>th</sup>, informal care providers 15<sup>th</sup>), professional care providers being timely and sufficiently acquainted with (changes in) the patient's situation (patients 3<sup>rd</sup>, informal care providers 12<sup>th</sup>), and being cared for by a fixed group of professional care providers (patients 14<sup>th</sup>, informal care providers 5<sup>th</sup>). With the exception of this last item, the informal care providers were more critical.

## Discussion

Patients in primary palliative care and their informal care providers are positive about the care provided. They were the most positive about the patient's GP and the most critical about the bureaucracy within organisations that has to be dealt with in acquiring material or equipment for (extra) care. However, patients and informal care providers sometimes differ considerably in their views. These findings are important, because of the number of patients who (want to) die in their own homes and the policy of stimulating palliative and terminal care in primary care.

Primary palliative care is known to be a complex, extensive, but rewarding experience<sup>10,27</sup>. GPs only see a limited number of palliative care patients per year, but the time and energy devoted to them is considerable. The patients and informal care providers in our study seem to appreciate this dedication by their GPs. This finding is in line with the high overall satisfaction with palliative care provided by GPs reported in a study using the views of carers as a proxy measure<sup>22</sup>. The problem of bureaucracy scored lowest of all the quality-of-care items; this corresponds with the recently reported findings of GPs themselves<sup>28</sup>.

Palliative care patients and their informal care providers are a 'captive audience'<sup>24,25,29</sup>; they are dependent on healthcare and healthcare providers and this dependence may have influenced their evaluations of care. The findings in our study must therefore be interpreted while bearing this possibility in mind.

A particularly interesting aspect of this study that deserves special attention is the recruitment of patients for participation. We are dealing with a particularly difficult group to include in research. Despite all our efforts, at the end of the inclusion period, data were only available for 32 patients and 27 informal care

providers. During the study, we asked the participating GPs about the reasons for the difficulty of inclusion of palliative care patients and how to improve it (box 1).

**Box 1. Reasons for laborious inclusion and suggestions for improvement**

**Reasons GPs mentioned why they did not approach patients for the study:**

- forgetfulness
- estimating life expectancy according to inclusion criteria is difficult
- patients are not suitable according to the GP, because of their poor (cognitive) condition or vulnerability and the complexity of the situation
- unclear study aims
- this study does not seem to be useful
- this study is too confrontational for my current palliative care patients

**Opportunities for improving inclusion (according to GPs):**

- remind me on a regular basis of the study
- remind my (practice) assistant on a regular basis
- utilise other resources for inclusion, for example clinical physicians or GPs in other regions

They mentioned various types of GP- as well as patient-related reasons, ranging from the presumed vulnerability of palliative care patients to difficulties with estimating life expectancy or their own forgetfulness.

The problems surrounding the recruitment of patients lie at the heart of palliative-care-patient research in primary care. We are firmly of the opinion that it is essential to include the patient perspective in studies on quality of care; this is increasingly considered an important component in comprehensive disease management<sup>15,30-32</sup>. The remarks made by the patients in our study strengthened our opinion. In our study, access to the patients was negotiated through their GPs. Since they play an important part in the daily care of palliative care patients, the GPs seemed to be understandably concerned about 'bothering' patients and families at such a time<sup>33</sup>. Participation carries the risk of depriving patients of the energy and time they could have used to complete 'unfinished business' and to be with their families. This gate keeping by GPs takes away from patients the opportunity to make autonomous, informed decisions about research participation. The above-mentioned issues are, however, not unique to the end of life. We agree with Casarett and colleagues that there is no reason to consider palliative care as a special case in which the established ethical principles and guidelines do not apply<sup>34</sup>.

How then can we improve the participation in research of primary palliative care patients without the intention of taking over from or ignoring the GP? In this type of study, much more energy needs to be invested in the relationship between the researcher and the GP in order to convince the GP of the necessity of the study and of the expertise and sympathy of the researchers. Researchers can assist in

the identification of possible participants, for example by means of screening the records at a GP's surgery. Furthermore, other professionals (district nurses or professionals concerned with a patient's discharge from hospital to home) might play a part in nominating possible palliative care patients.

Notwithstanding the problems encountered in our study, the results provide a basis for the optimisation of primary palliative care as a further line of research. Let us consider three important aspects. It is known that the situation of palliative care patients can change suddenly; the results of the present study are just a cross-sectional snapshot. It is important to follow palliative care patients over time in order to trace changes in their experience and to explore the possibility of linking these changes to patient characteristics.

Informal care provision is a critical element of palliative home care<sup>35</sup>; seriously ill patients have most of their care needs met by family and friends and not by paid assistants or volunteers<sup>36</sup>. The informal care providers in our study value the quality-of-care aspects somewhat less right down the line. Furthermore, the overall scores on depression, anxiety, and tiredness may indicate that their efforts carry significant burdens. Despite their readiness to give informal care and the positive aspects associated with it<sup>37</sup>, relief for informal care providers must be appropriately organised by means of early, timely, and regular voluntary support. Palliative day care facilities might also be an option. The respite value of day care is reflected in the phrase "a day out for the person afflicted with a chronic or terminal illness, and a day off for the caring relatives or friends in the home"<sup>38</sup>.

Furthermore, it is important to be alert to the differences between patients and informal care providers in their judgement of quality-of-care items. Merely communicating these differences might lead to a more open situation, room for the exchange of experiences and feelings, and better understanding. For example, the large rating difference concerning the district nurse item might be reduced with a little more professional nursing support resulting in more time and quietness to be the patient's loved one instead of only acting as nurse and housekeeper.

For a substantial group of palliative care patients, completing their lives in their own homes is of great importance. Policy makers, researchers, and practitioners now have at their disposal data capable of forming a basis for improvement projects.

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## Chapter 5

### Living on borrowed time: Experiences in palliative care

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## **Abstract**

**Objective:** To gain insight into the experiences of a palliative care patient and her husband who were living on borrowed time.

**Methods:** A qualitative single case design was used. Systematic content analysis of the interview data, obtained in an in-depth semi-structured interview, from the husband and wife was conducted to extract themes relating to living on borrowed time.

**Results:** Three themes were identified: shifts in the interpretation of physical signs and symptoms, altered view of the future and altered choices and priorities.

**Conclusion:** The identified themes lead to a better understanding of the phenomenon of living on borrowed time. Yet, refinement of, and variation within the themes still need to be studied in order to get more grips on the themes and to be better able to help patients to integrate the 'new reality'.

**Practice implications:** Our findings can be used to support professionals in the practical application of care when their patients need to integrate the 'new reality' and seek new equilibrium, e.g. converted into a conversational guide, or used for educational purposes.

## Introduction

A growing number of people require palliative care<sup>1</sup>, which increases the need for professionals who are able to meet the special needs of these patients. In palliative care, all efforts aim to improve quality of life<sup>2</sup>. However, attention should also be paid to the quality of the process of dying<sup>3,4</sup>, because it forms an inextricable part of palliative care. In many cases, professionals have difficulty predicting the life expectancy of their patients<sup>5</sup>, but generally, the last phases of illness follow the same broad outlines<sup>6</sup>.

Sometimes, a situation arises in which survival is surprisingly much longer than expected, without any spontaneous regression of the underlying disease. Then the patient, family and care providers gradually become aware that they must find ways to deal with the new, unexpected and often unpredictable situation of living on borrowed time. With the term “borrowed time” we do not only refer to living much longer than was expected but also to another perspective of these extra time; time to live in stead of time to prepare for death.

In the large volume of literature on experience in palliative care, we did not find any studies on how people handle this new situation and cope with the different perspective to the future. Based on a single case history, we made an in-depth exploration of what the meaning is of living on borrowed time and how people respond to this. A qualitative case analysis is appropriate to study experiences and beliefs surrounding a topic that is still poorly understood<sup>7</sup> and can therefore be used to start developing a concept. A second aim of the study was to derive key themes for further research into living on borrowed time, or for educational purposes.

## Methods

### *Design*

We used a qualitative single case study design; a method that relies on the ‘natural experiment’ in order to understand human functioning<sup>8</sup>. The data were obtained by means of an in-depth semi-structured interview with the patient and her husband, carried out by two of the researchers (ED & MG). This interview lasted about 2.5 hours. A short topic list was used as an interview guide (Box 1), based on a literature study on related topics and the personal experience of the first two researchers (both experienced nurses). The interview was audiotaped with the participants’ consent. Furthermore, one of the researchers took notes in case the audiotape installation failed. The interview took place at the patient’s home and we interviewed the patient and her husband together. Because of the

openness in their relationship, we had decided that separate interviews were not necessary. Written informed consent to participate in this study was obtained from the patient and her husband. Names and other identifiable characteristics have been changed to safeguard confidentiality.

**Box 1. Interview topics**

- Description of case history up to and including the breaking point
- Experience with living on borrowed time: physical, psycho-social, spiritual, relations
- Future prospects
- Bidding farewell
- New equilibrium
- Support strategies
- Factors that contribute to a new phase

***Data analysis***

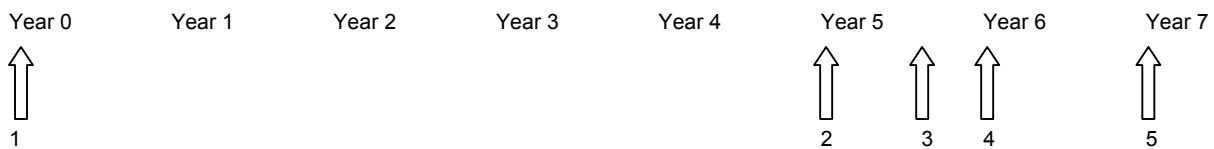
The audiotape of the interview was transcribed for analysis. The patient and her husband went through the transcript; they reported that the text was complete and they did not add or remove any information. Systematic content analysis<sup>9</sup> was performed by two of the authors independently of each other (MG & ED) to ensure reliability. Emerging themes were revealed by repeated study of the transcripts and the assignment of codes to text segments. A framework was built from the interview data and gradually refined by grouping related categories. We seek to uncover relevant conditions and determine how the actors respond to the changed condition (the borrowed time), to the consequences of the changed conditions and to catch this interplay<sup>10</sup>. The researchers compared their findings and, if necessary, consensus was reached by discussion.

***The case of Mrs. Johnson (time frame, see Fig. 1)***

Mrs. Johnson formed the focus of this study. She is a 63-year-old, slight, briskly talking woman who lives with her 60-year-old husband in a detached house in a small city. Mr. and Mrs. Johnson have two daughters with whom their relationship is good. Mrs. Johnson had been diagnosed with cancer of the colon 7 years before the interview (1). In the course of time, the tumour had disseminated to the lungs and caused total obstruction of one lung. This resulted in recurrent pneumonia that required the continuous use of antibiotics and occasional oxygen. Five years after the initial diagnosis (2), her condition deteriorated with severe dyspnoea, events of high fever and all medication made her vomit. At the end of that year (3), her hospital specialist had told her the bad news that they did not know of anything that could improve her situation. Owing to the seriousness of her illness, Mrs.

Johnson cared increasingly less about living. In the end, her general practitioner tried a new way of administering her antibiotics and suddenly the vomiting stopped. Her situation improved visibly and her will to live returned.

**Figure 1. Time frame**



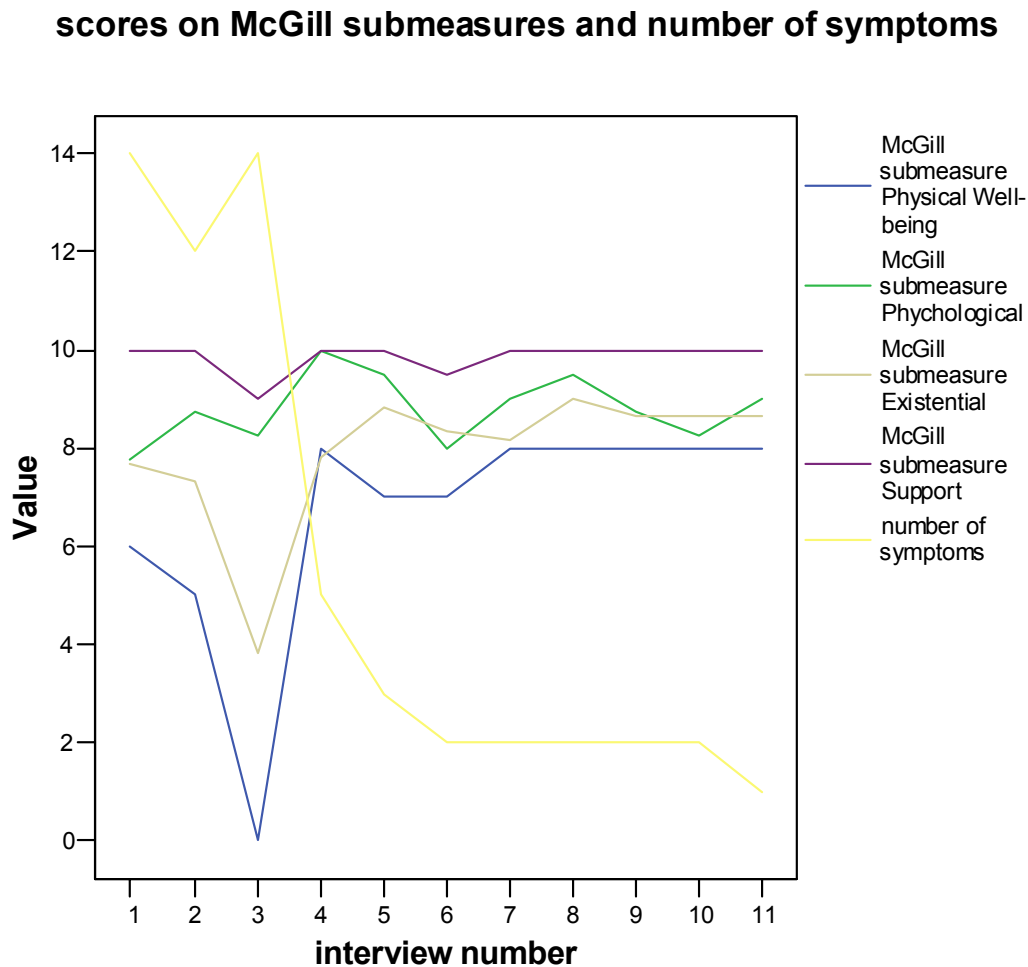
During the first few months of the new year (4), her situation varied, but gradually improved. A scan, done in the spring, revealed that the pneumonia in the obstructed lung had disappeared, but that unfortunately some metastases had developed in the other lung. The elderly couple decided that they did not want Mrs. Johnson to go through another course of chemotherapy. Instead, they chose a shorter life expectancy, but with a higher quality of life as opposed to a few months extra, possibly in a very poor condition.

Despite the bad news in May, Mrs. Johnson's situation did not deteriorate, but even seemed to improve slightly. The hospital bed could be removed from the living room and she considered her general well being to be fairly reasonable. At the time of this interview, January of the next year (5), Mrs. Johnson was feeling well. She was enjoying life and had a fairly good condition. She had been discharged from hospital care and only had contact with her GP.

We first met Mr. and Mrs. Johnson just after the hospital specialist had given them the bad news (at the end of the 5th year (3)). Our contact originated within the scope of a study on quality of care and quality of life of terminally-ill people in general practice<sup>11,12</sup>; this couple were among the first participants. When, after 11 quantitatively oriented interviews with questionnaires (about once a month), Mrs. Johnson's situation had changed from terminally ill to living on borrowed time, we asked her and her husband to participate in this case study, to which they agreed. In Figure 2 the changes in Mrs. Johnson's situation over the 11 quantitatively oriented interviews are represented; we showed the scores on the McGill quality of life submeasures<sup>a</sup> and the number of symptoms she experienced.

<sup>a</sup> Range 0-10. A higher score means a better judgement of the quality of life on that submeasure.

Figure 2



## Results

Three major themes were identified in relation with the couple's experience of living on borrowed time:

- Shifts in their interpretation of signs and symptoms.
- Different ways of looking ahead.
- Changed choices and priorities.

Below we present examples of the statements made by Mr. and Mrs. Johnson that explicate these major themes.

### *Shifts in the interpretation of signs and symptoms*

The interview data showed clearly that the couple were interpreting physical signs and symptoms somewhat differently from their approach at earlier times. After the positive change in the situation of Mrs. Johnson, she decided to have a last scan done to obtain an objective view of her physical health. At that time, she was feeling so well that she and her husband were hoping a miracle had happened.

*Patient: So, you go there. And subconsciously, you have hope. You notice that most clearly after hearing the results of the scan.*

*Husband: You think, yes, maybe something has happened to make the tumours smaller. Then we were both somewhat disconcerted.*

*Patient: I was obviously prepared for such news, but when they tell you, it is still disappointing and it takes another day to get over it a bit.*

Despite the fact that their hope of a miracle had been dashed, Mrs. Johnson remained well. Contrary to expectations, her condition improved and so did her energy and will to live. She and her husband had to find a new way to interpret the physical problems and signs and symptoms that Mrs. Johnson was experiencing. This became clear when they talked about their view of her coughing.

*Patient: No, it does not always concern us. Only in the middle of the night: I coughed terribly. My chest felt so tight. I thought: yes, here we go again! Maybe it is just a cold, but I know that sooner or later it will come. And then something must have been the cause or the turning point.*

*Husband: Huh, some cold .... It happens sometimes. I mean, you die of pneumonia, so cancer is not the cause of death. So, it is the first you think of, or at least I do! Like yesterday, when you were coughing and you did not feel well. Then I wondered what course we should take, because then things cannot often be undone.*

Mr. and Mrs. Johnson did not say much about the black cloud, but they mentioned that fears concerning what might went wrong were always present hanging somewhere above the surface of their daily lives. This also applied to their children. Their mother's vulnerability was always at the back of their minds.

*Patient: When our daughter said that she was expecting her second baby, she immediately added: "Mum, mind you are still here at the end of March!"*

In sum, Mrs. and Mr. Johnson tried hard not to worry constantly about signs and symptoms, but they acknowledge the vulnerability of Mrs. Johnson's situation.

### *Looking ahead*

Both Mrs. Johnson and her husband went through a process of reviewing their future. They labelled this as living in phases: their daughter had her baby, Mr. Johnson retired from work. Small steps, one at a time, looking ahead, but not too far!

*Patient: We are not making any holiday plans for next year.*

*Husband: No, but you have got as far as buying the clothes. That is always a problem: do we buy this coat, shall we have it or not? All right then, buy it and if things might be different, we will see! Yes, that is how it is; you live from day to day, it is narrow and claustrophobic.*

As time went by and Mrs. Johnson felt increasingly better, the couple slowly extended their plans and activities. However, they still sometimes built in certain conditions in case her situation deteriorated.

*Patient: During a yearly big festival, we used to have our niece and her friends to stay. We did not last year, but this year when she phoned I said: "Yes, you are welcome, the three of you can sleep here, but I will not be doing and cooking and if I am not well, you will have to put a caravan in the garden. That is the risk you'll have to take!"*

It repeatedly came to our notice that Mrs. Johnson's character played a very important role in how she was coping with the situation.

*Husband: You just do things (making curtains for their new grandchild's room, MG). I mean; you just carry on with your life, like you always have!*

*Patient: Well, I suppose that is true; I am like that. It is not hard for me to take!*

At the time of the interview, the couple were feeling confident about the future, but there was always the Sword of Damocles<sup>b</sup> hanging over their heads.

*Patient: Again and again, you push things away (deterioration and ultimate death, MG). So, I think: enjoy it, who knows what the future will bring! Husband: I like working in my vegetable garden, but when I am on my own (after Mrs. Johnson's death, MG), I will not want to take an onion, potato or green bean any more. So, I have made a children's garden, with a swing and a slide. I have seen to it all, so you do think about it!*

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<sup>b</sup> This statement derives from Damocles' history and stand for an impending danger in times of prosperity and good fortune.



In sum, Mrs. and Mr. Johnson slowly extended their daily activities and were able to look further in time. However, precautions 'just in case that' have been defined more or less explicitly.

### *Changed choices and priorities*

In the initial phase of Mrs. Johnson's illness, she still led a busy life. She was a member of a bridge club and a touring bicycle club. Furthermore, once a week she used to walk with a friend. As her situation deteriorated, she gradually gave up these activities. At a certain stage she resigned her membership to the bridge club and even sent them a farewell card. When her situation improved again, she did not go back to the club or her other former activities.

*Patient: There was a time when I used to sleep in the afternoon and anyway, I do not feel like doing those things any more.*

*For that matter, I am busy: I get up fairly late, drink a cup of coffee, someone visits us, I eat some sandwiches and often I have a rest in the afternoon. So you only have a couple of hours every day.*

*And, yes, you sometimes go out or go for a walk and then it is nice not to have all sorts of commitments.*

Mrs. Johnson felt that she had changed her priorities, other things were more important now.

