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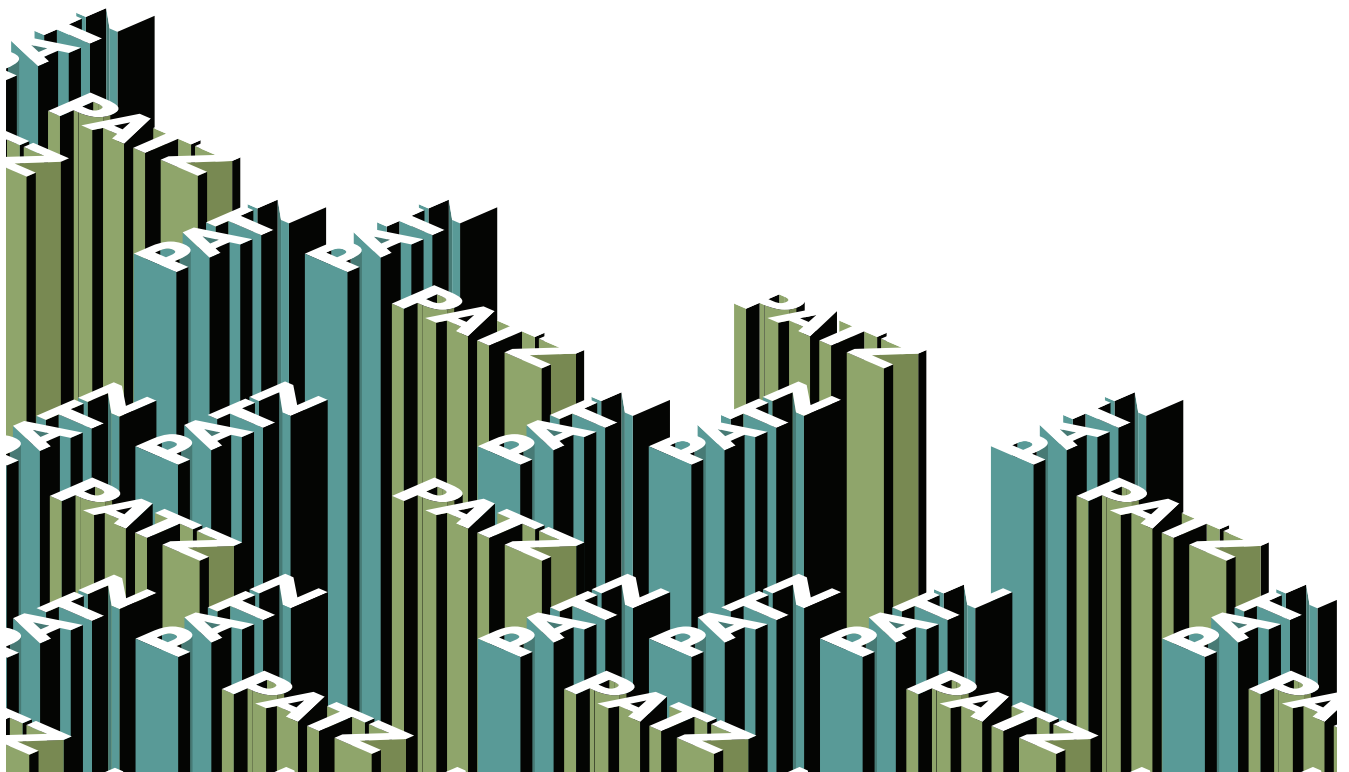
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# Improving primary palliative care in the Netherlands

Opportunities and the role of the  
PaTz-method

Ian Koper



## Colophon

Ian Koper  
Improving primary palliative care in the Netherlands,  
Opportunities and the role of the PaTz-method  
176 pages.

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# **Improving primary palliative care in the Netherlands**

**Opportunities and the role of the PaTz-method**

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de Vrije Universiteit Amsterdam,  
op gezag van de rector magnificus  
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door