*Patient: Maybe it is a bit strange, but you enjoy everything more. I like sitting in the garden, I do not know, the things you normally take for granted! Waking up in the morning and thinking: oh, what a lovely house. And also with the grandchildren, I feel so lucky that I have them. I am much more aware of things now. The feeling of taking everything for granted has disappeared!*

The (daily) activities of Mr. Johnson also changed. He had already reorganised his work earlier on so that he could spend more time at home. Furthermore, he had learned how to cook and do the laundry. As time went by and Mrs. Johnson's situation improved, she took over some of these tasks again.

During the period that Mrs. Johnson was still on chemotherapy treatment, she had consulted a homoeopathist. When she became extremely ill, she threw all the homoeopathic medicine away. At the time of our interview, she was taking homoeopathic granules again. With respect to this, she reported:

*Patient: I wanted to go back to the homoeopathist, because I felt that I had to do something about my situation. Whether it would help, I did not know, but I wanted to do something! And that was the simple importance for me.*

She does not only take the homoeopathic granules for herself:

*Patient: I think I want to do this, because I did not want any more chemo. So that they (her daughters, MG) cannot say: “Well, Mum is not doing anything!”*

In the present circumstances, the couple have found new balance: it is 10 steps backwards and they know that things will not improve, but they are satisfied. To retain this balance, they have decided not to experiment with the stable issues in their lives.

*Husband: Our GP visits us every four weeks. I think it is important to let him come to us (Mrs. Johnson would want to go to the doctor’s surgery otherwise, MG)! This is something for us to hold on to and we also do not want any changes in the medication.*

In sum, despite the fact that Mrs. Johnson’s situation improved and she experienced herself as living on borrowed time, she did not return to some former activities. New preferences and priorities were put in place and the borrowed time is filled in differently.

## **Discussion and conclusion**

### *Discussion*

So far we know, this is the first study to evaluate how people live on borrowed time. The qualitative case analysis revealed three important themes in the daily lives of a patient (and her husband) in an uncertain, surprisingly unexpected, but extra part of life. The patient and her husband had to find new ways of interpreting physical signs and symptoms; they developed different ways of looking at the future and changed their choices from those made previously.

Although our findings cannot be compared with the experiences described in other studies, it is well-known that patients with cancer or other chronic diseases, also experience shifts with regard to enjoying what they formerly considered as being unimportant or normal<sup>13</sup>. Furthermore, in most severely ill patients, like in our case, a narrowing of the social environment can be seen. However, there is an enormous difference compared to the case in our study: any moment, a change

can occur that will probably be the point of no return. Borrowed time is a very uncertain time! Conversely, next to this uncertainty borrowed time is 'time to live' instead of having more time to prepare for death.

### *Conclusion*

Based on a single case study, it is not possible to generalise. All patients are different and so are their ways of handling such alterations in the course of illness. Not everyone integrates this type of 'new reality' in a uniform way. Similarly, family circumstances, care situations and courses of disease differ. Nevertheless, this study provides insight into three main themes that patients encounter in similar circumstances.

### *Practice implications*

The themes revealed in our study can be incorporated into practical daily care, for example as a guide in the communication between the doctor or nurse and their patients. By designing a relevant framework, consisting of the three themes and within the themes some items deserving attention, an impression can be gained that sheds light on how specific persons integrate the 'new reality' into their lives. It is important to discuss integration strategies with the patient, in order to fill an important niche in their daily life.

Considering the impact of borrowed time on the lives of patient and family, this topic and the themes revealed in our study must be positioned in education on palliative care for healthcare professionals. Despite the concept being still in its infancy, it is of importance that they understand the concept and its implications.

Future research, for instance case series, should focus on refinement of and variation within the themes. Until now, we do not know how many patients live on borrowed time towards the end of their terminal illness, so it will not be easy to find patients for such research. To estimate the scope of this phenomenon, studies on GPs and hospital doctors must precede any case series, because it is assumed that they play a pivotal role in palliative care. Furthermore, living on borrowed time must not be confused with 'spontaneous regression', a situation that sometimes occurs in cancer patients<sup>14</sup>. The latter patients also need to find new equilibrium, but their prospects of survival are totally different.

In sum, our findings can be incorporated into daily practice and then the care process can be refined by means of future research. This will enable professionals to help patients integrate the 'new reality' and find new balance in their lives.

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### **THEME III**

**PROSPECTIVE STUDIES ON THE NATIONAL PROGRAMME  
FOR QUALITY IMPROVEMENT IN PALLIATIVE CARE:  
PALLIATIVE CARE CONSULTATION TEAMS (PCC TEAMS)**

## Chapter 6

### Requests from professional care providers for consultation with palliative care consultation teams

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## **Abstract**

**Goals of work:** Professional care providers need a substantial basis of competence and expertise to provide appropriate palliative care.

Little is known about the problems professionals experience in their palliative care provision in daily practice or about the nature of the advice and support they request from experts. Our aim was to investigate the extent to which professionals requested assistance from palliative care consultation teams and the reasons behind these requests to trace any gaps they experience in the provision of palliative care.

**Methods:** As part of a large national palliative care development programme, we studied requests for consultation made by professional care providers over a 2-year period. The requests for consultation were recorded on a specially developed standard registration form and classified according to 11 domains relevant to palliative care.

**Main results:** Professional care providers requested 4351 consultations on account of 8413 specific problems in 11 quality-of-life and quality-of-care domains. The distribution of problems over these domains was unbalanced: 42.2% of the specific problems were physical, while the percentages of psychological, pharmacological and organisational problems were 7.7, 12.5 and 12.8%, respectively. In contrast, issues of a spiritual nature or concerned with daily functioning were raised infrequently (1.1 and 0.9%). Details of the specific problems in all the domains are described in the text and tables.

**Conclusions:** The results of our study form a valid basis on which to develop and implement improvements in palliative care. We recommend that future well-founded policies for palliative care should incorporate palliative care consultation as well as educational and organisational interventions.

## Introduction

Appropriate care for patients facing life-threatening illness requires great competence, expertise and skills from professional care providers. Multifaceted interventions are often necessary in a limited time span and this sometimes calls for extensive organisation and coordination.

Practitioners in general palliative care do not always feel optimally equipped to perform all the extensive and complex tasks associated with palliative care<sup>1,2-4,5</sup>. One reason for this is the low number of palliative care patients that a professional usually treats or cares for per year, especially in primary care<sup>6,7</sup>. Although some hospital professionals may have developed more extensive expertise in palliative care, such work mostly only forms a small part of their job. Furthermore, the problems and needs of palliative care patients can be wide-ranging and sometimes interact within various quality-of-life and quality-of-care domains<sup>8-11</sup>. As palliative care is provided in the context of a constantly changing health system<sup>12,13</sup>, continuous vigilance is necessary.

Consulting with colleagues or experts is a well-established resource and support in problem-solving; this also applies to palliative care. However, the contents of such consultations largely remain obscure. Thus, little is known about the problems for which professionals seek advice and support in daily practice. It is difficult to compare the small number of studies that addressed consultation in palliative care, because of variations in the goals of the service, the patient population and settings<sup>14-16</sup>.

A special national palliative care policy programme was launched in the Netherlands in 1998 by the Dutch Government. This was a 5-year stimulation programme to improve the quality of palliative care for terminally-ill patients in the last few months, weeks or days of their lives. The programme comprises three main points:

- Attention to the structure and organisation of palliative care within the boundaries of regular healthcare.
- Stimulation of the promotion of competence in professionals who provide healthcare for terminally-ill patients.
- Promotion of insight into developments in supply and demand in palliative care.

For the purpose of readability, we refer to palliative care during the terminal phase with the term 'palliative care' throughout this article.

Part of this programme involved setting up several palliative care consultation (PCC) teams. The primary tasks of these teams are to provide information, support and advice to professionals in the palliative care for their patients. From March



2001 to March 2003, we studied the needs for advice and support expressed by professionals in the form of requests for consultations with PCC teams.

Our study investigated the extent and nature of the requests for consultations in palliative care and differences in requests between professional groups. The aim was to trace any gaps the professionals experienced in the provision of palliative care in order to develop starting points for quality improvements in palliative care. Greater insight into these issues will enable professionals as well as policy makers to plan, establish and take effective quality improvement actions in palliative care in general and it may also contribute to further (re)structuring of PCC teams.

## **Materials and methods**

### *Setting*

In the period from 1 March 2001 to 1 March 2003, 21 PCC teams participated in this national descriptive study by systematically recording the requests they received for consultation. The first PCC team started in 1997; by March 2003, 23 PCC teams were available that covered two thirds of the country. Two teams did not participate in our study: one was using a different registration method and the approach of the other team to consultation lacked comparability.

Some teams were based at hospitals and some in a primary care setting. Most of the teams were multidisciplinary and they provided support for professional care providers working at healthcare institutes or outside. The staff of the teams consisted of professionals from several disciplines, such as general practitioners (GPs), nurses, clinical physicians and nursing home physicians. All the team members had additional palliative care expertise obtained by means of specific education and work experience and received an internal course before the PCC teams started. The PCC teams conducted two types of consultation: (1) telephone consultations in which only the consulting professional was contacted without any contact at all with the patient and (2) bedside consultations in which both the consulting professional and the patient were seen and spoken with directly.

The PCC teams could be contacted during office hours at least, while a few teams were accessible 24 hours a day, 7 days a week. Most of the consultations were requested for cancer patients, but the teams also encountered patients with a wide range of other terminal illnesses.

### *Data collection*

Requests for consultation were recorded by the PCC staff on a standard registration form developed by a national multidisciplinary group of researchers.

This form was based on previous pilot studies with different PCC teams, the experience of the researchers and a review of the literature. All the data were entered into a nationwide computerised database that provides data for several studies (19).

In the present study, two sets of information were used:

1. Data on the nature of the requests for consultation. We studied the type and number of problems presented in the requests, both on a domain level and on the level of specific problems.
  - (a) The requests for consultation were classified according to 11 domains: physical, psychological, social, spiritual, daily functioning, pharmacological, organisation of care, support for the informal care provider, support for the professional care provider, other questions and general palliative care questions. These categories reflected all the domains relevant to palliative care and several other adjacent areas.
  - (b) Each domain was subdivided into a number of specific problems (pain, depression, interaction of the medication, etc.). The number of specific problems per domain ranged from 39 in the physical domain to five in several others, such as 'problems in daily functioning' or 'support for the informal care provider'.
2. Information on the characteristics of the professional who requested the consultation. These data comprised the profession and work setting of the requesting care provider. Distinction was made between GPs, nursing home physicians, clinical physicians, district nurses, nurses working at hospitals and others. Nurses working in homes for the elderly, nursing homes, or hospices were classified under the hospital group.

### *Statistical analysis*

The unit of analysis was threefold:

1. Requests for consultation: we used frequencies and proportions to study the numbers of requests for consultation per professional group (Table 1). Analysis of variance was used to test whether there was a statistically significant relationship between the type of professional discipline and the mean number of specific problems (Table 1).
2. Domains of problems: the extent of the relationships between the various professional groups and the problem domains was investigated by means of a  $\chi^2$  test (Table 2).

3. Specific problems: on this level we used frequencies and proportions to determine the number of specific problems per professional group (Table 1) and the specific problems for which professionals requested consultations (Tables 3,4).

All the analyses were performed using the SPSS system for personal computers.

## **Results**

Over the 2-year research period, 4351 consultation requests were recorded by the PCC teams. These requests had been made by professionals as classified in our study, who had brought forward a total of 8413 specific problems.

### *Requests for consultation*

In the course of the study period, the 21 Dutch PCC teams dealt with 4740 requests for consultation. We excluded the following: 166 requests because the person who made the request was the patient or the informal care provider, 25 cases because it was not known who had made the request, 92 requests because no problems at all had been recorded, 80 requests from nurses because of unknown or unclassifiable work settings and 26 requests to a team that could not vouch for the correctness of the registration forms. Thus, we analysed 4351 requests for consultation.

In the second year, more requests for consultation were registered than in the first year: 2489 and 1862, respectively. Over the 2-year period, 18 teams recorded the consultation requests; 15 teams recorded data in both years, while six recorded data in only one of the years. Over the 2 years, the number of requests for consultation increased at every centre but one. These increases ranged from 37 to 56%.

More than half of all the requests for consultation came from GPs. The two groups of nurses together accounted for nearly a quarter of the requests for consultation. The remaining quarter came from several smaller groups, in which the clinical physicians made the most requests (Table 1).

**Table 1. Number and percentage of requests for consultation (n=4351) and number and percentage of specific problems (n=8413) per professional group**

Professional group	Requests for consultation		Problems		Mean number of problems		
	N	%	N	%	Mean	SD	
General practitioner	2372	54.5	4741	56.4	2.0	1.57	**
Nursing home physician	119	2.7	208	2.5	1.75	1.34	
Clinical physician	447	10.3	947	11.2	2.12	1.78	***
District nurse	380	8.7	713	8.5	1.86	1.51	
Nurse at hospital	702	16.1	1284	15.2	1.83	1.77	****
Other*	331	7.6	520	6.2	1.57	1.14	
<b>Total</b>	<b>4351</b>	<b>100.0</b>	<b>8413</b>	<b>100.0</b>			

\* E.g. pharmacist, manager and/or policy advisor in care services, pastoral worker

\*\* Significantly different from 'other',  $p$ -value < 0.01)

\*\*\* Significantly different from 'other' and 'nurse at hospital',  $p$ -value < 0.01)

\*\*\*\* Significantly different from 'medical specialist/resident',  $p$ -value < 0.01)

### *Domains of problems discussed by types of professional*

Requests for consultation covered the entire range of palliative care. The problems brought forward were divided into 11 domains. Table 2 shows the distribution of problems over the domains for each professional group. More than half of the requests for consultation included one or more physical problems. Although problems in the physical domain played an important part in all the professional groups, there were a few differences. Nearly three quarters of the requests from GPs involved one or more physical problems. There was a discrepancy between the nurses working at hospitals and the district nurses. In the latter group, nearly half of the requests for consultation concerned physical problems, whereas in the hospital nurses this was the case in approximately a quarter.

In the pharmacological domain, more requests for consultation were made by GPs, district nurses and nursing home physicians than by clinical physicians, nurses at hospitals and other professionals. In the domain 'organisation of care' the distribution was somewhat different. Relatively more requests for consultation came from clinical physicians and nurses (both groups) than from GPs and nursing home physicians.

**Table 2. Number and percentage of requests for consultation per professional group and domain (n=4351)**

<b>Professional group</b>	<b>n</b>	<b>Physical</b>	<b>Psycho-logical</b>	<b>Social</b>	<b>Spiritual</b>	<b>Daily functioning</b>	<b>Pharmaco-logical</b>	<b>Organisa-tion of care</b>	<b>Support for informal care provider</b>	<b>Support for profes-sional care provider</b>	<b>Other questions</b>	<b>General palliative care questions</b>
	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
General practitioner	2372	72.3	13.5	3.0	1.5	0.9	23.1	12.5	2.5	5.6	7.8	5.6
Nursing home physician	119	59.7	13.4	2.5	-	-	16.8	8.4	-	8.4	6.7	15.1
Clinical physician	447	47.9	15.2	6.5	2.5	2.0	5.4	39.8	5.4	4.3	16.3	7.8
District nurse	380	46.1	7.6	6.6	2.1	1.6	15.5	29.5	4.7	13.2	4.5	16.3
Nurse at hospital	702	27.6	10.5	7.0	2.7	2.6	4.4	27.6	6.8	4.1	30.2	20.9
Other	331	11.8	6.6	6.0	1.2	1.8	7.3	30.5	5.4	2.1	3.9	46.8
<b>Total</b>	<b>4351</b>	<b>55.3</b>	<b>12.2</b>	<b>4.5</b>	<b>1.8</b>	<b>1.4</b>	<b>16.2</b>	<b>20.5</b>	<b>3.8</b>	<b>5.7</b>	<b>11.7</b>	<b>12.6</b>

\*\* E.g. pharmacist, manager and/or policy advisor in care services, pastoral worker

\*\*\* Significant relation (p-value < 0.01)

\*\*\*\* Significant relation (p-value < 0.05)

Number of requests for consultation from that specific professional group

**Table 3. Number of specific problems per domain per professional group (n=8413)**

<b>Professional group</b>	<b>Physical</b>	<b>Psychological</b>	<b>Social</b>	<b>Spiritual</b>	<b>Daily functioning</b>	<b>Pharmaceutical</b>	<b>Organisation of care</b>	<b>Support for informal care provider</b>	<b>Support for professional care provider</b>	<b>Other questions</b>	<b>General palliative care questions</b>	
General practitioner	4741	2478	376	97	42	24	809	343	81	152	194	145
Nursing home physician	208	99	20	3	-	-	36	11	-	11	9	19
Clinical physician	947	355	85	37	11	11	36	241	36	22	75	38
District nurse	713	239	36	28	9	9	89	130	21	65	17	70
Nurse at hospital	1284	314	102	71	19	24	39	226	66	41	214	168
Other	520	61	32	27	4	9	36	124	22	11	14	180
<b>Total***</b>	<b>8413</b>	<b>3546</b>	<b>651</b>	<b>263</b>	<b>85</b>	<b>77</b>	<b>1045</b>	<b>1075</b>	<b>226</b>	<b>302</b>	<b>523</b>	<b>620</b>

\* E.g. pharmacist, manager and/or policy advisor in care services, pastoral worker

\*\* Number of specific problems per professional group

\*\*\* Number of specific problems per domain

Table 2 also shows that all the professional groups except for the nursing home physicians had experienced problems in all 11 domains. In the group of nursing home physicians no requests for consultation were made in three domains: spiritual care, daily functioning and support for the informal care provider.

### *Specific problems*

On average, each request for consultation comprised nearly two specific problems. The number of problems ranged from 1 to 17. There was a significant difference in the mean number of specific problems between the professional groups. The most relevant significant difference was found between the clinical physicians (mean 2.1) and the nurses at hospital (1.8) (Table 1).

Table 3 shows the distribution of specific problems over the domains for each of the professional groups. In general terms, this table confirms the findings in table 2. In each professional group, many of the specific problems were physical, but there were differences between the groups. Clinical physicians only raised a small number of specific problems in the pharmacological domain. This was also the case for the nurses at hospital. The other professional groups, however, encountered a larger number of specific problems in this domain. Spiritual and daily functioning problems were only mentioned rarely by any of the groups.

Details of the specific problems per domain, not subdivided according to professional groups, are presented in table 4. The results show that the problem of 'pain' was dominant: one specific problem out of seven concerned pain. In the physical domain itself, the proportion rose to one in three. Other frequently mentioned specific problems were the choice of medication, requests for a general inventory and problems surrounding nausea or dyspnoea.

Table 4 also shows which specific problems were in the top third of each separate domain (minimum 3; maximum 10). The problem of pain ranked highest in the physical domain, but the requests also contained many other physical problems. In the psychological domain, agitation/confusion and anxiety were the most frequent specific problems. There were also various specific pharmacological problems: medication choice, dosage and administration method.

The organisation of palliative care was another domain in which there were many requests for consultation. These included requests for an inventory of the care situation, requests for help with admitting patients to palliative care units and specific problems concerning the use or availability of necessary materials and equipment.

**Table 4. Number and percentage of specific problems (n=8413)**

<b>Problem</b>	<b>% of total number of problems within specific domain</b>		<b>% of total number of specific problems (n=8413)</b>
<b>Physical problems</b>			
Pain	33.4	(1183)	14.1
Nausea	8.9	(317)	3.8
Dyspnoea	8.1	(286)	3.4
Vomiting	5.4	(190)	2.3
Delirium	4.1	(147)	1.7
Constipation	3.0	(107)	1.3
Fatigue	2.5	(89)	1.1
Sleeping problems	2.2	(77)	0.9
Appetite/anorexia	2.0	(71)	0.8
Oral problems	2.0	(71)	0.8
Gastro-intestinal obstruction	1.9	(68)	0.8
Other <sup>a</sup>	26.5	(940)	11.2
<b>Total</b>	<b>100.0</b>	<b>3546</b>	<b>42.2</b>
<b>Psychological problems</b>			
Agitation/confusion	34.7	(226)	2.7
Anxiety	22.9	(149)	1.8
Coping with problems	9.2	(60)	0.7
Depression	8.0	(52)	0.6
Other <sup>b</sup>	25.2	(164)	1.9
<b>Total</b>	<b>100.0</b>	<b>651</b>	<b>7.7</b>
<b>Social problems</b>			
Lack of informal care	24.0	(63)	0.7
Communication with loved ones	19.8	(52)	0.6
Dependence	16.3	(43)	0.5
Other <sup>c</sup>	39.9	(105)	1.2
<b>Total</b>	<b>100.0</b>	<b>263</b>	<b>3.0</b>
<b>Spiritual problems</b>			
Acceptance of illness	65.9	(56)	0.7
Significant engagement	9.4	(8)	0.1
Meaning of death	8.2	(7)	0.1
Other <sup>d</sup>	16.5	(14)	0.2
<b>Total</b>	<b>100.0</b>	<b>85</b>	<b>1.1</b>
<b>Problems in daily functioning</b>			
Mobility	35.1	(27)	0.3
Personal care	24.7	(19)	0.2
Domestic work	16.9	(13)	0.2
Other <sup>e</sup>	23.3	(18)	0.2
<b>Total</b>	<b>100.0</b>	<b>77</b>	<b>0.9</b>
<b>Pharmacological problems</b>			
Choice of medication	35.0	(366)	4.4
Dosage of medication	27.4	(286)	3.4
Route of administration	24.1	(252)	3.0
Other <sup>f</sup>	13.5	(141)	1.7
<b>Total</b>	<b>100.0</b>	<b>1045</b>	<b>12.5</b>



Table 4 continued. Number and percentage of specific problems (n=8413)

Problem	% of total number of problems within specific domain		% of total number of specific problems (n=8413)
<b>Organisation of care</b>			
Inventory situation of care	22.4	(241)	2.9
Admission to palliative care unit	18.3	(197)	2.3
Use/availability of materials and equipment	17.0	(183)	2.2
Support discharge/transfer	12.5	(134)	1.6
Other <sup>g</sup>	29.8	(320)	3.8
<b>Total</b>	<b>100.0</b>	<b>1075</b>	<b>12.8</b>
<b>Support for informal care provider</b>			
Emotional support	46.9	(106)	1.3
Practical support	23.9	(54)	0.6
Communication with professional care provider	14.6	(33)	0.4
Other <sup>h</sup>	14.6	(33)	0.4
<b>Total</b>	<b>100.0</b>	<b>226</b>	<b>2.7</b>
<b>Support for professional care provider</b>			
Lack of medical knowledge	31.4	(95)	1.1
Lack of technical skills	19.9	(60)	0.7
Lack of counselling skills	11.3	(34)	0.4
Other <sup>i</sup>	37.4	(113)	1.3
<b>Total</b>	<b>100.0</b>	<b>302</b>	<b>3.5</b>
<b>Other questions</b>			
General inventory	55.6	(291)	3.5
Euthanasia	19.3	(101)	1.2
Inventory in hospice/almost-like-home house	9.8	(51)	0.6
Other <sup>k</sup>	15.3	(80)	1.0
<b>Total</b>	<b>100.0</b>	<b>523</b>	<b>6.3</b>
<b>General palliative care questions</b>			
Leaflet/information material	33.2	(206)	2.4
Supply of addresses	22.6	(140)	1.7
Request for education	10.0	(62)	0.7
Other <sup>l</sup>	34.2	(212)	2.5
<b>Total</b>	<b>100.0</b>	<b>620</b>	<b>7.3</b>
<b>Total</b>		<b>8413</b>	<b>100.0</b>

<sup>a</sup>Anaemia, ascites, haemorrhagic diathesis, cachexia, comatose, decubitus, dehydration, diarrhoea, thirst, vertigo, singultus, cough, skin damages, hypocalcaemia, pruritus, pyrexia, lymph edema, micturition problems, nephro-insufficiency, gastrointestinal obstruction, rhonchus, dysphagia, musculature spasms, drowsiness, paraesthesia, (excessive) perspiration, visual problems, acid eructation and non-specified problems

<sup>b</sup>Decision-making, concentration problems, anger, powerlessness, pre-existing problems, coping with loss, a troubled self image, non-specified problems and missing (n=3)

<sup>c</sup>Solitariness, accommodation/financial problems, lack of disease perception, relational problems, role alteration, non-specified problems and missing (n=2)

<sup>d</sup>loss of confidence in God or religion, non-specified problems and missing (n=1)

<sup>e</sup>uncomfortable position, non-specified problems and missing (n=3)

<sup>f</sup>Interaction medication, re-adaptation of medication and non-specified problems

<sup>g</sup>Coordination of care, use/availability of professional care, request/arranging admission palliative unit, request/arranging treatment, request/arranging second opinion, non-specified problems and missing (n=2)

<sup>h</sup>Communication with patient, non-specified problems and missing (n=3)

<sup>i</sup>Personal emotions, determining own limitations, relationship with informal care providers, relationship with patient, problems with collaboration, non-specified problems and missing (n=2)

<sup>k</sup>Selection of other supporting persons and non-specified problems

<sup>l</sup>Logistics of supply materials, participation in study group/project and non-specified problems

The concept of palliative care includes attention and care for the patient's partner. Professional care providers also consulted the PCC teams with problems that concerned emotional or practical support for the informal care provider and communication issues.

## Discussion

In the 2-year study period, professionals made 4351 requests for support in their daily provision of palliative care. Over 40% of the specific problems behind the requests were physical. In addition, psychological problems, pharmacological problems and organisation of care problems were fairly frequent. In contrast, spiritual issues and problems with daily functioning were rarely encountered. All the professional groups, except for the nursing home physicians, requested support for problems in every domain.

A limitation of the study was that more than 20 different PCC team members filled in the registration forms. The researchers gave repeated written and oral instructions with the aim of diminishing interpersonal variation, but the practice of PCC and the registration form itself were too complex to completely exclude variation. However, on the basis of the high number of requests for consultation and the nationwide character of the study, we believe that the reasons behind the requests for consultation uncovered by this study are representative of the problems generally experienced in the daily provision of palliative care.

Although consultation between professionals has been customary practice for a very long time, it has seldom formed the focus of research. Similarly, studies on requests for professional consultation in the field of palliative care are also scarce. In much of the literature, consultation only appears as a side issue among support teams whose primary task was the direct provision of care to the patient and family<sup>17-23</sup>. A few studies addressed purely advisory services<sup>5,24</sup> or concentrated on referrals to consultation services<sup>14,16</sup>. Unfortunately, no comparisons could be made, because the consultation activities fell outside the regular (hospice) activities<sup>5,24</sup> or the reasons for referral were classified under totally different problem domains<sup>14,16</sup>.

The results revealed by our systematic recording of requests made to PCC teams showed similarity with studies on education in palliative care. Several

authors reported that professionals gave priority to (additional) training in pain and symptom management, communication and support<sup>4,25-27</sup>. Management of a wide range of symptoms corresponded with our frequently encountered domains of physical and psychological problems. With regard to communication and support, distinction should be made between a wish for education and the explicit expression of a personal gap in knowledge by means of a request for consultation because of less tangible and more intuitively oriented topics.

Our study provided insight into the extent of the need for support in daily palliative care. This offers a firm basis on which to develop and implement improvements in palliative care. However, for several reasons, this is only the tip of the iceberg. A recent study found that the number of problems identified by palliative care consultants in a patient-related situation was significantly higher (by a factor of nearly 2–3 times) than the number of initial questions<sup>28</sup>. Furthermore, we know nothing about the backgrounds of the large group of professionals who did not request consultations: they may not want it or need them, or they may be prevented from becoming aware of any gaps in their care provision. Some professionals may have developed their own problem-solving techniques, for instance, by seeking direct and swift contact with expert colleagues other than members of institutional PCC teams. This may be the case with euthanasia, for example. In the Netherlands, euthanasia has been a topic of debate for many years<sup>13</sup>, but this was not reflected in the contents of the requests made to the PCC teams: only 1.2% of the specific problems concerned euthanasia. Other consultation services aimed primarily at euthanasia problems may have caused this low percentage. GPs, for instance, have access to a network of independent and specially trained doctors, the Euthanasia Support and Consultation Network, who offer advice and information<sup>29</sup>.

It can be assumed that our results will be useful in the (re) structuring of PCC teams by lending support to decisions, such as which professions should be included in a PCC team and the level of their involvement.

Daily palliative care can also be improved by several other means: education, organisation, guidelines, etc. In order to choose and develop the most effective strategies, it is important to carefully document the reasons why professionals make requests for consultation, because the availability of services shapes their use<sup>30</sup>. Interventions to meet requests for consultation based on lack of knowledge or skills differ from those based on lack of time to solve the problems independently. Similarly, consulting a member of a PCC team to exchange thoughts and opinions is a very different approach from making a request for

practical information, such as the address of a particular healthcare organisation or a list of the facilities available.

As palliative care is a fairly young discipline in the Netherlands, relatively few Dutch professionals have followed adequate, appropriately planned tuition in this field during their vocational training<sup>1</sup>. Topics relevant to the quality of palliative care include knowledge of frequently occurring symptoms (e.g. pain, constipation, nausea) and various psychological states (e.g. confusion and adjustment to bereavement) and the skill to deal with them. Although education will be beneficial, it is questionable whether the education of professionals who are usually only confronted with a few palliative care patients a year could be a complete substitute for consultation services in this complex and constantly changing field. To solve this apparent contradiction, it is necessary to use a combination of quality improvement strategies, for example, consultation and education, side by side.

The requests for consultation differed between the professional groups. This may be due to differences in the professional focus of doctors and nurses in their provision of palliative care. For example, Grande<sup>31</sup> found that GPs and nurses in primary care differed greatly in the types of symptom they felt confident about controlling. Therefore, interdisciplinary cooperation might help to achieve optimal, comprehensive care for terminally-ill patients and their families and it might also have a positive effect on the job satisfaction of the professionals concerned. Innovative projects directed towards these goals need to be accompanied by research to enable the construction of tailor-made interventions.

Although the problems presented to the PCC teams covered all the domains, the distribution of the problems was very unbalanced. It may therefore be questioned whether the concept of palliative care that emphasises the patients and their families and underlines the importance of physical, psychosocial and spiritual aspects, is fully integrated into the daily routine of healthcare professionals. Future research is needed to investigate whether more extensive exploration of the problem by a PCC team member during the presentation of a request helps to uncover other and/or more obscure problems. Furthermore, studies on a patient level and on a professional level are essential to discover the extent to which professionals are able to adequately handle problems in the various domains (i.e. for which they do not need consultation) and to identify any gaps in their daily care provision.

In the next few decades, the need for palliative care will continue to increase<sup>12</sup>. Our study contributed to the existing body of knowledge and forms a further basis

to aid the development of a well-founded policy for palliative care that incorporates consultation teams, education and organisational interventions.

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## Chapter 7

### Consultation in palliative care: The relevance of clarification of problems

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### **Abstract**

This study aims to determine the extent and nature of problems in palliative care that are newly identified in the consultation process and the factors influencing their identification. The consultation process includes clarification of problems mentioned by professionals requesting advice. Data are derived from the standard registration forms of Palliative Care Consultation teams. Multilevel logistic regression analysis was carried out with newly identified problem as dependent variable. Fifty seven percent of problems (n=7854) were newly identified. Most newly identified problems were related to physical and pharmacological problems. If psychosocial/spiritual problems were identified, this occurred in most cases through clarification (70%). Newly identified problems were more likely to be identified in the domain of spiritual and psychosocial problems, in bedside consultations, in requests from clinical physicians, and for patients accommodated in a hospice or hospital. Explicit clarification of problems facilitates the identification and addressing of a more comprehensive and specific scope of problems.

## Introduction

Palliative care requires professionals to address patients' physical, psychosocial, and spiritual needs<sup>1</sup>. Fulfilling specialist requirements is difficult for a professional when palliative care is not the main focus of daily activity. General practitioners for example lack specialist knowledge and skills on symptom treatment. Furthermore, they are unacquainted with the activities of other healthcare professionals<sup>2</sup>. As a result, important available resources and expertise are underused. The formation of Palliative Care Consultation (PCC) teams was stimulated within a national programme to improve palliative care. In such a team, experts from several disciplines and settings (hospital and primary care) work together to provide consultation for other professionals with less experience<sup>3</sup>. With a few exceptions, these teams are multidisciplinary. The exceptions are teams consisting solely of general practitioners or nurses specialised in palliative care.

The teams override the usual boundaries between healthcare disciplines in a joint attempt to address the problems of a specific patient. The agenda is set by the problems related to a specific patient rather than to the rules and structure of the disciplines and organisations involved. The teams cross the boundaries between settings and disciplines, thus providing transmural or integrated care<sup>4</sup>. In doing so and in being meticulous about leaving the responsibility for care in the professional requesting advice, the teams present an example of how transmural collaboration at the interface of different disciplines can be used to improve the quality of care.

The quality of support and advice given to professionals in palliative care depends not only on the palliative care expertise of the consultant, but also on the quality of the professionals' interaction. Consultation refers to the process of one professional requesting advice from another more experienced professional. Without a clear expression or identification of the problem, inappropriate actions might be proposed<sup>5</sup>. Adequate clarification of the questions and problems posed and exploration of the problem context offer the opportunity to identify the scope of problems related to the palliative phase of a disease. A more specific and comprehensive overview of problems would lead to a better understanding of the problems that should be addressed and the priorities that should be set in addressing these problems. A previous 1-year study of the PCC teams revealed that more than 50% of all the advices they gave were based on problems identified through clarification and exploration; these problems were not mentioned in the initial request for consultation<sup>3</sup>. In this study, we focus on these newly identified problems. They include (a) those identified in the clarification and exploration of

the problems initially mentioned by professionals requesting advice and also (b) addressed in the advices given. The aim of this study is the identification of the nature and extent of problems derived from explicit clarification in consultations and to investigate the factors influencing whether or not such new problems are identified. It is hypothesised that newly identified problems arise most often in the domain of psychosocial and spiritual problems, since the primary reason for requesting medical consultation is the patient's physical problems<sup>6</sup> and professionals might hesitate to ask consultation for non-medical problems.

#### **Box 1. Explanation of terms used in palliative care consultation**

**Consultation:** the process of a professional requesting advice from another more experienced professional.

**Request for consultation:** a less experienced professional requesting advice and support from a Palliative Care consultation Team. One request can contain several (initial) problems.

**Initial problem:** a patient-related problem posed by the professional requesting consultation.

**Newly identified problem:** (a) problems identified through the clarification and exploration of the problems initially mentioned by the professional requesting advice and also (b) addressed in the advices given.

**Clarification:** retrieving more explicit information on problems mentioned by the professional requesting consultation.

**Exploration:** investigation of the context of problems (other domains of palliative care, for example)

## **Patients and methods**

### *Respondents and design*

Respondents were PCC teams registering their consultations. A national prospective study was conducted, registering all consultations of the PCC teams throughout a period of 2 years. In the period 1st March 2001–1st March 2003, PCC teams participated in this descriptive study by systematically recording the requests they received for consultation<sup>6</sup>. Some teams are based in hospitals, some in a primary care setting. Most teams are multidisciplinary and support professional caregivers working within as well as outside healthcare institutions. The teams consist of professionals from several disciplines, including general practitioners (GPs), nurses, clinical physicians, and nursing home physicians. Clinical physicians are specialised physicians like neurologists, they are often referred to as consultant physicians, but the term would be confusing in the context of this article. All team members have at their disposal their own expertise gained through training and experience and the expertise of fellow team members. The PCC teams conduct two sorts of consultations: (1) telephone consultations with the consulting professional and no contact at all with the patient and (2) bedside consultations in which the expert sees and speaks with both the

consulting professional and the patient. All PCC expert teams are accessible during office hours; a few teams can be reached 24 hours a day, 7 days a week.

PCC teams were specially trained in the clarification and exploration of problems and in sharing decisions on treatment with other professionals.

### *Data collection*

Each consultation was registered with the aid of a common registration form developed by a national multidisciplinary group of researchers on the basis of previous pilot studies undertaken by the different PCC teams and a literature study. The form contained questions on the characteristics of the requesting caregiver and the patients involved<sup>3</sup>. In addition, the initial problems posed by the professional requesting consultation (initial problems), and the newly identified problems were registered by the consultant. All data were entered into a national computerised database. To prevent selective non-response, missing items were systematically checked with the consultant and the form completed as far as possible. Registration forms were entered into a Microsoft Access database.

### *Instruments*

The following data were collected on the determinants of the presentation of newly identified problems:

- (a) domain of palliative care: physical/pharmacological problems; psychosocial/spiritual and organisational problems (reference category)
- (b) discipline of the requesting professional: nursing home or clinical physician; district nurse; clinical nurse and general practitioner (reference category)
- (c) discipline of the professional providing advice: nurse (district or clinical nurse); nursing home or clinical physician; and general practitioner (reference category)
- (d) type of consultation: telephone or bedside consultation
- (e) patient characteristics: patient's age was classified into < 70 and ≥ 70 years of age; residence into home; hospital; nursing home and hospice. Patient's diagnosis was classified into oncological disease or other; prognosis into > 1 month; or ≤ 1 month; functional status into ECOG 0 - 2 and 3 - 4.

### **Analysis**

Descriptive information is first given on the initial problems and the newly identified problems. In addition, the new problems most frequently identified are presented per domain.

Problems in palliative care were classified into three domains: physical/pharmacological problems; psychosocial/spiritual; and organisational problems.

Multilevel logistic regression analysis was conducted to determine the factors influencing the presence of newly identified problems. We applied multilevel logistic regression because of the hierarchical structure of the data (with problems nested within patients). The dependent variable was the presentation of at least one newly identified problem (yes/no); the independent variables were the domain of palliative care problems, the disciplines of the requesting professionals, the disciplines of the professional providing advice, the type of consultation, and patient characteristics. The multilevel logistic model included a random intercept and fixed effects for the independent variables. The multilevel logistic model was built by backward rejection of explanatory variables with insignificant fixed effects. The high number of cases allowed to include all explanatory variables included in the study. The level of significance was set at  $p < 0.05$ . We assessed the association between the variables by odds ratios, with 95% confidence intervals.

## **Results**

In the period from 1st March 2001 to 1st March 2003, 21 PCC teams participated in this descriptive national study.

Twenty-three PCC teams were involved, covering two-thirds of the country. Two teams did not participate in our study: one used a different registration method; the approach to consultation of the second lacked comparability. The areas covered by the teams varied from 20,000 to 2.2 million inhabitants.

Table 1 describes the study population. In this study on consultations in palliative care, we focus on the regions involved in the study. Per region we provide information on a number of teams, requesting professionals and patient characteristics.

**Table 1. Characteristics of PCC teams, professionals requesting consultations and patients per region**

	Region 1	Region 2	Region 3	Region 4	Region 5
<b>Number of teams</b>	6	1	4	8	2
<b>Number of patient related requests for consultation</b>	421	698	880	744	673
<b>Type of consultation</b>					
• Bedside	17	307	311	289	53
• Telephone	404	391	569	455	620
total	421	698	880	744	673
<b>Profession requesting care provider</b>					
• Nursing home physician	10	11	15	24	26
• Clinical physician	9	105	191	29	53
• District nurse	50	38	56	124	17
• Clinical nurse	20	206	166	94	16
• General practitioner	332	338	452	473	561
total	421	698	880	744	673
<b>Patient characteristics</b>					
<b>Setting</b>					
• Hospital	14	148	223	32	59
• Nursing home	32	34	41	54	39
• Hospice	24	103	10	23	22
• Home	332	397	572	606	528
• Other	6	13	10	9	9
• missing	13	3	24	20	16
total	421	698	880	744	673
<b>Age</b>					
• < 70 year	168	343	521	368	377
• 70 years and older	163	305	307	324	246
• missing	90	50	52	52	50
total	421	698	880	744	673
<b>Diagnosis</b>					
• Oncological	344	648	792	676	610
• Non-oncological	71	49	74	58	47
• missing	6	1	14	10	16
total	421	698	880	744	673
<b>Prognosis</b>					
• > 1 month	138	365	284	249	138
• 1 month or less	279	323	551	473	489
• missing	4	10	45	22	46
total	421	698	880	744	673
<b>ECOG</b>					
• 0 – 2	74	117	136	104	76
• 3 – 4	331	568	675	619	538
• missing	16	13	69	21	59
total	421	698	880	744	673

Five regions with 21 PCC teams have been involved in this study. Most teams were multidisciplinary. The number of teams per region varied from 1 to 8. The number of patient-related requests for consultation was 3416. The use of bedside consultations varied from 4% (n=17) in region 1 to 44% in region 2. The majority of

requests for consultation in each region came from general practitioners: 83% in region 5 to 48% in region 2. Patient prognosis of 1 month or less varied from 46% in region 2 to 73% in region 5.