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geboren te Haarlemmermeer

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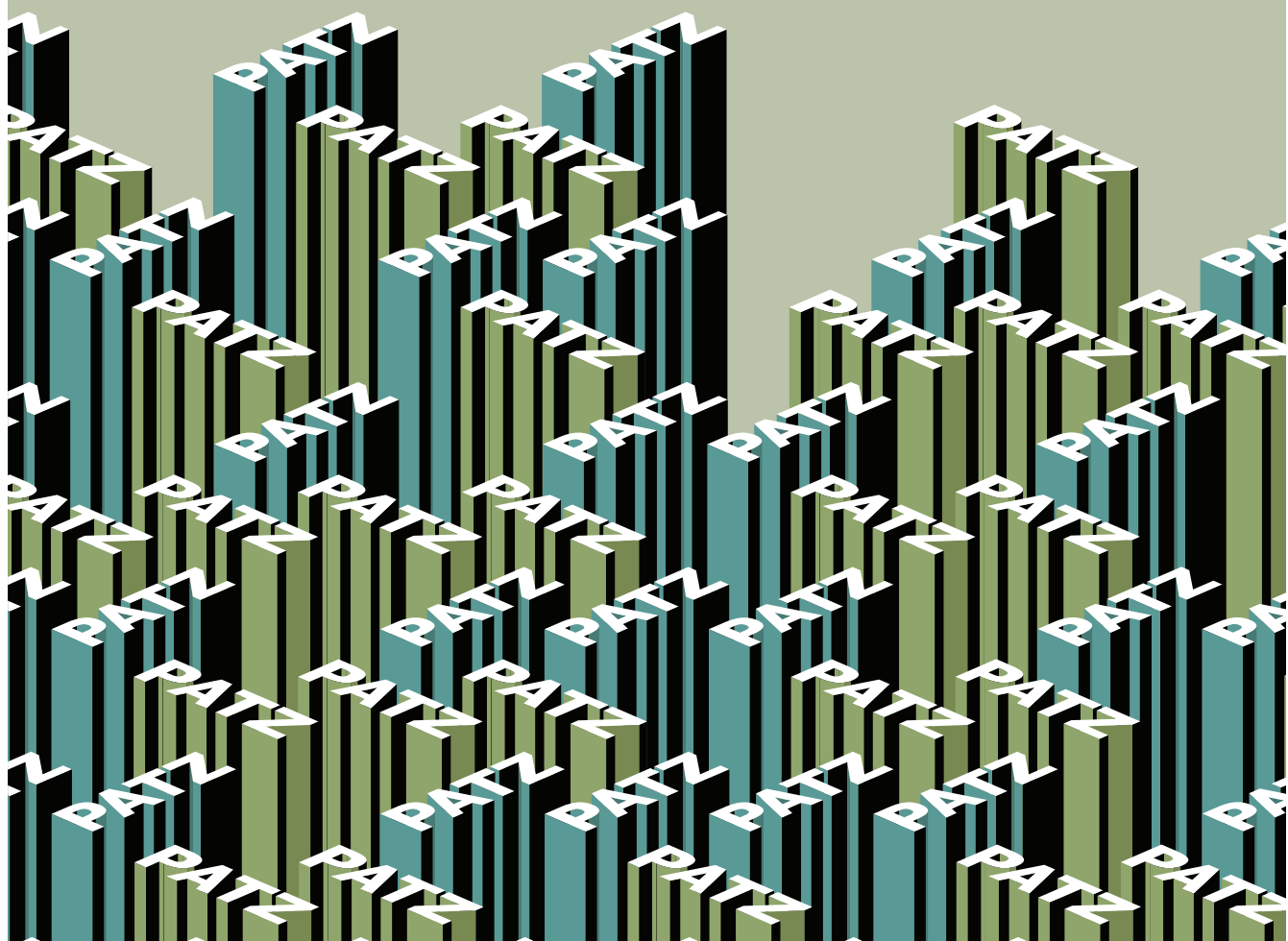
*All's well that ends well.*