The number of initial patient-related problems was 6001; the number of newly identified problems after clarification and exploration by the experts was 7854; the total number of problems was thus 13855. The percentage of newly identified problems in this 2-year period was 57%. Of the physical problems, 53% were newly identified; the share of newly identified problems in the psychosocial domain was 70% and in the organisation-of-care domain it was 52% (Table 2). With respect to bedside consultations, 69.5% of all problems were newly identified through clarification; this percentage was 47.4 for telephone consultations. The highest percentage of newly identified problems (71.9%) was found when clinical physicians requested a consultation. Patient characteristics had little influence on the identification of new problems.

**Table 2. Frequencies and percentages of newly identified problems and characteristics of consultation in palliative care**

Categories	Initial problems	Newly identified problems	Newly identified problems/total number of problems per category
<b>Problem category</b>			
• Physical /pharmacological	4262	4863	53.3
• Psychosocial/spiritual	873	2071	70.3
• Organisational	866	920	51.5
<b>Type of consultation</b>			
• Bedside	1778	4055	69.5
• Telephone	4223	3799	47.4
<b>Professional requesting consultation</b>			
• Nursing home physician	143	147	50.7
• Clinical physician	695	1782	71.9
• District nurse	468	399	46.0
• Clinical nurse	689	1453	67.8
• General practitioner	4006	4073	50.4
<b>Consultant</b>			
• Nursing home physician and medical specialist	1276	1350	51.4
• General practitioner	284	259	47.7
• Nurse	4441	6245	58.4

**Table 2 continued. Frequencies and percentages of newly identified problems and characteristics of consultation in palliative care**

Categories	Initial problems	Newly identified problems	Newly identified problems/ total number of problems per category
<b>Setting</b>			
• Hospital	708	1708	70.7
• Nursing home	386	348	47.4
• Hospice	177	520	74.6
• Home	4540	5055	52.7
<b>Age</b>			
• < 70 year	3272	4542	58.1
• 70 years and older	2219	2896	56.6
<b>Diagnosis</b>			
• Oncological	5444	7268	57.2
• Non-oncological	496	548	52.5
<b>Prognosis</b>			
• > 1 month	2044	3110	60.3
• 1 month or less	3780	4581	54.8
<b>ECOG</b>			
• 0 - 2	856	1191	58.2
• 3 - 4	4881	6447	56.9

The percentage of newly identified problems among persons younger than 70 years of age (58%) is similar to that for persons aged 70 and older (57%). Table 3 presents the five most prevalent newly identified problems per palliative-care-problem domain. The most prevalent newly identified specific physical problem was pain.

Although pain problems were often mentioned initially, the percentage of newly identified pain problems was 31.5%. Constipation problems were mostly identified in the exploration and clarification procedure (79.4%). This procedure also revealed more than 50% of the problems related to choice of dosage of medication. The majority of the specific psychosocial and spiritual problems were such newly identified problems as acceptance of illness (75.1%) and grief (79.5%).



**Table 3. Nature and extent of five most prevalent newly identified problems per domains**

<b>Specific problems</b>	<b>Number of initial problems</b>	<b>Number of newly identified problems</b>	<b>Number of specific newly identified problems/total number of specific problem</b>
<b>Physical/pharmacological</b>			
• Pain	1109	510	31.5
• Choice medication	334	403	54.7
• Constipation	103	396	79.4
• Application form	221	392	63.9
• Dosage medication	255	269	51.3
<b>Psychosocial/spiritual</b>			
• Anxiety	132	278	67.8
• Agitation/confusion	209	207	49.8
• Acceptance illness	50	151	75.1
• Lack of informal care	52	133	71.9
• Grief	34	132	79.5
<b>Organisation of care</b>			
• Use of materials	153	232	60.3
• Use professional care	81	202	71.4
• Coordination of care	80	159	66.5
• Inventory care situation	212	122	36.5
• Support care transition	105	73	41.0

Table 4 presents the results of the multilevel logistic regression analysis. With respect to the variance in the newly identified problems, about 29.9% was accounted for by the domains of palliative care problems, type of consultation, type of professional requesting advice, and residence. Newly identified problems were found in the domain of psychosocial and spiritual problems more often than in organisational problems and than in physical and pharmacological problems. They were also more often found in bedside consultation, when the requesting professional was a clinical physician rather than a general practitioner, and in a hospice or hospital setting rather than a home situation. Newly identified problems were found less often when the requesting professionals were district nurses rather than general practitioners. No significant influence was found of the disciplines of the professional providing consultation, the age of the patient, the patient's diagnosis, the patient's prognosis or the patient's functional status.

**Table 4. Multilevel logistic regression analysis**

	Odds Ratio(OR)	95% Confidence Interval (CI)	Prob.
<b>Problem domain</b>			
• Physical /pharmacological	1.20	1.07-1.35	0.0001
• Psychosocial/spiritual	2.24	1.95-2.57	
• Organisational	ref		
<b>Type of consultation</b>			
• Bedside	2.22	1.93-2.55	0.0001
• Telephone	ref		
<b>Professional requesting consultation</b>			
• Nursing home physician	1.08	0.72-1.63	0.0069
• Clinical physician	1.37	1.09-1.73	
• District nurse	0.78	0.63-0.97	
• Clinical nurse	1.19	0.96-1.47	
• General practitioner	ref		
<b>Setting</b>			
• Hospital	1.29	1.05-1.60	0.0001
• Nursing home	0.83	0.64-1.09	
• Hospice	2.65	2.01-3.51	
• Home	ref		

## Discussion

Explicit clarification and exploration accounted for 57% of the problems dealt with by the expert palliative consultation teams. The majority of these newly identified problems were physical and pharmacological in nature. Problems presented in the psychosocial/spiritual problems domains were mostly identified by clarification and exploration by the experts during the consultation. Newly identified problems were also more likely to be identified in bedside consultation, when the requesting care provider was a clinical physician, and when the patient was accommodated in a hospice or hospital.

These results underline the importance of the explicit clarification and exploration of the initial problems posed by professional carers. Such exploration facilitates the formation of a comprehensive and specific overview of problems. High percentages of certain specific problems such as choice and dosage of medication and patient grief were identified. In contrast with our expectations, most newly identified problems were found in the physical and pharmacological domain.

However, the highest percentage of newly identified problems was found in the domain of psychosocial problems (including spiritual problems): 70% of these problems were identified by exploration and clarification. Since these are the most

prevalent problems of patients in the palliative phase of the disease<sup>7</sup>, it is important for PCC teams to be alert to them.

In line with the results of Koedoot and colleagues, the characteristics of the person requesting a consultation influenced the communicative behaviour of the professional giving it<sup>8</sup>. The higher likelihood of identification of new problems in the clinical setting as compared to home care setting might be related with the more specialised perspective of that setting as compared to the more holistic perspective prevalent in primary care and in the face to face contact with the professional requesting advice and the patient.

Despite the differences in disciplines involved in the consultation teams, no significant difference was found between professionals providing consultation, nor were patient characteristics influential. The specific training in exploration and clarification seems to be effective.

The expertise of several healthcare disciplines is used through the mediation of one team member. This team approach is convenient for the person requesting consultation. The joint endeavour of professional carers of several disciplines to address the problems of a specific patient is efficient.

In addition, this model of transmural collaboration stimulates the use of available resources. Moreover, leaving the responsibility to the professional requesting advice resolves the key problem in transmural care: the division of responsibilities. Palliative care consultation depends on good communication. In this, the explicit clarification and exploration of problems is a first and crucial step in consultation communication.

Further steps to be taken include the explicit agreement of problem definition, the discussion of treatment options, and the final decision on how the professional requesting advice should treat the patient. Processes of this kind between patients and physicians are described as shared decision making. Clinicians using shared decision making perceived significantly higher patient satisfaction with the information given and general overall satisfaction with the consultation<sup>9</sup>. However, little is known about the use of the shared decision making model among professionals. Evaluation of the palliative care consultations teams revealed that two-thirds of the professionals requesting a consultation indicated that the consultation had improved the quality of care and three quarters of them said that the consultation was helpful for the patient<sup>10</sup>.

More rigorous evaluation is needed of the process of sharing decisions among professionals and the effects on both professionals and patients with respect to satisfaction with the consultation and compliance with advices given.

**Limitations**

More than 20 different PCC teams completed the registration forms. Although the researchers attempted to diminish the inter-consultant variation by means of repeated written and oral instructions, a limitation of this study is the complexity of both the practice of palliative care consultation and the registration form itself. However, the high numbers of requests for consultation and the nationwide character of the study justify our assumption that the results for the problems experienced in daily palliative care ending in consultation are representative.

The consultation procedure reflects an efficient way of providing transmural collaboration by using the combined expertise of a team. A more thorough problem investigation yielded knowledge over a broader range of problems, including problems that were often mentioned initially, such as pain. The practical implication is that the education and training of consultants should feature not only expert advice and information giving, but also the procedures of the identification and exploration of problems and sharing decisions on treatment with other professionals. The effects on professionals, patients, and their informal care providers warrant further rigorous study.

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## Chapter 8

### Expert advice given in palliative care consultation

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## **Abstract**

**Aims:** This national multicentre study concentrates on the expert advice given by members of Palliative Care Consultation (PCC) teams to the requesting care providers: a topic as yet unexplored. This information is relevant to the future development of palliative care and the arrangement of the optimal composition of PCC teams. Study aims: 1) to determine the extent and nature of advice given in PCC; 2) to identify the factors influencing differences in advice given.

**Methods:** Expert advice given was recorded on specifically-developed standard registration forms. Variables: 1): advice given was classified according to four general expert advice domains (pharmacological advice; providing information; direct patient care; advice to refer to other professional care providers); 2): consultation characteristics: problem domain; type of consultation; profession of the requesting care provider; profession of the consultant. Frequencies and proportions were analysed to assess the nature and extent of the advice given. Logistic regression analysis was used to determine the factors associated with the advice.

**Main results:** More than half of all the expert advice given concerned pharmacological advice; providing information was the second most frequent action. Over 10 percent of all actions concerned direct patient care. Significant relationships with expert advice in all four general domains were found for most elements of the consultation characteristics. Pharmacological advice was related to telephone consultations; GPs as requesting care provider; advice given by clinical or nursing home physicians; and problems in the physical/pharmacological domain. Advice to refer to other professional care providers was related to problems within the psychosocial- and organisational domain coming from requesting care providers other than GPs and advised by GPs, nurses or a multidisciplinary team.

**Conclusions:** This study shows that several elements of consultation characteristics have a particular influence on the expert advice given by PCC teams. To optimise the Dutch model of PCC, choices with regard to PCC team composition and the type of consultation should be made, because these characteristics evidently result in different advice domains. Further research is needed to address issues on the level of patients as well as requesting care providers.

## Introduction

In general, palliative care is considered to be complex care. Palliative care requires the expertise, competence, skills, and dedication of professional healthcare providers working in various parts of the healthcare system. Because of this complexity and the fact that palliative care usually forms only a small part of the job for most professionals<sup>1,2</sup>, consulting with colleagues or experts is a well-established resource and source of support in problem-solving in palliative care.

In the last few decades, such consultation with palliative care experts has become increasingly institutionalised. Different types of palliative care services were developed in order to meet the increasing demand for palliative care expertise and advice. The primary task of most palliative care support teams is the direct provision of care to the patient and family<sup>3-6</sup>; providing consultation to professionals seems to be a subsidiary task for these teams. However, in the Netherlands one of the basic elements of a government stimulation programme on palliative care consultation was the creation of teams specifically focusing on expert advice instead of direct care provision. Palliative Care Consultation teams (PCC teams) were set up throughout the country to provide information, support, and advice to professionals in the palliative care of patients.

Our previous research on PCC teams in the Netherlands has enabled us to identify the extent and nature of the requests for consultation with PCC teams from the side of the professionals<sup>7,8</sup>. The results proved to be important in tailoring the quality improvement of the PCC teams appropriately to suit the needs of the various professionals involved in palliative care. In the present study, we have concentrated on the advice given by PCC team members to the requesting care providers, a topic as yet unexplored. This information is very relevant to those wishing to keep abreast of future developments and assemble an optimal composition of palliative care consultation teams. Furthermore, owing to the unique situation of the Netherlands' model of PCC (giving expert advice instead of care provision), this study might add useful information to the wider discussion of the improvement of quality of palliative care.

Our study had the following aims: 1) to determine the nature and extent of the advice given related to the most frequently occurring problems in the requests for consultation; 2) to identify the factors influencing the differences in advice given.



## **Methods**

### *Setting*

In the period from 1 March 2001 to 1 March 2003, twenty-one PCC teams participated in this national descriptive study by systematically recording the requests they received for consultations and the advice they provided in response. The first PCC team started in 1997; by March 2003, twenty-three PCC teams were available, which taken together covered two thirds of the country. Two of these teams did not participate in our study.

Some teams are based in hospitals and some in a primary care setting. Most of the teams are multidisciplinary and their aim is to provide expert advice for all the professionals involved in palliative care in their region. The staff of most PCC teams consists of professionals from several disciplines, such as general practitioners (GPs), nurses, clinical physicians, and nursing home physicians. The teams have acquired additional palliative care expertise through education and work experience; they attended some specific courses before the PCC teams started. In the study period, the PCC teams conducted two types of consultation: (1) telephone consultations in which only the consulting professional was contacted without any contact at all with the patient; (2) bedside consultations in which both the consulting professional and the patient were seen and spoken with directly.

All PCC teams could be contacted during office hours, while a few teams were accessible 24 hours a day seven days a week. Most of the consultations were requested for cancer patients, but the teams also encountered patients with a wide range of other terminal illnesses.

### *Data collection*

The characteristics of the palliative care consultation were recorded by the PCC staff on a standardised registration form developed by a national multidisciplinary group of researchers. This form was based on pilot studies with different PCC teams, the experience of the researchers, and a review of the literature. All the data were entered into a nationwide computerised database that provides the data for different studies<sup>7-9</sup>.

In the present study, three sets of information were used<sup>a</sup>:

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<sup>a</sup> For clarification of the consultation procedure as well as the general advice domains, see box 1

**Box 1. Palliative Care Consultation in the Netherlands**

**Consultation procedure:** For all kind of professionals in healthcare (*requesting care providers*) it is possible to contact PCC teams with a *request for consultation*. The request is categorised at a general problem level (*problem domain, for example the psychosocial problem domain*) and then more specifically (*specific problems, for example anxiety*). The PCC team members (*consultants*) give up to five *specific advices* (*for example, referral to psychiatrist, information about coping*) per specific problem. All specific advices are part of one of four *general expert advice domains* (*for example, advice to refer to other professional care providers, providing information*).

**Clarification general advice domains:** all specific advices can be classified into four general advice domains:

- *Pharmacological advice:* providing opinion about the best procedure with regard to medication in the patient's current situation and in the near future.
- *Providing information:* providing knowledge or facts about the disease, treatment, and care.
- *Direct patient care:* providing care and support to the patient/informal care provider and actually assisting the professional by means of bedside teaching or organising and coordinating the care.
- *Advice to refer to other professional care providers:* giving an opinion about sending the patient/informal care provider to another person or place for (further) help, information or advice

All domains except the third focus exclusively on providing PCC team members' expert advice to the requesting care provider. In the interests of clarity, we only use the term '(expert) advice', but 'direct care' is incorporated in this term.

(1) Data on the nature of the advice given in answer to the requests for consultation. We studied the type and number at a general level and also at the level of specific advice.

(1a) Expert advices were classified according to four general advice domains: pharmacological advice; providing information; direct patient care; advice to refer to other professional care providers.

(1b) Each general domain was subdivided into a number of specific advice domains (information concerning homecare technology; bedside teaching; referral to a psychiatrist; and so forth). The number of specific advices per general domain ranged from three in the pharmacological domain to 12 in the referral domain.

(2) Data on the nature of the problems presented in the requests for consultation. We concentrated on the following:

(2a) The number of problems within three problem domains, namely the pharmacological/physical domain; the psychosocial domain; and the domain of the organisation of care.

(2b) The five most frequently mentioned specific problems within each of these three problem domains.

(3) Information on the characteristics of the consultation that we hypothesised would influence the advice given.

(3a) The problem domain of the request for consultation: pharmacological/physical domain; psychosocial domain; and the domain of the organisation of care.

(3b) The type of consultation: telephone or bedside consultation.

(3c) The profession of the requesting care provider. GPs; nursing home physicians; clinical physicians; district nurses; and nurses working in hospitals were distinguished. Nurses working in homes for the elderly, nursing homes, or hospices were classified under the hospital group.

(3d) The profession of the consultant. GPs; other physicians (clinical – or nursing home physician); nurses; and a multidisciplinary team were distinguished.

### *Statistical analysis*

The unit of analysis was threefold:

(1) Advice given: we used frequencies and proportions to study their numbers on both the domain and the specific levels. In addition, we calculated the percentage of consultations in which the four different advice domains occurred (tables 1 and 2).

(2) Advice related to problems in requests for consultation: these were also assessed by means of frequencies and proportions (table 2).

(3) Identifying factors related to advice: a logistic regression analysis was carried out to determine the factors related to advice given (table 3). A  $p$ -value less than or equal to 0.05 was considered significant. The selected independent variables (see methods/data collection/(3)) were group-variables, so one of each group was used as the reference variable. The dependent variables were the four general advice domains: pharmacological advice; providing information; direct patient care; and advice to refer to other professional care providers. These variables were dichotomised (yes/no). All the analyses were performed using the SPSS 12.0 system for personal computers.

### **Results**

Over the two-year research period, 20,174 specific advices were provided by the PCC teams. These advices originated from 3242 requests for consultation in which 11,327 specific problems were raised.

Table 1. Extent and nature of expert advice (n=20174)

Advices	% of number of specific advices given within a general advice domain		% of total number of advices (n=20174)
<b>Pharmacological advice</b>			
Modification of medication	37.1	(4420)	21.9
Information about medication	32.8	(3909)	19.4
Anticipating pharmacological advice	30.1	(3590)	17.8
<b>Total</b>	<b>100.0</b>	<b>11919</b>	<b>59.1</b>
<b>Providing information</b>			
Healthcare services	17.2	(611)	3.0
Homecare technology	18.3	(649)	3.2
Coping	6.8	(242)	1.2
Disease	13.4	(474)	2.3
Nursing/caring	30.8	(1091)	5.4
Euthanasia	0.8	(30)	0.1
Other	12.7	(451)	2.2
<b>Total</b>	<b>100.0</b>	<b>3548</b>	<b>17.4</b>
<b>Direct patient care</b>			
Psychosocial support patient/informal care provider	40.9	(946)	4.7
Bedside teaching	5.3	(122)	0.6
Technical action	7.1	(165)	0.8
Coordination/organisation of care	24.6	(567)	2.8
Arrange admission	13.4	(309)	1.5
Other	8.7	(201)	1.0
<b>Total</b>	<b>100.0</b>	<b>2310</b>	<b>11.4</b>
<b>Advice to refer to other professional care providers</b>			
General practitioner (GP)	14.4	(346)	1.7
Nursing home physician	1.5	(36)	0.2
Clinical physician	18.1	(435)	2.2
Psychiatrist	2.6	(61)	0.3
Psychologist	5.6	(133)	0.7
Social worker	3.1	(76)	0.4
Clergyman	3.9	(94)	0.5
Physiotherapist	2.6	(61)	0.3
Speech therapist	0.4	(10)	0.1
Nursing specialist	4.3	(103)	0.5
Home care	22.6	(542)	2.7
Other healthcare providers	20.9	(500)	2.5
<b>Total</b>	<b>100.0</b>	<b>2397</b>	<b>12.1</b>
<b>Total</b>		<b>20174</b>	<b>100.0</b>

### *Extent and nature of expert advice given (tables 1 and 2)*

More than half of all the advices given concerned pharmacological advice. It concerned the patient's current and also future situation. Providing information was the second most frequent action, particularly information about available nursing/caring, homecare technology, and healthcare services. Despite the

emphasis of the PCC teams on providing expert advice rather than direct care to patients, over 10 percent of all their actions concerned giving direct care.

These ranged from providing psychosocial support to patients and their informal care providers or organising and coordinating the necessary care to bedside teaching to the professionals who requested support. PCC teams regularly referred to professional care providers outside their team; home care, clinical physicians and GPs were most frequently referred to.

Table 2 reveals the huge number of pharmacological advices and shows that one or more were given in over three quarters of all requests for consultations in our study. Information was provided in nearly half of all requests for consultation; direct patient care and advice to refer both fluctuated around one quarter of all requests for consultations.

**Table 2. Number of requests for consultations in which the advices occurred (n=3242)**

	<b>Number of requests for consultations in which <math>\geq 1</math> advice in this general advice domain occurred</b>	<b>% of total number of requests for consultations (n=3242)</b>
Pharmacological advice	2565	79.1%
Information giving about	1481	45.7%
Practical support in care provision	787	24.3%
Advice to refer to other professional care providers	1028	31.7%

### *Advice related to problems (table 3)*

Pharmacological advice mostly responded to problems in the physical/ pharmacological domain. The number of advices almost doubled the others for four of the specific problems, including pain and nausea. Providing information and advice to refer followed at some distance in this problem domain. Pharmacological advice was also often given in cases of agitation/confusion and anxiety problems. Socially-oriented specific problems, such as the lack of informal care or acceptance of illness, involved direct patient care more often. This was also often provided for problems concerning the organisation of care. However, for this type of problem, providing information was the most frequent action. For example, two thirds of the specific problems relating to the use/availability of materials and equipment and the inventory situation of care were (also) faced with providing information.

Table 3. Advice in the case of the five most frequently presented specific problems (per main domain, absolute numbers)

Specific problem (five highest in problem domain)	n	Pharmacological advice	Providing information	Direct patient care	Advice to refer to other professional care providers	Total
<b>Physical/ pharmacological</b>						
• Pain	1470	2582	244	97	361	3284
• Choice of medication	694	1248	32	4	34	1318
• Route of administration	564	712	137	40	121	1010
• Dosage of medication	506	907	22	5	20	954
• Nausea	471	829	79	15	37	960
<b>Psychosocial**</b>						
• Agitation/confusion	372	585	65	40	37	727
• Anxiety	340	308	113	116	81	618
• Lack of informal care	153	--	88	87	108	283
• Acceptance of illness	135	1	41	82	57	181
• Coping with problems	119	12	74	62	48	196
<b>Organisation of care***</b>						
• Use/availability of materials and equipment	327	9	257	83	112	461
• Use/availability of professional care	255	4	149	77	154	384
• Inventory situation of care	219	2	153	131	70	356
• Coordination of care	182	2	70	110	62	244
• Admission to palliative care unit	172	--	60	167	23	250

Ad : in all 7599 problems were raised in the physical/pharmacological domain

Ad \*\*: in all 2280 problems were raised in the psychosocial domain

Ad \*\*\* : in all 1448 problems were raised in the organisation of care domain

Table 4. Influencing factors for expert advice

Variables	Pharmacological advice			Providing information			Direct patient care			Advice to refer to other professional care providers		
	Odds Ratio	95% CI	P-value	Odds Ratio	95% CI	P-value	Odds Ratio	95% CI	P-value	Odds Ratio	95% CI	P-value
<b>Problem domains</b>												
• Physical/pharmacological	1			1			1			1		
• Psychosocial	0.17	(0.16 0.19)	0.000	1.39	(1.26 1.53)	0.000	9.68	(8.55 10.96)	0.000	2.63	(2.36 2.92)	0.000
• Organisational	0.004	(0.003 0.006)	0.000	3.35	(3.02 3.71)	0.000	15.17	(13.17 17.48)	0.000	3.04	(2.69 3.43)	0.000
<b>Consultation</b>												
• Bedside	1			1			1			1		
• Telephone	2.18	(1.99 2.38)	0.000	0.98	(0.89 1.08)	ns	0.11	(0.10 0.13)	0.000	1.64	(1.46 1.85)	0.000
<b>Profession requesting care provider</b>												
• GP	1			1			1			1		
• Nursing home physician	0.74	(0.57 0.95)	0.017	1.17	(0.89 1.53)	ns	1.07	(0.67 1.71)	ns	1.39	(1.02 1.92)	0.038
• Clinical physician	0.64	(0.58 0.72)	0.000	1.13	(0.99 1.27)	ns	0.61	(0.53 0.70)	0.000	2.99	(2.62 3.42)	0.000
• District nurse	0.51	(0.44 0.59)	0.000	1.19	(1.02 1.38)	0.026	1.40	(1.13 1.74)	0.002	1.83	(1.55 2.16)	0.000
• Nurse working at hospital	0.66	(0.59 0.74)	0.000	1.40	(1.25 1.58)	0.000	0.81	(0.70 0.93)	0.004	1.87	(1.62 2.16)	0.000
<b>Profession consultant</b>												
• Physician (clinical and nursing home)	1			1			1			1		
• GP	0.46	(0.36 0.59)	0.000	1.56	(1.18 2.08)	0.002	0.89	(0.44 1.81)	ns	2.34	(1.69 3.25)	0.000
• Nurse	0.20	(0.17 0.23)	0.000	2.73	(2.32 3.22)	0.000	2.05	(1.59 2.65)	0.000	2.68	(2.18 3.30)	0.000
• Multidisciplinary team	0.42	(0.37 0.47)	0.000	1.93	(1.68 2.22)	0.000	1.49	(1.18 1.87)	0.001	2.22	(1.85 2.65)	0.000

### *Factors influencing advice given*

Pharmacological advice proved to be given more often in the case of physical/pharmacological problems and in the case of telephone consultations. The Odds Ratio (OR) for telephone consultation was twice as high as that for bedside consultation. When the requesting care provider was a GP, the consultation resulted in pharmacological advice more often than to other requesting care providers.

More Information was provided in the case of organisational problems and, to a somewhat lesser extent, in the case of psychosocial problems. Providing information was furthermore determined by the profession of the consultant: nurses, multidisciplinary teams, and GPs provided information more often than did clinical- and nursing home physicians acting as consultants.

Organisational and psychosocial problems were more often followed by direct patient care. This was also the case with bedside consultation. When the requesting care provider was a district nurse, more direct patient care was given than for a GP. Conversely, GPs in the capacity of a requesting care provider were more often supported with direct patient care than were clinical physicians or nurses working in a hospital.

For the last general advice domain, advice to refer to other professional care providers, a similar picture emerges. Here also, psychosocial and organisational problems led to advice to refer more often than did physical/pharmacological problems. With bedside consultations, when GPs were the requesting care provider and when the advice was given by clinical and nursing home consultants, advice to refer was given less often.

### **Discussion**

More than half of all advices given by PCC teams in the Netherlands were pharmacological. Providing information was the second most frequent action. Most pharmacological advice was related to physical/pharmacological problems (in particular, specific problems concerning pain and choice of medication) and the two most frequently occurring specific psychosocial problems: agitation and anxiety. In terms of frequency, providing information and giving advice to refer followed organisation of care problems. Contrary to the primary aims of Dutch palliative care consultation, namely giving advice rather than care provision, PCC teams sometimes actually provided direct patient care. This provision mostly followed organisation of care problems.



Our study demonstrates that advice given by PCC teams is influenced by all four consultation characteristics; problem domain; type of consultation; profession of the requesting care provider; and the profession of the consultant. With regard to the type of consultation, bedside consultation led more often to direct patient care, whereas telephone consultation was more often followed by pharmacological advice and advice to refer to other professional care providers. GPs as requesting care providers were more often furnished with pharmacological advice, whereas other requesting professionals received advice more often in the other three general advice domains. Providing information, direct patient care, and advice to refer were more frequently provided by GP-consultants, nurse-consultants or a multidisciplinary team.

What lessons can be learnt from the results of our study? Expertise development and education programmes must aim expressly at managing the problems for which advice is most often given; pain relief, medication problems, nausea, agitation, and anxiety. Furthermore, projects directed towards alleviating organisational problems, such as dealing with logistics and routing concerning the palliative care trajectory, might also prove worthwhile.

The multidisciplinary composition of PCC teams needs to be adapted to this situation. Given the massive share of pharmacological advice, medical involvement is of significance. Adding a pharmacist to the PCC team might be worthy of consideration.

The high number of requests for consultation and the nationwide character of the study ensure representative results for PCC teams in the Netherlands. Some caution is necessary, because of the high number (more than 20) of different PCC team members who completed the registration forms. The researchers tried to decrease interpersonal variation through repeated written and oral instructions, but the practice of palliative care consultation and the registration form itself were too complex to exclude variation completely.

The need for palliative terminal care is expected to increase considerably in the next few decades<sup>10-12</sup>. To meet this increasing need, palliative care services have been developed throughout the world<sup>13,14</sup>. As one model of a palliative care service, PCC teams are perceived to have a positive impact on patient care and appear to fill a gap in the multi-specialty provision of care<sup>3,15,16</sup>. The results from our study might help others who have an interest in establishing a similar programme and might contribute to an optimal composition of palliative care consultation. However, some further remarks are called for.

Direct care to patients comprised 12 percent of the total advices. These 12 percent typically took place as an answer to organisational problems and, to a lesser extent, to psychosocial problems. It is important to discover the reasons why PCC team members provide this direct patient care. Is the problem so urgent that it cannot wait a little while? Are consultants of the opinion that other professionals are less capable than they are? Are the bureaucratic procedures within organisations the cause? If consultation instead of taking over care remains the preferred palliative care model, policymakers will have to invest in the removal of the barriers.

Previous research on the Dutch PCC teams has indicated that bedside consultations have an added value compared with telephone consultations<sup>9</sup>. Bedside consultations with a further exploration of the problems presented in the presence of the patient appear to cover the complete range of possible problems better and fit the definition of palliative care more closely (support for the family and attention to psychosocial and spiritual problems<sup>17</sup>). Bedside consultations are, however, time-consuming and a choice for bedside consultation as a possibility might influence the team composition. Our results showed that, if a PCC team aims to provide comprehensive advice for problems to be approached from several sides, multidisciplinary in the consultant team is essential. The various disciplines, nurses and doctors, can complement each other with regard to their views of a problem and ways of resolving it. This multidisciplinary, however, is not needed in every consultation; a simple advice might well suffice to answer a straightforward question (dosage of specific medication for a specific symptom, for example).

Despite the fact that consultation teams are aimed primarily at professionals, the ultimate goal for all activities in palliative care is quality-of-life improvement for patient and family. We consider that further research on PCC teams must address outcomes on the level not only of professionals, but also of patients. Several studies on patient care teams (some with consultation as a subsidiary issue) have shown, although with caution, that palliative care teams offer some benefits to palliative care patients<sup>4-6,18</sup>. It would be helpful to know whether these benefits also occur with regard to purely advisory or consultation teams. Comparing them might reveal some interesting points.

Palliative care consultation is becoming an important aspect of palliative care services. Removing the obstacles in order to optimise it is a challenge.

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## Chapter 9

### General discussion



## Introduction

Palliative care is an important public health issue. It is concerned with the suffering, the dignity, the care needs, and the quality of life of people at the end of their lives together with the care and support of their families and friends<sup>1</sup>. In the Netherlands, palliative care went through a rapid and substantial development from 1998, following the Ministry of Health's financial support of a five-year palliative-care stimulation programme. Part of this programme was the establishment of six Centres for the Development of Palliative Care (COPZ). The research projects reported here were carried out within the collaborative research programme of these Centres. This thesis addresses three pertinent themes: the barriers in daily palliative care experienced by general practitioners (GPs) (theme 1); the experiences of patients and informal care providers in primary palliative care (theme 2); and the monitoring of a national programme for quality improvement in palliative care: the Palliative Care Consultation teams (PCC teams) (theme 3).

An important part of the governmental stimulation programme was the establishment of PCC teams throughout the country. These were designed to support and enhance the expertise of professionals concerned with palliative care. The design was based on the assumption that the problems and barriers confronting professionals might be decreased through consultation. However, no comprehensive picture of the barriers actually occurring in palliative care was available. First of all, therefore, we investigated the barriers experienced by GPs in their daily provision of palliative care (**theme 1, chapters 2 and 3**). We concentrated on GPs, first because of the strong emphasis national policy put on primary palliative care<sup>2,3</sup> and second because of the presumed central role of GPs in primary palliative care<sup>2,4-6</sup>. To complement the picture of primary palliative care, we studied the experiences with different aspects of palliative care of the persons most directly involved: the patients and their informal care providers (**theme 2, chapters 4 and 5**).

The last theme (**theme 3, chapters 6, 7 and 8**) concerns several aspects of palliative care consultation. We studied the requests for consultation, the clarification process of a request in order to identify possible additional problems, and the support and advice given by PCC team members. In this final chapter (chapter 9), we present and discuss the main conclusions from each part of the thesis. Furthermore, we consider the most relevant methodological limitations and reflect on the consequences of this study for palliative care in general terms and for further research.

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***Theme 1: Barriers in daily palliative care experienced by GPs*****Conclusions and discussion**

The studies reported in the two first chapters were concerned with barriers in daily palliative care from the perspective of the GP. Through a qualitative focus group study, we gathered GPs' opinions of their tasks in palliative care and the barriers encountered in performing these tasks. A subsequent survey concentrated on the prevalence of these barriers and their variation among GPs.

GPs described their tasks in palliative care as satisfying and varied, but burdensome. They were unanimous in their views about their tasks in somatic and psychosocial care, but their opinions differed, however, with respect to whether the coordination of care belonged to their primary tasks in palliative care. They experienced barriers on three levels: (1) personal: barriers related to knowledge, skills, and emotions; (2) relational: barriers concerning communication and collaboration; (3) organisational: barriers related to the organisation of care and compartmentalisation in healthcare.

Our second study within this theme - a survey - was based on the points raised in these focus groups. We rigorously developed a questionnaire containing five groups of barriers: (1) communication with patients and relatives; (2) organisation and coordination of care; (3) knowledge and expertise; (4) integrated care; (5) time-for-relatives. We found that GPs experienced substantial obstacles in all five groups. The most prevalent were problems with bureaucratic procedures, the time necessary to arrange homecare technology (both situated within the aspect 'organisation and coordination of care') and the difficulties brought about by the wish or necessity to obtain extra care (situated within 'integrated care'). Within the 'communication with patients and relatives', GPs reported the most difficulties with handling relatives' hidden agendas and situations in which relatives had mutual disagreements.

We questioned the GPs also on expertise development activities in this field and on GP characteristics. When considering the variation among GPs in relation to these variables, we found that gender, consultation, and reading the literature had no influence on the number of barriers a GP perceived. Attending specific educational meetings was associated with encountering fewer obstacles in communication with patients and relatives. With regard to the 'organisation and coordination of care' scale, no contributing variables were found to account for differences between GPs. Obtaining extra care, another highly problematic aspect, was only associated with GP characteristics, namely practice setting and region.

In the Netherlands, national healthcare policy has encouraged terminal care in the home of the patient. GPs have a pivotal role in this primary (community) care<sup>7-10</sup>. The fact that most GPs are now affiliated with a large-scale out-of-hours general practice service might play a part in the discussion of the GP as coordinator of care. General practice is responsible for 25 percent of the hours in the week; the other 75 percent is covered by GPs' out-of-hours organisations<sup>11</sup>. Research is currently being undertaken into the care for terminal patients given by GPs' out-of-hours organisations. The results of a pilot study suggested that the transfer of information from GPs to their out-of-office organisation was the greatest barrier<sup>12</sup>. This corresponds to an older study, which demonstrated that communication between GPs and the cooperative from the out-of-hours organisation was poor for terminally-ill patients<sup>13</sup>. Since the need for palliative care is not restricted to office hours, other ways of providing the continuity and coordination of care must be found. Handing over this coordinating role to another professional might offer some relief. By nature of their education and job description, primary care nurses might be in a position to undertake this coordinating role<sup>14</sup>; this mutation of professionals might not be enough, however. Nurses also have to work within office hours to complete most of their work, albeit to a lesser extent, and palliative care is not always prioritised in their large-scale organisations. So, besides having another professional take care of some of the coordination and continuity tasks, organisational changes must be implemented to develop palliative care in the community. Having at least three organisational frameworks seems worth investigating. Organising proactive palliative care in the community might be possible by means of a model like the Gold Standards Framework (GSF)<sup>15,16</sup>. Palliative care patients are depicted and registered at an early stage and then followed through during the whole process. This procedure might prevent the patient's situation getting out of control. Such a palliative care registration is in fact one of the new indicators in the Quality and Outcomes Framework (QOF), a component of the new general medical services (GMS) contract that was introduced into general practice in the UK in April 2004<sup>17</sup>, confirming that this topic is also considered important elsewhere. Another possibility is an integrated care programme. Ouwens and colleagues<sup>18</sup> concluded that these programmes had some positive effects on the quality of care for chronically-ill patients. The third opportunity is the use of a systematic approach in palliative care needs-assessment. Recently, Osse and colleagues described the development and evaluation of specific instruments for cancer patients in palliative care and their families for the systematic assessment of their problems and

needs<sup>19</sup>. The use of these Problems and Needs in Palliative Care (PNPC) questionnaires might well lead to a palliative care that is better tailored to the specific needs of patients and caregivers.

Early recognition is a necessary, but not sufficient condition for care to be effective<sup>20</sup>. So, should a patient, the patient's family, or the primary care providers encounter discontinuity, overburdening of the informal care providers or the nuisance of a multitude of interacting problems hardly capable of resolution, hospices and almost-like-home-houses can be a good alternative. It is absolutely necessary for all the parties involved in palliative care to reorientate themselves to come to terms with the near future. As for the boundaries of primary palliative care now impinging on our society, all the aspects mentioned above must have a clearly perceptible and prominent role in this discussion.

### **Methodological considerations**

The studies described within theme 1 of this thesis were performed according to two different perspectives: qualitative and quantitative. Research often requires a qualitative design in a field where much remains in a 'black box'. Our focus-group study enabled us to obtain an insight view of primary palliative care. Quantitative insights were gathered by means of a survey based on this initial study.

The studies had some possible limitations. It could be argued that, in both studies, we may have assembled a group of GPs with a special interest in palliative care. This might result in both an under- as well as an over-presentation of the barriers experienced. At the same time, since the common values in palliative care – holistic, patient-centred, delivered in the context of families and friends – are in common with the values in primary care<sup>21</sup>, we can expect most GPs to be intrinsically motivated to provide optimal palliative care. We therefore assume that both studies present a realistic picture of the perceived obstacles in palliative care.

To a certain extent, healthcare professionals in the Netherlands are free to (re)organise care around complicated care issues. The independent variables in our survey did not include such organisational characteristics. As a result, we might have missed some important variables based on what GPs experience as obstacles.

To receive a full picture of the obstacles in primary palliative care on which to base improvement programmes, these results must be complemented with studies from other perspectives such as patients and their families and primary care nurses.



## Recommendations

Primary care is the most common preference in advanced cancer<sup>22</sup>. The challenge for the providers of primary palliative care is to deliver high-quality care to their patients within the boundaries of the changes in their specialty. Personal continuity must be transferred to factual continuity: arranging continuity among all the possible participants in care by using information from all involved. Documentation, collaboration, deliberation, and organisational structures are needed to achieve this continuity.

The tension which we detected in GPs concerning their role as care coordinator must be placed in a broad multidisciplinary discussion. Furthermore, research on the consequences for the barriers of various organisational structures in primary palliative care will clarify the complex web of barriers and their determinants. Accordingly, all contributors must invest willingly in optimising primary palliative care. A programme such as the Gold Standards Framework (GSF), widely used by primary care teams in the United Kingdom, might help develop a practice-based system to improve the organisation and quality of care in the community for patients in the last stages of life<sup>15,16,23</sup>. Implementation of such a model (adapted to the Dutch healthcare system) in our society must be followed through and monitored carefully.

Furthermore, more research is needed on the reasons why patients and family choose to stay (temporarily) in a hospice or almost-like-home-house and the boundaries that they had to cross before acceptance and decision. Higginson and colleagues found inpatient hospice care to be a second preference in their review<sup>22</sup>. Meeting preferences is an important outcome for palliative care services, but preferences for the place of care are known to change with time<sup>1</sup>. The evidence found in the systematic literature review of preferences was of varied quality and not sufficient to enable a comprehensive picture of preferences for place of terminal care in advanced cancer to be constructed<sup>22</sup>. Since, judging by the studies in this part of the thesis, the boundaries of primary palliative care in the Netherlands seem to have been reached, this picture is important to inform discussion concerning the future.

The multidisciplinary PCC teams are a special feature of palliative care in the Dutch healthcare system. The primary tasks of these teams are to provide information, support, and advice to professionals providing palliative care. Both studies in this part of the thesis were performed before these teams were established. It would be interesting to repeat our survey to discover what impact the teams have had on the perceived barriers in day-to-day primary palliative care.

## ***Theme 2: Experiences of patients and informal care providers***

### **Conclusions and discussion**

Research on palliative care patients in primary care is still in its infancy. At the time we conducted the study described in chapter 4, no similar research had been published. One of our results was that palliative-care patients and their informal care providers were positive about the palliative care provided in primary care. They were most positive about the patient's GP and most critical about the bureaucracy within organisations. These findings correspond with the conclusion drawn by de Vogel-Voogt and colleagues (2006) that 'patients with incurable cancer, on average, are satisfied with the care offered by their healthcare professionals'<sup>24</sup>. Van den Muijsenberg<sup>25</sup> (2001) also reported high rates of satisfaction. The matter of acquiring care, or material and equipment for care, was not a subject of research in the other studies reviewed, so our negative findings regarding this bureaucracy cannot be compared. However, de Vogel-Voogt reported that patients had difficulties with regard to the fine-tuning of different professionals and with access to help: aspects both touched on indirectly in our topic.

In Chapter 4 we report not only patient experiences, but also the views of their informal care providers. We concluded that, in general, informal care providers were somewhat more critical in their opinions than the patients were. Like the patients, informal care providers criticise most strongly the bureaucratic procedures for acquiring care or material and equipment for care. Results published recently by Osse support this finding. He and his colleagues reported that, in their study, over 50 percent of the informal care providers found access to help from agencies/professional organisations difficult and that over 60 percent of them reported unmet needs regarding this topic<sup>26</sup>. A huge bureaucracy is encountered in palliative care for children; the informal care providers - the children's parents - report unacceptably inert procedures and rigid rules, all leading to a lower quality of care, which impacts on the quality of life<sup>27</sup>.

In chapter 5, we report a study of a totally different aspect within palliative care. We conducted an in-depth interview with a woman and her partner who were living on borrowed time. It is hard to determine how many patients experience a period of borrowed time, so more research is needed to discover the scope of this phenomenon. What we discovered was that finding new ways of interpreting physical signs and symptoms, developing different ways of looking at the future, and changed choices and priorities were important themes in the daily lives of our

patient and her husband in this uncertain, unexpected, extra lease of life. The 'extra time' spent in a relatively good condition means extra time to live and enrich the last phase of life instead of just having more time to prepare for death. We believe that these aspects are of such importance that the professionals involved in the care of these patients should focus their attention on the themes we observed and give appropriate support to such a patient and family.

### **Methodological considerations**

Researching palliative-care patients can be a complex and precarious task. Below, we discuss some points concerning selection bias in the patient group and the problem of patient recruitment by GPs. Finally, we comment on our case-study design.

The group of patients we studied in chapter 4 was a selected group: no patients were interviewed whose physical or psychosocial health status (according to the patients themselves or their GPs) was too poor for them to participate in the study. With a longitudinal design and the first contact moment earlier in the palliative care phase, and maybe even in the curative phase, we could have followed the patients through in situations during which their health status became poorer<sup>24</sup>. Another point of attention regarding the selection bias is the way in which the inclusion criteria were described. In a recently published study by Borgsteede and colleagues<sup>28</sup>; it was concluded that there were substantial differences in study populations according to the different inclusion criteria used to select them.

Both conclusions might form a basis for the better recruitment of patients for palliative care research in primary care. In our study, including patients turned out to be extremely difficult and we finally had to close the study before we had reached our intended number of participants. During the study, we asked the participating GPs about the reasons for the difficulty of inclusion and how we might improve it. They mentioned various types of GP- and patient-related reasons, ranging from the presumed vulnerability of palliative care patients to difficulties with estimating life expectancy or their own forgetfulness. In spite of these problems, we take the position that a substantial measure of time and energy must be invested in patient recruitment for studies of palliative care patients.

As far as we know, our study on borrowed time was unique. Where research evidence is lacking, an in-depth qualitative case study is an accepted and appropriate method. It is not possible to generalise on the basis of a single case study and no reference material in other palliative care research literature. However, when the research is viewed as the first in an uncultivated research

area, the main themes explored might form a basis for use in practice as well as for further research.

## Recommendations

Research is imperative for an evidence-based approach to the improvement of primary palliative care<sup>29</sup>. So much that could influence patient care or quality of life is still unknown at different levels, so that research using different scientific methods is needed. Palliative-care researchers have to accept that a randomised controlled trial, often considered the ideal scientific method, often cannot be used in their research designs<sup>30</sup>. Under certain conditions other designs can, however, produce reasonably strong evidence, relevant data, and findings capable of unlocking 'the black box' of palliative care<sup>30,31</sup>. We put forward some suggestions for improvement on the basis of our experiences with research on primary-palliative-care patients and recent literature.

In order to identify patients for research in primary palliative care and address the problems concerning the description of the inclusion criteria, GPs could ask themselves one simple question with regard to their patients: *Would I be surprised if this patient were to die in the next 12 months*<sup>20,32</sup>? This question might lead to the identification of a greater number of patients in need of palliative care as well as more potential research participants. After this first identification, further steps have to be taken before a patient can enter a study programme. GPs seem to be understandably reluctant to 'bother' patients and families in their last period together<sup>33</sup>. However, participation in research is already surrounded by all kinds of established ethical principles and guidelines<sup>34-36</sup>. If researchers apply these in a decent and respectful manner, palliative care is similar to other research areas<sup>37</sup>. The remarks made by the patients in our study strengthened this opinion. At the end of every interview, we asked the participants how they felt regarding their contribution to the study. They invariably reported that talking to an independent person about one's life, disease, and experiences was valuable. Some stated that parts of the study were confrontational and in all probability would lead to later reflection. No one, however, regretted consenting to participate. Many explicitly expressed the hope that future patients would benefit from their participation through improvements in the quality of care and its organisation, for example. Therefore, in conclusion we recommend GPs not to be so reserved, afraid and paternalistic as for asking their patients to participate in palliative care research. Most patients are able to independently form an opinion and decide whether or not they will join the study.

***Theme 3: Monitoring of a national programme for quality improvement in palliative care: PCC teams*****Conclusions and discussion**

The questions to be addressed in the prospective studies reported in this part of the thesis concerned several aspects of palliative care consultation. We studied the requests for consultation, the clarification process of a request in order to identify possible additional problems, and the support and advice given by PCC team members. One overall conclusion that we can draw from these studies is that, as one of the core elements in the national programme for quality improvement in palliative care, the PCC teams have positively filled a gap in the everyday practice of palliative care.

Our study of the requests made by professional care providers to the PCC teams showed that well over half of all requests (63 percent) came from professionals working in primary care: GPs and district nurses. The fact that primary care professionals more often requested consultations is in line with the size of the primary-palliative-care population. Currently, there are nearly 8500 GPs in the Netherlands<sup>38</sup>. Despite the fact that there are no exact national figures regarding the total number of palliative care patients in general practice, we nevertheless have some indications that on average GPs give palliative care to 5 – 6 cancer patients each year<sup>39</sup>. A GP spends about 45 minutes on palliative care each week<sup>25</sup>. Furthermore, we know that 65 percent of all the Dutch patients who died as a result of cancer died at home<sup>40</sup>. Notwithstanding the relatively small amount of palliative care provided by every individual GP, the overall primary-palliative-care population is substantial.

Only a minority of the GPs, less than 100<sup>41,42</sup> had followed a vast and specific course on palliative care ('kaderopleiding palliatieve zorg') and could be seen as an expert for that or other reasons, such as extensive experience. Bearing this in mind, it can conversely be argued that, with regard to the size of the primary-palliative-care population, a request for consultation is only requested for a small percentage (< 10 percent) of the patients. This low percentage supports our opinion that the currently expressed requests for consultation are only the tip of the iceberg. Unravelling the background of the large groups of professionals who did not request consultations might be interesting. Of course, this procedure could also be applied to the professionals in the other settings from which the requests for consultation came. In this light, and also because of the recent changes in the palliative care consultation, from January 2004 onwards the Comprehensive

Cancer Centres (IKCs) in the Netherlands have become responsible for the palliative care consultation<sup>43</sup>. Since occasional changes in the structure and basis of the teams take place, continual research on palliative care consultation is needed.

The initial problems posed by professionals requesting advice from a PCC team, can be seen as step 1 in the process of consultation. Step 2, the subject of our second study in this part of the thesis, was the clarification of these initial requests. PCC consultants always investigated the context of the problems and tried to retrieve more information about the problems reported by the professional care provider requesting consultation. This procedure could result in additional problems that also needed the consultant's attention. It was also possible that the problems posed initially became overshadowed by newly-identified problems, because one was derived from the other, for example. We found that clarification accounted for 57 percent of the problems ultimately addressed in the advices given by the PCC team members. This figure means that the amount of initial problems more than doubled as a result of this clarification process!

More detailed examination reveals that physical and pharmacological problems play the most prominent part in the total amount of newly-identified problems. This group is similar to that of the problems expressed in the primary request for consultation. The most striking difference between initial and newly-identified problems concerns psychosocial and spiritual problems. These account for more than a quarter of the newly-identified problems and just less than 15 percent of the initial problems. When relating the number of newly-identified problems to the total number of problems in this category, the merits of clarification become even more visible: the share of newly-identified problems in this domain was 70 percent. The reasons why psychosocial/spiritual problems were often not mentioned until the clarification phase in the consultation process might be an interesting topic to investigate. Are the psychosocial/spiritual issues affecting their patients difficult for professional care providers to envisage or do their professionally-trained eyes rest more readily on more tangible physical and pharmacological problems? The most prevalent problems of patients in the palliative phase of the disease are psychosocial/spiritual<sup>44</sup> and it is important to be alert to them. The most important aspect for the patient is that their care providers address these problems. Combining the huge palliative care population for whom no consultation was asked with the focus on psychosocial/spiritual problems only with the help of a consultant will require a huge effort if holistic palliative care for all is to be achieved!

We also investigated the factors influencing whether or not new problems are identified. Of the variables we included, the discipline of the professional providing consultation and certain patient characteristics (age, diagnosis, prognosis, functional status) had no significant influence. The specific training all PCC team members followed in exploration and clarification seems to have been effective. Furthermore, nurses (most often working as primary consultants) seemed to be capable of interacting with all professional care providers requesting advice, including the large group of physicians. Bedside consultation led more often to newly-identified problems. These were also found more often when the requesting professional was a clinical physician rather than a GP, and in a hospital setting rather than a home situation. The policy of the Dutch government<sup>45</sup> concerning the PCC is that telephone consultations are preferred and that PCC consultants should make as few bedside visits as possible. This forms a threat to good quality palliative care; surely, if they achieve nothing else, palliative professional care providers ought to learn how to deal with psychosocial/spiritual problems.

Our study of the expert advice given in palliative care consultation, step 3 in the process, has led to a better understanding of the extent and nature of the advice given by a PCC and to our knowledge of the factors influencing the differences in the advice given. This study shows, following the same line as that described above concerning bedside consultations, that these were more often followed by direct patient care carried out by the PCC team members. Furthermore, bedside consultations led less often to pharmacological advice and advice to refer to other professional care providers, probably because several tasks were performed by the consultants themselves.

More than half the advices given by the PCC teams in the Netherlands were pharmacological; providing information was the second most frequent action. Specific problems concerning pain and choice of medication induced pharmacological advice. Pain and its alleviation require effort, skills, and knowledge. Differentiated knowledge is needed about pharmacological and other remedies and specific techniques and skills. These are not always possessed by the professionals working in daily palliative care, so it is good that PCC teams fill that gap and develop specific knowledge and expertise concerning pain.

With regard to the provision of information, PCC teams provided information about available nursing/caring, home care technology and health services in particular. This emphasis might say something about the extent of surveyability (the social map) of palliative care services. All those involved in palliative care should discuss whether they ought to open up the complex field of palliative care

services in order to make access easy for every care provider or whether specific institutions, such as PCC teams and more recently the palliative care networks (a collaboration of organisations involved in palliative care in a specific region) are needed for this purpose.

### **Methodological considerations**

Some caution concerning the representativeness of the results for PCC in the Netherlands is necessary, because of the high number (more than 20) of PCC team members who completed the registration forms. The researchers tried to diminish inter-personal variation through repeated written and oral instructions, but the practice of palliative care consultation and the registration form itself were too complex to exclude variation completely.

Similar comments apply to the decision whether or not a bedside consultation is appropriate. It is known that some teams more than others explicitly opted for bedside consultations; furthermore, it is unclear whether and to what extent the decision-making process is influenced by the complexity of the patient's situation, available time, or the working experience of the consultant or requesting caregiver. More research of these issues is needed.

### **Recommendations**

Fortunately, the conclusion of the five-year government palliative care stimulation programme has not meant the cessation of activities in palliative care in the Netherlands. Since the beginning of 2004, the nine IKCs have worked with sections for palliative care<sup>46,47</sup>. One of the tasks was the establishment of consultation activities. The existing PCC teams came within the responsibility of the IKC in their region; new teams were formed in order to achieve national coverage with palliative care consultation. It is important to monitor the extent and nature of consultation activities in order to reveal and anticipate trends resulting from all the new developments<sup>48</sup>. Careful registration is necessary of activities of all kinds in palliative care in the regions of the IKCs, including educational programmes, activities from the palliative care networks, the implementation of the recently-developed palliative-care guidelines<sup>49</sup>, and any new palliative care services.

We concluded that PCC teams have positively filled a gap in palliative care. We have learned from our experience with the consultations that most of them were requested for cancer patients, although the teams received some questions for other patients with a wide range of terminal illnesses. Palliative care seems to be



too strongly associated with cancer patients, while other patient groups will often be in need of palliative care. We therefore recommend that the teams explicitly extend their consultation activities to professionals working with other target groups, for example children in need of palliative care, lung- and heart failure patients, patients with progressive neuromuscular diseases, mentally disabled people or patients with a psychiatric disorder. Such a development should be carefully monitored in close collaboration with the IKCs in order to find out what fits best in the structures that already exist around these patient groups.

Several further research questions arise from our research reported in this thesis and our experience with the PCC teams. It is important to discover which professional care providers in primary care and healthcare institutes do not request a consultation. Research on PCC teams must address outcomes systematically at the level not only of professionals, but also of patients. The type of consultation, telephone or bedside, and the consequences must obviously be taken as a study variable. Our research indicated that bedside consultations have a surplus value; nevertheless, the Dutch Ministry of Health, Welfare and Sport (VWS) discourages bedside consultation<sup>45</sup>. Finally, international comparison of the Dutch PCC model, giving advice instead of taking over care versus the palliative care support teams in which the direct provision of care to the patient and family is a primary task, could lead to a coherent vision of the future of palliative care consultation in our society.

### **The future of palliative care in the Netherlands**

During the last decade, great efforts have been made in the Netherlands to eliminate the backlog in palliative care provision. The developments both completed and planned, the place that palliative care has captured in many organisations, the number and range of projects (research as well as developmental and practical), lead us to the conclusion that we have succeeded in some measure. Currently, there are 36 consultation services, 700 places in intramural services for palliative terminal care, 70 palliative care networks, and over 200 volunteer organisations offering all kinds of support to palliative care patients and their informal care providers<sup>47,50</sup>. The Ministry of Health also developed a policy and financially regulated the national organisation AGORA, a place for the exchange of information and support of palliative care initiatives<sup>51</sup>, the departments of palliative care housed within the 9 IKCs and an arrangement for the coordination of voluntary palliative and terminal care<sup>45,46</sup>. Furthermore, the

appointment of 4 professors dedicated to various parts of the broad spectrum of palliative care indicates that it has begun to be embedded in the university world.

While these developments are to be welcomed, there is still much to do<sup>52</sup>! The task now is to consolidate what has been reached and give it a more structural basis to further the continuous development of palliative care in the Netherlands. In addition to the recommendations made earlier in this chapter, palliative care needs structural nesting in all kinds and at all levels of educational programmes for healthcare professionals<sup>53</sup>. Concrete association with the Universities of applied sciences (HBO/Hogescholen) by means of lectureships dedicated to the professionalism of palliative care, research, and the development and dissemination of knowledge, and innovation of the educational programmes would facilitate a major step forward.

Fortunately, policymakers have recently conceded that palliative care research still needs a firm and specifically dedicated financial impulse, so a new national palliative care research programme has been initiated. Proposals are currently being assessed so that in a few months the Dutch palliative care research agenda for the coming years will be known.

In addition to the advancement of knowledge, education, and research, attention needs to be paid to the widespread implementation of results. Knowledge alone is not enough to improve practice; evidence based clinical guidelines, audits, care pathways, involving users of services in designing and monitoring change are also needed. Methods that encourage teams of professionals to work together to improve the quality of the services provided must be devised and evaluated. This approach<sup>1</sup> might also result in a lowering of the financial and bureaucratic barriers, factors that were recently identified as serious problems yet again<sup>46,54</sup>.

In contrast with earlier times, death and dying on a contemplative level has nowadays been eliminated from the public domain. Although there have been improvements since palliative care became a spearhead in the Netherlands, a public debate is needed to reintegrate death and dying. Moreover, awareness must be increased about what is known and what is uncertain about the causes of death and what help can be offered. Enhanced awareness may allow people to consider more realistically the choices they will want to make in the future<sup>1</sup>. Palliative care must not be something that only specialised palliative care teams, palliative care services or hospices offer when other treatment has been withdrawn. Palliative care should be an integral part of care and capable of being put in place in any setting<sup>1,53</sup> and performed by all kinds of professional healthcare providers and volunteers. The broadening of the concept must take place not only

with respect to persons, but also to timing. Parts of the concept of palliative care can be used in a much earlier phase of disease<sup>9,55</sup>. Palliative care, just like geriatrics and nursing home care, is a non-organ (group) science<sup>56</sup>. Ideas from these sciences should be used throughout the whole spectrum of healthcare. Challenges enough for the coming decades!

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## Summary

This thesis elaborates on three themes within **primary palliative care**. First, two studies covered the barriers in daily palliative care experienced by general practitioners (GPs); the professionals invariably responsible for primary palliative care patients. The second theme concentrates on those to whom palliative care primarily and ultimately relates -the patients and their informal care providers- and explores several aspects of their experiences in primary palliative care. The last theme concerns the Palliative Care Consultation teams (PCC teams) and the process initiated by a request for consultation and proceeding via the clarification of the request to the advice and support given.

GPs play a crucial part in primary palliative care. It is therefore of importance to examine their opinions about their tasks and the barriers that confront them in daily practice. By addressing the barriers they perceive, the quality of primary palliative care can be improved. The studies described in the **first theme, barriers in daily palliative care experienced by GPs (chapters 2 and 3)**, were both carried out at the beginning of the Dutch national programme 'Palliative Care in the Terminal Phase'. We examined the GPs' task perception in palliative care in a qualitative study and we investigated, quantitatively as well as qualitatively, the barriers that confront them in their daily palliative-care practice.

In **chapter 2**, we report the qualitative focus group study on task perception and barriers experienced by GPs in their daily practice. In the year 2000 we gathered together three groups of GPs representing a broad range of experience in palliative care. Content analysis was performed on the transcriptions of the recorded interviews to derive a comprehensive view of the tasks and barriers encountered in daily palliative care. GPs described their palliative-care tasks as 'satisfactory and varied, but burdensome'. Palliative-care tasks included somatic and psychosocial care. Opinions differed with respect to whether the coordination of care was a primary GP task. Barriers were classified according to three levels: (1) personal: barriers related to knowledge, skills, and emotions; (2) relational: barriers concerning communication and collaboration; (3) organisational: barriers related to the organisation of care and compartmentalisation in healthcare. The study revealed a complex web of tasks and barriers. A problem (lack of knowledge, for example) on the personal level may be traced back to an isolated knowledge gap, but the problem may well have originated from communication or

compartmentalisation problems. To maintain GPs' feelings of being at ease with palliative care requires helping them acquire the appropriate balance between technical and organisational interventions and a compassionate orientation to their terminally-ill patients.

The study described in **chapter 3** is based on the results of the focus group study reported in chapter 2. With a rigorous procedure, we developed a questionnaire in which the perceived obstacles were grouped as follows: communication, organisation & coordination of care, knowledge & expertise, integrated care, time for relatives. In the survey we aimed to identify the prevalence of the obstacles and its determinants.

The potential determinants were GP characteristics and expertise development activities. The results of the survey show that GPs experienced considerable obstacles in all palliative care aspects. The most prevalent obstacles were: problems with bureaucratic procedures, the time necessary to arrange home care technology and the difficulties accompanied with the wish or necessity to obtain extra care. 'Number of years of experience', 'region', 'practice setting' and '(multidisciplinary) case discussions' were significant determinants in two or more scale- or item scores.

In general, more years of GP experience and the participation in (multidisciplinary) case discussions was associated with less perceived obstacles. Based on these results policymakers and practitioners can plan and set priorities in handling the obstacles, choose the (additional) expertise needed in the future and realise the preferred expertise advancement activities.

The **second theme (chapters 4 and 5)** is concerned with two studies of **the experiences of patients and informal care providers**. It is important that the professionals, policymakers, and managers involved in care provision and the improvement of primary palliative care take to heart the experiences and judgements of the quality of care of patients and informal care providers.

In **chapter 4**, we describe the quality of primary palliative care from the perspective of the patient and informal care provider. This study was performed in the period 2001 – 2003 as part of a larger study of healthcare status, quality of life, and healthcare utilisation among primary palliative care patients and their informal care providers. Since recruitment problems are a major obstacle to the study of the

perspective of patients and informal carers in palliative care, we also sought to evaluate the recruitment and surveying of patients and informal care providers.

We developed the Quality of Palliative Care – Questionnaire (QPC–Q); this is a 16-item questionnaire on specific aspects of care, scored on a 5-point rating scale, for both patients and informal care providers. Interviews (written or oral) were conducted with patients about their disease history, sociodemographic variables, and their healthcare utilisation and with their informal care providers on their health characteristics and in their experience in caring. Patients in primary palliative care and their informal care providers are of the opinion that the level of palliative care in primary practice is fairly good. Both patients and informal carers rated the GP at the highest rank; importantly, the patient can always appeal to the GP. Both groups criticised the delay in acquiring care or material/equipment for care owing to the rules and procedures of organisations. In general, the opinions of the informal care providers were more critical than the patients; their rankings of the QPC–Q items differ markedly. Rigorous efforts must be invested in the clarification of the differences in the judgements of the patients and the informal care providers. Such clarification may lead to a more stable basis for patients ending their lives at home and for their relatives caring for them without feeling overburdened.

In our study, including patients turned out to be extremely difficult and we finally had to close the study before we had reached our intended number of participants. During the study, we asked the participating GPs about the reasons for the difficulty of inclusion and how we might improve it. They put forward various GP- and patient-related reasons. However, participation in research is already surrounded by all kinds of established ethical principles and guidelines. If researchers apply these in a decent and respectful manner, palliative care is no different from other research areas. The remarks made by the patients in our study strengthened this opinion and no one regretted participating. GPs could therefore be less reticent in informing and asking their palliative care patients for research at the end of life.

The study described in **chapter 5** was aimed to gain insight into the experiences of a palliative care patient and her husband who were living on borrowed time. We used a qualitative single case study design, an appropriate and accepted method in a research area where evidence is lacking. We performed systematic content analysis on the transcription of the in-depth semi-structured interview data in order to extract themes relating to living on borrowed time. Three themes were identified:



shifts in the interpretation of physical signs and symptoms; an altered view of the future; and altered choices and priorities. Concentration on these identified themes leads to a better understanding of the phenomenon of living on borrowed time; it is very uncertain time, but alongside the uncertainty is the realisation that there is still 'time to live' rather than just more time to prepare for death. Nevertheless, the refinement of and variation within the themes still need to be studied in order to obtain a firmer grasp of the themes and be able to help patients integrate such a 'new reality'. Our findings could be used in practice, for example by converting them into a conversational guide to support care professionals whose patients need to integrate the 'new reality' and seek new equilibrium; they could also be used for education and training purposes.

The **third and last theme (chapters 6, 7 and 8)** features studies regarding aspects of palliative care consultation. An important element of the governmental programme on palliative care in the Netherlands (1996–2003) was the establishment of PCC teams throughout the country. In contrast with most other countries, the Netherlands opted for a transmural palliative care consultation model: a team of professional care providers, coming from different settings and with extensive expertise in palliative care, give advice and support to their healthcare colleagues encountering problems in daily practice. The three chapters report three **prospective studies in the national programme for quality improvement in palliative care: PCC teams**. These studies cover the range of the consultation process: from the extent to which professionals requested assistance from PCC teams and the reasons underlying these requests, via the clarification process identifying the additional problems derived from clarification in palliative care consultation, to the extent and nature of the support and advice given by PCC team members to the requesting care providers.

In **chapter 6**, we describe the results of a study investigating the extent to which professional care providers requested assistance from PCC teams, and the reasons underlying these requests, to trace the gaps experienced in the provision of palliative care. A standard registration form was used to register aspects of the requests for consultation, such as the nature of the request (on a general domain level and subdivided into a number of specific problems) and information on the characteristics of the professional who requested the consultation. This form was based on previous pilot studies with different PCC teams, the experiences of the national multidisciplinary group of researchers, and a review of the literature. The

research period was 2 years: from 2001–2003. In this 2-year period, professional care providers requested 4351 consultations with respect to 8413 specific problems in 11 quality-of-life and quality-of-care domains. The distribution of problems over these domains was unbalanced: 42.2 percent of the specific problems were physical, while the percentages of psychological, pharmacological, and organisational problems were 7.7, 12.5, and 12.8 percent, respectively. In contrast, issues of a spiritual nature or concerned with daily functioning were raised infrequently (1.1 and 0.9 percent respectively). The results of this study form a valid basis on which to develop and implement improvements in palliative care. We recommend that future well-founded policies for palliative care should incorporate palliative care consultation as well as educational and organisational interventions.

During the process of consultation, the PCC team consultant clarifies the request for consultation by exchanging thoughts with the requesting care provider, perusal of the patient's file, and contact with the patient (for bedside consultation only). In **chapter 7**, we concentrate on this clarification process in order to identify the additional problems derived through the clarification process and to reveal the factors influencing the identification of additional problems. The standard registration form referred to above was also used for this study. In addition to the characteristics of the requesting professional care provider, we collected data on the discipline of the professional providing advice, the type of consultation, patient characteristics, and the nature of the problems (in domains as well as specifics) after clarification. Fifty seven percent of problems (n=7854) were newly identified; most of these were related to physical and pharmacological problems. In most cases, any psychosocial/spiritual problems raised were identified through clarification (70 percent). Newly-identified problems were more likely to be identified in the domain of spiritual and psychosocial problems, in bedside consultations, in requests from clinical physicians, and for patients accommodated in a hospice or hospital. We found no significant differences in newly-identified problems between the professionals providing consultation; the specific training in clarification seems to be effective. The explicit clarification of problems facilitates the identification and addressing of a more comprehensive and detailed range of problems. More information is needed to find out what the effects are of this form of shared decision on the quality of care, satisfaction with consultation, and compliance with advices given.

In **chapter 8**, we close the circle of the consultation process. Here, we describe our study that concentrated on the nature and extent of the support and advice given by PCC team members to the requesting care providers and on the factors that influence the differences in the advice given. The data for the study were also registered on the national standard registration form. We used as variables ‘advice given’ (classified according to four domains: pharmacological, providing information, direct patient care, advice to refer to other professional care providers) and some consultation characteristics (problem domain, type of consultation, requesting professional care provider, profession consultant). We used frequencies and proportions to assess the nature and extent of the advice given and logistic regression to determine the factors associated with the advice. More than half of all the expert advice given concerned pharmacological advice; providing information was the second most frequent action. Over 10 percent of all actions concerned direct patient care. Significant relationships with expert advice in all four general domains were found for most elements of the consultation characteristics. Pharmacological advice was related to consultation by telephone; a GP as the requesting care provider; advice given by a clinical or nursing home physician; and problems in the physical/pharmacological domain. Advice to refer to other professional care providers was related to problems within the psychosocial- and organisational domain coming from requesting care providers other than GPs and advised by GPs, nurses or a multidisciplinary team. We can conclude that several elements of consultation characteristics have a particular influence on the expert advice given by PCC teams. To optimise the Dutch PCC model, choices with regard to team composition (adding a pharmacist, for example) and the type of consultation should be made, because these characteristics evidently result in different advice domains. The topic of direct patient care from consultant to patient also needs further research if consultation rather than taking over care remains the preferred palliative-care model. Finally, research on PCC teams must address outcomes at the level of not only the professionals, but also the patients. The Dutch PCC model should also be compared with the patient-care-team models in other appropriate countries.

In **chapter 9**, the final chapter of this thesis, the most important findings and conclusions from the studies in chapters 2 through 8 are discussed. The results are placed in wider perspectives, the most relevant methodological limitations are considered, and recommendations are put forward for further research and for palliative care in general.

During the last decade, strenuous efforts have been made in the Netherlands to eliminate the backlog that had accumulated with respect to palliative care. The known and coming developments, the place that palliative care has captured in many organisations, the amount of projects (research as well as developmental and practical) lead us to draw the conclusion that considerable success has been achieved. There still remains, however, much to be done. The immediate task ahead is to consolidate what has been reached and give it a firm structural basis so as to continue to develop palliative care in the Netherlands on a firm footing.

## Samenvatting

Dit onderzoek verkent 3 thema's binnen de palliatieve zorg. Het eerste thema betreft een tweetal studies die zich verdiepen in de dagelijkse praktijk van huisartsen; de professionals die over het algemeen verantwoordelijk zijn voor de palliatieve zorg voor patiënten in de eerste lijn. Deze studies richten zich op de door hen ervaren problemen in de dagelijkse praktijk van palliatieve zorg. Het tweede thema focust op diegenen waar palliatieve zorg om draait: patiënten en hun naasten. Binnen dit thema worden twee studies beschreven waarin ervaringen van patiënten en naasten met eerstelijns palliatieve zorg aan bod komen. Het laatste thema betreft palliatieve zorg consultatie teams ('Palliative Care Consultation teams'/PCC-teams), teams opgericht ter ondersteuning van hulpverleners in de palliatieve zorg. De drie onderzoeken binnen dit thema focussen op het consultatieproces dat start met een consultverzoek, gevolgd wordt door de methode van vraagverheldering en afsluit met het advies of de geboden ondersteuning.

Huisartsen spelen een cruciale rol in de eerstelijns palliatieve zorg. Het is daarom van belang hun mening over hun taakopvatting te onderzoeken en kennis te nemen van de problemen waar zij tegenaan lopen in de dagelijkse praktijk van palliatieve zorg. Door aandacht te besteden aan deze problemen, kan de kwaliteit van de eerstelijns palliatieve zorg verbeteren. De studies beschreven in het eerste thema van dit proefschrift, **problemen in de dagelijkse praktijk van de eerstelijns palliatieve zorg zoals ervaren door huisartsen (hoofdstukken 2 en 3)**, zijn beiden uitgevoerd aan het begin van het nationale programma 'Palliatieve Zorg in de Terminale Fase'. In een kwalitatieve studie hebben we allereerst de taakopvatting van huisartsen met betrekking tot palliatieve zorg onderzocht en tevens een grondig beeld verkregen van de problemen waar zij in de dagelijkse praktijk mee te maken hebben. Daarnaast hebben we in een tweede studie op basis van het kwalitatieve materiaal een survey uitgevoerd waarin de problemen in de dagelijkse palliatieve zorg gekwantificeerd konden worden.

In **hoofdstuk 2** beschrijven we het kwalitatieve focusgroeponderzoek naar taakopvatting en ervaren problemen in de dagelijkse palliatieve zorg van huisartsen. Drie groepen huisartsen, met een brede range aan ervaring in palliatieve zorg, hebben in het jaar 2000 deelgenomen aan de focusgroep-interviews. Door een inhoudsanalyse op de transcripten van de groepsinterviews

hebben we een omvattend beeld verkregen van taken en problemen waarmee huisartsen in hun palliatieve zorgverlening worden geconfronteerd. Huisartsen omschrijven hun taken in de palliatieve zorg als 'bevredigend en gevarieerd, maar zwaar'. Hun taak omvat zowel somatische- als psychosociale zorg. Over de vraag of coördinatie van zorg een primaire huisartsentaak is, verschilden de huisartsen van mening.

De ervaren problemen hebben we geclassificeerd op drie niveaus: (1) persoonlijke problemen, gerelateerd aan kennis, vaardigheden en emoties; (2) problemen op het gebied van relaties, dat wil zeggen met betrekking tot communicatie en samenwerking; (3) organisatorische problemen, problemen op het vlak van de organisatie van zorg en de 'schotten' in de gezondheidszorg. Het onderzoek bracht een complex web van taken en problemen aan het licht. Een probleem op persoonlijk niveau (bijvoorbeeld gebrek aan kennis) kan het gevolg zijn van een geïsoleerd kennistekort, maar het probleem kan ook terug te voeren zijn op communicatieproblemen of de schotten in de gezondheidszorg.

Teneinde de positieve gevoelens van huisartsen over palliatieve zorg als belangrijk en speciaal onderdeel van hun vak te behouden, is het van belang dat zij een passende balans vinden tussen technische en organisatorische aspecten van palliatieve zorg en de gevoelscomponent die het werken met patiënten aan het einde van hun leven met zich meebrengt. Het oplossen van de door hen ervaren problemen kan hieraan een bijdrage leveren.

De studie die beschreven wordt in **hoofdstuk 3** is gebaseerd op de resultaten van het focusgroeponderzoek van hoofdstuk 2. Op wetenschappelijke wijze is een vragenlijst ontwikkeld waarin de ervaren problemen als volgt zijn gerubriceerd: communicatie, organisatie & coördinatie van zorg, kennis & vaardigheden, integrale zorg, tijd voor naasten. In de survey hebben we zowel de prevalentie van de problemen geïdentificeerd evenals de bepalende factoren voor het optreden van die problemen.

Als mogelijke determinanten zijn huisartskenmerken en ontplooiende activiteiten op het gebied van deskundigheidsontwikkeling opgenomen. De resultaten van de survey laten zien dat huisartsen aanzienlijke problemen ervaren binnen alle aspecten van palliatieve zorg. Problemen met bureaucratische procedures, zoals de benodigde tijd om thuiszorgtechnologie te regelen en de problemen die optreden bij een wenselijke of noodzakelijke uitbreiding van de te leveren zorg, waren de meest frequent voorkomend. Het aantal jaren ervaring van een huisarts,

de regio en de praktijkvorm en (multidisciplinaire) casusbesprekingen bleken significante determinanten in twee of meer schaal- of itemscores.

In het algemeen kan gesteld worden dat meer ervaringsjaren als huisarts en de deelname aan (multidisciplinaire) casusbesprekingen geassocieerd waren met het ervaren van minder problemen. Op basis van deze resultaten kunnen beleidsmakers en praktijkmensen hun prioriteiten stellen met betrekking tot het oplossen van de problemen. Verder zijn de resultaten behulpzaam bij de beeldvorming over noodzakelijke toekomstige deskundigheid en de deskundigheidsbevorderende activiteiten die de voorkeur genieten van de doelgroep.

Binnen het **tweede thema (hoofdstukken 4 en 5)** worden twee studies besproken die ingaan op **de ervaringen van patiënten en naasten**. Het is van groot belang dat professionals, beleidsmakers en zorgmanagers ervaringen en oordelen van patiënten en naasten ter harte nemen, zowel in hun dagelijks werk als in hun pogingen en plannen de palliatieve zorg te verbeteren.

**Hoofdstuk 4** gaat in op de kwaliteit van de eerstelijns palliatieve zorg gezien vanuit het perspectief van de patiënt en diens naasten. Deze studie is uitgevoerd in de periode 2001–2003 als onderdeel van een groter onderzoek naar ervaren gezondheid, kwaliteit van leven en zorgconsumptie in de eerstelijns palliatieve zorg. Aangezien palliatieve zorg onderzoek met patiënten en naasten vaak te kampen heeft met instroomproblemen, is in ons onderzoek ook de wijze van opsporen en inclusie van patiënten en naasten grondig gevolgd.

Ten behoeve van het onderzoek ontwikkelden we een vragenlijst, de ‘Quality of Palliative Care – Questionnaire’ (QPC-Q). Deze vragenlijst bestaat uit 16 items over specifieke zorgaspecten voor zowel patiënten als naasten. Naast het afnemen van de QPC-Q omvatte het onderzoek interviews evenals schriftelijke vragenlijsten over ziektegeschiedenis, sociaaldemografische variabelen en zorgconsumptie (voor patiënten) en ervaren gezondheid en ervaringen met zorgen (voor naasten). Patiënten in de eerstelijns palliatieve zorg en hun naasten zijn van mening dat het niveau van palliatieve zorg redelijk goed is. Zowel patiënten als naasten waarderen van alle concrete zorgaspecten van de QPC-Q de zorg door hun huisarts het hoogst: de patiënt kan op hem altijd een beroep doen. Beide groepen respondenten uitten kritiek op de traagheid, door regels en procedures van organisaties, waarmee zorg of materiaal ten behoeve van zorg verkregen moet worden. In het algemeen zijn de naasten kritischer in hun beoordeling dan

patiënten; hun QPC-Q scores verschilden duidelijk. Deze verschillen tussen de beoordelingen van patiënten en naasten dienen verhelderd te worden. Daardoor zal er een meer stabiele basis ontstaan waarop patiënten hun leven thuis kunnen afronden en waarbij naasten kunnen zorgen voor de patiënt zonder zich overbelast te voelen.

Het is erg moeilijk gebleken om patiënten te includeren in ons onderzoek. Uiteindelijk hebben we zelfs de studie moeten sluiten voordat we het voorgenomen aantal respondenten geïncludeerd hadden. Gedurende het onderzoek hebben we de deelnemende huisartsen gevraagd naar redenen voor deze moeizame inclusie en hoe we dit mogelijk zouden kunnen verbeteren. Zij meldden allerhande, zowel patiënt- als huisartsgerelateerde, factoren. Een belangrijk probleem bleek de kwetsbaarheid van de onderzoekspopulatie en de hieraan verbonden terughoudendheid van huisartsen hen te benaderen voor onderzoek. Echter als onderzoekers de bestaande ethische principes en richtlijnen rondom onderzoek met patiënten toepassen, is er geen reden palliatieve zorg onderzoek als anders dan andere onderzoeksterreinen te beschouwen. Onze mening hierover werd gesterkt door de patiënten in ons onderzoek; niemand had spijt van zijn deelname aan de studie. Huisartsen kunnen dus minder terughoudend zijn als het gaat om het informeren van hun palliatieve zorg patiënten over onderzoek aan het einde van hun leven.

Het onderzoek dat beschreven wordt in **hoofdstuk 5** had tot doel inzicht te verkrijgen in de ervaringen van een palliatieve zorg patiënt in 'reservetijd' en haar echtgenoot. We hebben gebruik gemaakt van een kwalitatieve case studie, een passende en geaccepteerde methode binnen een onontgonnen onderzoeksterrein. Na systematische inhoudsanalyse op het transcript van het semi-gestructureerde interview, waren we in staat drie thema's te identificeren die te maken hebben met het 'leven in reservetijd'. Deze thema's zijn: veranderingen in de interpretatie van fysieke tekenen en symptomen; een gewijzigde kijk op de toekomst; en gewijzigde keuzen en prioriteiten. Door aandacht te schenken aan deze thema's wordt een beter begrip bereikt van het fenomeen 'leven in reservetijd'. Het is een zeer onzekere tijd, maar naast die onzekerheid realiseert men zich dat er nog 'tijd van leven' is in plaats van alleen meer tijd om zich voor te bereiden op de dood. Nader onderzoek moet plaatsvinden om een meer verfijnd beeld te krijgen van het fenomeen 'leven in reservetijd' en van individuele variaties binnen de thema's. Daardoor is het beter mogelijk patiënten te ondersteunen in het omgaan met deze 'nieuwe realiteit'. Onze bevindingen kunnen in de praktijk



gebruikt worden, bijvoorbeeld door de thema's om te zetten in een leidraad voor gesprek die door zorgprofessionals gebruikt kan worden bij hun ondersteuning van patiënten, die staan voor deze realiteit en zoeken naar een nieuw evenwicht. De thema's kunnen ook ingezet worden voor scholing en training.

Binnen het **derde en laatste thema (hoofdstukken 6, 7, en 8)** worden studies beschreven die gaan over aspecten van palliatieve zorg consultatie. Een belangrijk element van het Nederlandse overheidsprogramma palliatieve zorg (1996–2003) was de oprichting van PCC-teams over het gehele land. Tegengesteld aan veel andere landen heeft Nederland gekozen voor een transmuraal PCC-model: een team van professionals vanuit verschillende zorgsettings en met uitgebreide deskundigheid in palliatieve zorg, die advies en ondersteuning geven aan hun collegae bij problemen in de palliatieve zorgverlening. De drie hoofdstukken in dit thema beschrijven drie **prospectieve studies binnen het nationale programma voor kwaliteitsverbetering in de palliatieve zorg: PCC-teams**. Deze studies omvatten de hele range van het consultatieproces: beginnend met de mate waarin professionals ondersteuning vragen van PCC teams, via de methode van vraagverheldering, tot de inhoud van de gegeven adviezen door de PCC-teams.

In **hoofdstuk 6** beschrijven we de resultaten van een studie naar de mate waarin zorgprofessionals ondersteuning vragen van PCC-teams en de onderliggende redenen van deze consultverzoeken, met als doel inzicht te verkrijgen in de ervaren hiaten in palliatieve zorg. Er is gebruik gemaakt van een standaard registratieformulier waarop aspecten van het consultverzoek, zoals de inhoud van de consultvraag (zowel op domeinniveau als gespecificeerd) en informatie over karakteristieken van de consultvrager geregistreerd werden. Dit formulier was ontwikkeld op basis van eerdere pilotstudies rondom verschillende PCC-teams, de ervaringen van de nationale multidisciplinaire onderzoeksgroep en literatuurstudie. De onderzoeksperiode besloeg twee jaar, van 2001–2003. Gedurende deze periode hebben zorgprofessionals 4351 maal consult gevraagd bij de PCC-teams. Het ging hierbij om 8413 specifieke problemen binnen 11 kwaliteit-van-leven en kwaliteit-van-zorg domeinen. Er was sprake van een ongebalanceerde verdeling over deze domeinen: 42.2 procent van de specifieke problemen waren fysiek van aard, terwijl de percentages van de psychologische, farmacologische en organisatorische problemen respectievelijk 7.7, 12.5 en 12.8 procent waren. In contrast staan de vragen rondom spirituele zaken en consultvragen met

betrekking tot problemen in het dagelijks functioneren, deze werden weinig frequent gesteld (respectievelijk 1.1 en 0.9 procent). De resultaten van dit onderzoek vormen een valide basis voor de ontwikkeling en implementatie van verbeteringen in palliatieve zorg. Het verdient aanbeveling dat in toekomstige plannen voor palliatieve zorg er een plaats moet zijn voor consultatie, evenals voor educatie en organisatorische interventies.

Gedurende het consultatieproces zal de PCC-consulent de consultvraag verhelderen door middel van doorvragen en overleggen met de consultvrager, het eventueel inzien van het patiëntendossier en direct contact met de patiënt (alleen van toepassing bij een bedside-consult). In **hoofdstuk 7** concentreren we ons op dit proces van vraagverheldering met als doel inzicht te krijgen in mogelijk bijkomende problemen en om de factoren te ontdekken, die de identificatie van deze bijkomende problemen beïnvloeden. Het standaard registratieformulier zoals hiervoor al beschreven is ook gebruikt voor deze studie. Aanvullend op de karakteristieken van de consultvrager hebben we data verzameld over de discipline van de consultverlener, het soort consult, patiëntenkenmerken en de inhoud van de problemen (zowel op domeinniveau als gespecificeerd) na vraagverheldering. Zevenenvijftig procent van de problemen (n=7854) bleken nieuw geïdentificeerd (dat wil zeggen door de vraagverheldering): dit waren vooral fysieke en farmacologische problemen. In de meeste gevallen was er wel een psychosociaal/spiritueel probleem opgekomen door de vraagverheldering (70 procent). Nieuw-geïdentificeerde problemen werden eerder gevonden in de domeinen van de spirituele en psychosociale problemen, bij bedside-consulten, bij consultverzoeken van ziekenhuisartsen en bij patiënten opgenomen in ziekenhuis of hospice. We hebben geen significante verschillen gevonden met betrekking tot nieuw-geïdentificeerde problemen tussen de consultverleners; de specifieke training in vraagverheldering die ze hebben gehad lijkt effectief. Het expliciet verhelderen van problemen vergemakkelijkt de identificatie van en het aandacht geven aan een meer integraal en gedetailleerd scala aan problemen. Er is meer informatie nodig om te kunnen bepalen wat de effecten zijn van deze manier van 'shared decision making' op de kwaliteit van zorg, de tevredenheid met de consultatie, en het accepteren van en meegaan met de gegeven adviezen.

In **hoofdstuk 8** wordt de cirkel van het proces van consultatie gesloten. We beschrijven hier onze studie naar de hoeveelheid en inhoud van de adviezen gegeven door PCC-teamleden aan de consultvragers, en op de factoren die de

verschillen in gegeven adviezen beïnvloeden. Data voor deze studie werden ook geregistreerd op het landelijk gebruikte standaard registratieformulier. Als variabelen gebruikten we ‘gegeven advies’ (geclassificeerd in vier domeinen: farmacologisch, verschaffen van informatie, geven van directe patiëntenzorg, advies om door te verwijzen naar andere professionele zorgverleners) en een aantal consultatiekenmerken (probleemdomein, soort consultatie, discipline consultvrager, discipline consulent). We gebruikten frequenties en proporties om hoeveelheid en inhoud van de gegeven adviezen te bepalen en logistische regressie om de factoren te bepalen die geassocieerd kunnen worden met het advies. Meer dan de helft van alle adviezen betrof farmacologische adviezen, het verschaffen van informatie stond op de tweede plaats. Net iets boven de 10 procent van alle acties ging om directe patiëntenzorg. Met betrekking tot alle vier de domeinen van advies vonden we significante relaties met bijna alle consultkenmerken. Farmacologisch advies was gerelateerd aan telefonische consulten, een huisarts als consultvrager, een ziekenhuisspecialist of een verpleeghuisarts als consulent en problemen in het fysieke/farmacologische domein. Advies om door te verwijzen naar andere professionele zorgverleners had een relatie met problemen binnen het psychosociale en organisatorische domein, komend van andere consultvragers dan huisartsen en consulenten vanuit de groepen huisartsen, verpleegkundigen of een multidisciplinair team. We kunnen concluderen dat bepaalde consultatiekenmerken invloed hebben op het advies zoals gegeven door PCC-team consulenten. Teneinde het Nederlandse consultatiemodel te optimaliseren, dienen er keuzes gemaakt te worden met betrekking tot de samenstelling van de PCC-teams (bijvoorbeeld over het toevoegen van een farmacoloog) en de consultatievorm, omdat deze kenmerken duidelijk blijken te resulteren in andere adviesdomeinen. Het aspect ‘geven van directe patiëntenzorg door de consulent’ behoeft ook nader onderzoek indien ‘consultatie’ in tegenstelling tot ‘directe patiëntenzorg’ het model van voorkeur blijft. Als laatste dient er aandacht te komen voor consultatieteam onderzoek met niet alleen uitkomsten op het niveau van professionals maar ook met patiëntenuitkomstmaten. Het Nederlandse model dient ook vergeleken te worden met de modellen in andere landen waarin ‘directe patiëntenzorg’ het belangrijkste is.

In **hoofdstuk 9**, het laatste hoofdstuk van dit proefschrift, worden de meest belangrijke bevindingen en conclusies van de studies uit de hoofdstukken 2 tot en met 8 besproken. De resultaten worden in perspectief geplaatst, de meest

relevante methodologische beperkingen worden in ogenschouw genomen en aanbevelingen voor nader onderzoek en voor de praktijk van palliatieve zorg worden gedaan.

Gedurende het laatste decennium heeft Nederland hard gewerkt om haar achterstand met betrekking tot de palliatieve zorg te verkleinen. Gebaseerd op de plek die palliatieve zorg heeft ingenomen in veel organisaties en het aantal projecten (op het gebied van onderzoek, (beleids)ontwikkeling en praktijk) kunnen we de conclusie trekken dat hierin een aanzienlijk succes is geboekt. Toch blijft er nog veel te doen! De meest voorliggende taak is die van consolidatie en inbedding in de reguliere gezondheidszorg, zodat op krachtige en voortvarende wijze verder gewerkt kan worden aan de ontwikkeling van palliatieve zorg in Nederland.

## Dankwoord

Er zijn weinig mensen die twee keer promoveren. Na het uiteindelijk afronden van mijn promotie-onderzoek, begrijp ik maar al te goed waarom dat zo is! Vanaf november 1999 ben ik gedurende meer of minder uren per week steeds bezig geweest met het onderzoek dat uiteindelijk uitmondde in dit volgeschreven 'schrift' (ja Sara, het is eindelijk af!). De basis hiervoor is mede gelegd door de patiënten die ik in mijn jaren als verpleegkundige heb ontmoet en van wie er mij nog een aantal helder voor de geest staan.

De een beetje vergeetachtige oude mevrouw met haar prachtig gerimpelde, zachte handen die je altijd vastpakte als je wegging en je toefluisterde 'veel liefde, hoor!' Een leukemiepatiënte die langdurig en regelmatig in veel eenzaamheid doorbracht vanwege de geïsoleerde verpleging, maar toch altijd haar hartelijkheid en humor bewaarde. En de kritische meneer die door zijn houding naar ons en de gezondheidszorg ervoor zorgde dat je zeer alert bleef.

En dan de patiënten in deze studie: de jonge man die ondanks zijn verloren strijd deze tijd als de mooiste beschouwde, de wat narrige, bozige man die pas langzamerhand ontdooide en veel te vertellen bleek te hebben, de 'case study' mevrouw met haar weloverwogen kijk op haar extra levenstijd.

Al deze mensen hebben dit proefschrift mede gevormd! Ik heb het dan wel grotendeels geschreven, maar zonder hen was het er niet geweest en was ik niet de onderzoeker geweest die ik nu ben, (te) veel verbonden aan de praktijk, en altijd op zoek naar een link met die praktijk, want dat is, in mijn ogen, waar ik het onderzoek voor heb gedaan.

Ik heb de afgelopen jaren te maken gehad met een begeleidingcommissie die net als ikzelf een 'lange adem' had. Zonder hen had dit boek er waarschijnlijk niet gelegen! Richard Grol, promotor en voorzitter van de begeleidingscommissie: je kreeg het elke bijeenkomst weer voor elkaar om mij met een waslijst aan 'to do activiteiten' maar toch positief gestemd de deur uit te laten gaan. Je kennis, kritisch opbouwende blik en helikopterview zijn fenomenaal en van alledrie heb ik veel geleerd. Heel erg veel dank daarvoor! Ben Crul, ook promotor, het is voor mij een voorrecht geweest om begeleid en geïnspireerd te worden door iemand die een zeer belangrijke bijdrage heeft geleverd aan het in Nederland op de (nationale) kaart plaatsen van palliatieve zorg. Ook na je emeritaat (als eerste hoogleraar pijnbestrijding) nam je nog tijd om mij door de laatste loodjes heen te helpen, dank je wel voor al je positieve inbreng! Vanaf dag één in het onderzoek

had ik te maken met Myrra Vernooij, mijn copromotor en 'onderzoeksmoeder'. Myrra, je hebt een cruciale rol gespeeld in het onderzoek. Je deskundige, inhoudelijke en persoonlijke begeleiding, je (soms) noodzakelijke rem als mijn plannen iets te veel uit de pas liepen en je enthousiasme voor de resultaten (zeker als ik dat zelf niet zag) zijn van onschatbare waarde geweest. Ik wil je heel hartelijk danken voor alles!

Beste alledrie, ik kan me haast niet voorstellen dat jullie niet soms getwijfeld hebben aan mijn mogelijkheden en/of 'drive' om dit af te maken! Zeker toen het langer ging duren dan was voorzien en ik toch zonodig die 7 artikelen wilde.....Toch is het gelukt en dat is mede dankzij jullie, nogmaals veel dank!

De onderzoeken beschreven in dit proefschrift zijn uitgevoerd in het kader van het landelijke stimuleringsprogramma palliatieve zorg. Een landelijk programma betekent vaak ook een landelijke onderzoeksgroep. Ik wil daarom Annemieke Kuin, Annemie Courtens, Lia van Zuylen en Barbara van der Linden (de 'landelijke Myrra's') van de andere regionale COPZ-en hartelijk bedanken voor hun meedenken met opzet, uitvoering en beschrijving van de consultatieteam-onderzoeken.

De consultatieteam onderzoeken waren totaal onmogelijk geweest als er verspreid door Nederland geen ruim 20 consultatieteams waren geweest die bereid waren hun activiteiten te registreren. Ik heb voornamelijk te maken gehad met de teams in de Nijmeegse regio en op het gevaar af iemand te vergeten wil ik onder andere Paul Vogelaar, Marjo Gribling, Lieneke Homans, Jolanda Prins, Hilde Bosch, Jolanda van Loenhout en Nancy Foppen heel erg bedanken voor de tijd en moeite die ze zich getroost hebben om de registratieformulieren goed en volledig in te vullen. Palliatieve zorg consultatie heeft zich een plek verworven binnen de Nederlandse palliatieve zorg en ook dat komt mede door jullie inzet en deskundigheid. Dank je wel!

Dank ook aan de huisartsen die hun 'ziel en zaligheid' hebben blootgelegd in de focusgroep interviews. Ik was onder de indruk van jullie openhartigheid. Een deel van de 'focusgroep huisartsen' met daarnaast een aantal anderen heeft ook deelgenomen aan de patiëntenstudie. Ik heb gemerkt dat het voor veel van jullie niet eenvoudig was om 'jullie patiënten' bloot te stellen aan levenseindeonderzoek. Deze bescherming van jullie patiënten is enerzijds bijzonder om mee te maken, maar was anderzijds lastig voor mij als onderzoeker en, getuige de patiënten die

hebben deelgenomen, vaak niet nodig. Ik wil jullie bedanken voor de kans die ik gekregen heb om patiënten en naasten te interviewen en voor de tijd die jullie zelf in het onderzoek hebben gestoken.

Ook al heb ik sinds geruime tijd alleen maar een ‘gedoogverklaring’ van aanwezigheid op de WOK, toch teer ik nog steeds op de prettige sfeer en collegialiteit van mijn WOK-jaren. Dank voor alle collegae die in welke mate dan ook hebben bijgedragen aan een prettige werktijd. Speciale dank natuurlijk voor mijn (al dan niet tijdelijke) kamergenoten en een aantal andere collegae: Els Derksen, Josien van den Berg, Anouk Spijker, Nicole Krol, Bart Osse, Kalinka van der Camp, Monique van Eijken, Maud Graff en Reinier Akkermans. Jullie zijn zeer belangrijk voor mij geweest vanwege het (werk)plezier en de onderlinge uitwisseling! Dank je wel. Jolanda van Haren wil ik bedanken voor alle logistieke en organisatorische zaken rondom ‘de laatste loodjes’. Je hield het heft gelukkig strak in handen, raakte niet in de stress (ogenschijnlijk dan) als ik weer eens iets te laat of op het nippertje afleverde. Dank je wel, dit is voor mij van groot belang geweest.

In eerste instantie was het palliatieve zorg onderzoek van het UMCN een coproductie van de afdeling KWAZO (toen nog WOK) en de afdeling MTA. Met Mieke Nieuwenhuizen ben ik hieraan begonnen. Zij is na een jaar toch iets anders gaan doen maar toch wil ik haar en Paul Krabbe, ook van MTA, bedanken voor de samenwerking; de eerste klap is een daalder waard! Ondanks het vertrek van Mieke en het besluit van MTA het promotieonderzoek palliatieve zorg bij hen niet te continueren is er vanuit MTA in de vorm van onderzoekers en onderzoeksassistentie toch support geleverd. Ik ben met name Nadia Heinen, Jeroen Koning en Kristel Janssen erkentelijk voor hun aandeel in het goed uitvoeren van de verschillende delen van het onderzoek. Kristel heeft onder andere in de patiëntenstudie bergen werk verzet en hoewel ik het moeilijk en jammer vond dat ik niet alle patiënten en naasten zelf kon spreken, ben ik haar erg dankbaar. Dankjewel!

Ook bij de WOK is er heel wat aan gedaan de onderzoeken goed af te ronden, zeker toen de voltijds MTA-aanstelling wegviel. Josien van den Berg, Bertinel van den Akker en Els Derksen ben ik veel dank verschuldigd, niet alleen voor het werk en hun inzet voor ‘de goede zaak’, maar zeker niet minder in hun rol als uitlaatklep en sparringpartner. Dank dank dank.

Lieve Els, nu ik toch bij jou ben aangeland: ik vind het geweldig dat je mijn paranimf wilt zijn op woensdag de 13<sup>e</sup> juni 2007. Je bent een geweldige tegenhanger voor mijn wat chaotische inborst: je rust, deskundigheid, positivisme en geweldige collegialiteit hebben me zeker geholpen de afgelopen jaren. Ik ben erg blij dat je 'opeens op mijn kamer bleek te zitten en daar bent gebleven'. Ik hoop dat jouw onderzoek net zo voorspoedig mag eindigen als dat van mij en je ziet het ..... een jaartje meer of minder maakt uiteindelijk niet uit. Nogmaals dank je wel. Lieve Kalinka, ook jij was er opeens als 'pupil van Myrra'. We hebben veel gedeeld de afgelopen jaren en ik had het geweldig gevonden als je ook mijn paranimf had kunnen zijn. Er zijn echter belangrijker zaken; een hopelijk gezond kind ter wereld brengen en daarbij zelf letterlijk 'de benen eronder kunnen houden' is er daar één van! Hoe dan ook, ook jij erg bedankt voor alles!

Gelukkig heb ik een geweldige vervanger gevonden voor het paranimf-schap in de persoon van mijn 11-jarige oudste zoon Stijn. Lieve Stijn, geweldig dat je dit voor mij wilt doen. Onbewust haal je misschien nog een beetje stress weg voor 'de grote dag' doordat ik toch ook nog een beetje voor jou moet zorgen vandaag en ook dat scheelt weer!

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De laatste 1½ jaar vóór de legendarische 13 juni 2007 heb ik het geluk gehad te mogen werken bij het IKO. Al na het sollicitatiegesprek had ik het gevoel 'goed te zitten'. Dit ligt niet in de laatste plaats aan mijn kamergenoten en meest directe collega's. Ik wil met name Saskia Vonk, Mirjam Coppens, Rene Limbeek, Monique Huibers en Cilia Galesloot noemen. Jullie zijn geweldige, hardwerkende, hartverwarmende en ook zeer gezellige mensen. Wat ik ook ga doen na januari 2008, ik zal jullie niet zomaar vergeten! Dank je wel voor alles!



En dan de basis! Lieve pa en ma. Dank je wel voor alles wat ik van jullie heb meegekregen en geleerd. Met warmte en dankbaarheid denk ik aan jullie kennis, levenservaring, aandacht en betrokkenheid. Deze gelden niet alleen mij, maar ons hele gezin. Zowel wij als Stijn, Sara, Sieb en Minke varen wel bij deze onbetaalbare structurele bijdrage in ons leven en 'zorgsysteem'!

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Lieve Stijn, Sara, Sieb en Minke: het 'schrift' is af, de computer weer voor algemeen gebruik en nu heb ik nog maar één baan! Heerlijk! Jullie bieden (deels onbewust) het broodnodige tegenwicht voor een te eenzijdige kijk op het leven! Ik ben dolblij met jullie! Lieve, lieve Neel. Ik weet niet of je dit had bedacht toen ik enthousiast met de advertentie voor palliatieve zorg onderzoeker aankwam. Ik denk het eigenlijk niet (ik namelijk ook niet)! Zonder jouw relativeringsvermogen, humor, geweldige vaderschapskwaliteiten en steun had ik dit niet afgerond! Dank je wel voor alles wat je bent! Ooit was het de bedoeling dat we rond 2004 allebei een belangrijke mijlpaal zouden halen; ik mijn proefschrift, jij een nieuwe winkel! Mijn deadline is 'een beetje' uitgelopen, ach ja, maar nu is het jouw tijd! Ik zal er voor je zijn!

## Over de auteur

Marieke Groot werd op 13 juni 1967 geboren in Ens (Noordoostpolder) als oudste dochter en tweede kind van Jan Groot & Fien van Haasteren. Na haar volgen nog 2 kinderen. Gedurende haar lagere en middelbare schoolperiode woonde ze in Didam. In 1985 haalt ze haar VWO diploma aan het Liemers College in Zevenaar. Ze reist af naar Wageningen, waar ze begint aan de inservice opleiding tot verpleegkundige in het toenmalige Pieter Pauw Ziekenhuis. Na de opleiding en het fuseren van 4 regionale ziekenhuizen, is ze betrokken bij de start van de afdeling oncologie van het inmiddels geheten ziekenhuis Gelderse Vallei. Vanaf september 1992 tot eind 1994 volgt ze het doorstroomprogramma gezondheidswetenschappen aan de Universiteit van Maastricht, afstudeerrichting 'Theorie van de Gezondheidswetenschappen'. Ze gaat na de afronding van die studie werken als (eerste) verpleegkundig specialist (aandachtsgebied oncologie) in ziekenhuis Gelderse Vallei. Halverwege 1998 verruilt ze deze pioniersfunctie voor een baan als beleidsmedewerker kwaliteit en transmurale zorg in hetzelfde ziekenhuis.

Vanaf november 1999 is ze werkzaam als eerst AIO en later junior-onderzoeker op de afdeling Kwaliteit van Zorg van het UMCN. Van de onderzoeksresultaten van deze periode wordt verslag gedaan in dit proefschrift. Gedurende de jaren 2004–2006 werkt ze, naast het afronden van de onderzoeken zoals beschreven in dit proefschrift, deels als beleidsmedewerker bij het landelijke steunpunt palliatieve zorg AGORA en deels bij hospice Bennekom als onderzoeker. Vanaf januari 2006 werkt Marieke bij het Integraal Kankercentrum Oost (IKO) aan projecten ten behoeve van de oncologische en palliatieve zorg.

Marieke deelt leven en liefde met Cornelis Mostert en hun 4 kinderen Stijn (1995), Sara (1998), Sieb (2000) en Minke (2003).