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## Preface

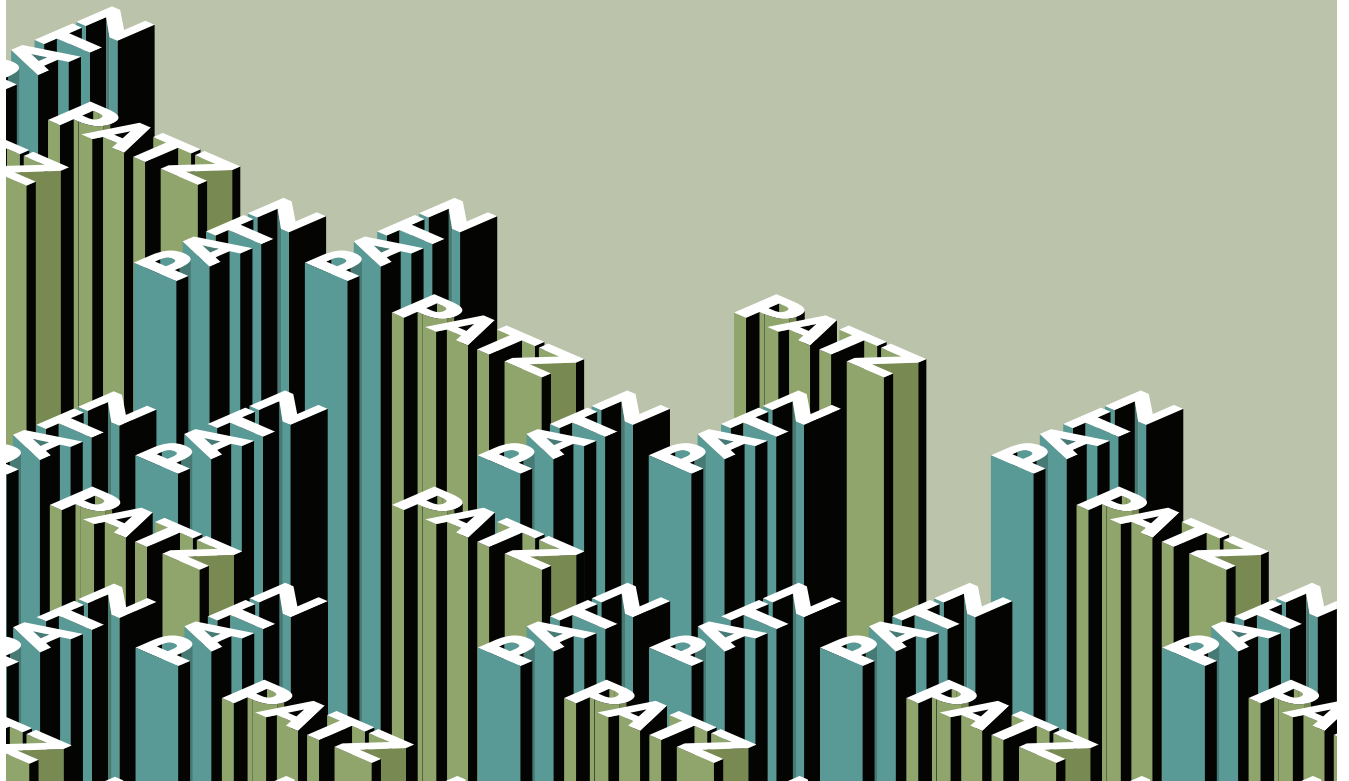
What matters to people in the end? What is a good death? When I started my PhD-project, I was fascinated by questions like these regarding the end of life. During the past four years, I came to realise that there are no simple answers to these questions. What matters to people is personal, and a good death is different for everyone. I also came to understand that palliative care is not so much about a good death as it is about living well until the end. Palliative care is about setting goals, thinking about what we are willing to sacrifice to reach these goals when time is limited and achieving the best quality of life considering the circumstances. With this thesis I hope to contribute to better palliative care in the primary care setting in the Netherlands, and through that, more quality of life for people nearing death.





# Chapter 1

## General introduction



This thesis is about improving care for people at the end of their lives. More specifically, it examines opportunities to improve palliative care for people residing in the primary care setting, and the role of the PaTz method (acronym for Palliatieve Thuiszorg: palliative care at home) in this care. This chapter first gives some background information on palliative care, the Dutch policy on palliative care and the role of general practitioners in this form of care. Next, this chapter provides information on the PaTz method and its potential in primary palliative care. Finally, the research questions that are addressed in this thesis are described, together with the methods used to answer these questions.

## What is palliative care?

Palliative care is care for people with a life-threatening illness, focused on symptom alleviation and quality of life rather than on cure or life prolongation. Common ideas about palliative care are that it is restricted to the dying phase, that it is a synonym for terminal care, or that it is exclusively for people whose curative treatment options have been exhausted. The pertinacity of these ideas is shown particularly well in the American healthcare system, where the federal health insurance programme Medicare requires patients to formally resign from curative treatment in order to be eligible for hospice care.<sup>1</sup> In the consensual way of thinking about palliative care, however, it is much broader than terminal care, and the either-or choice is redundant.

The World Health Organization (WHO) defines palliative care as *“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*<sup>2</sup> The WHO also states that palliative care affirms life and regards dying as a normal process, and that it intends neither to hasten nor to postpone death. Palliative care uses a team approach to address the needs of patients and families, and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.<sup>2</sup> This simultaneity is well depicted in the concept of palliative care proposed in 2003 by Lynn and Adamson, who presented palliative care as a continuum, starting at the diagnosis of a life-threatening illness, and becoming more prominent as the illness progresses (figure 1.1).<sup>3</sup>

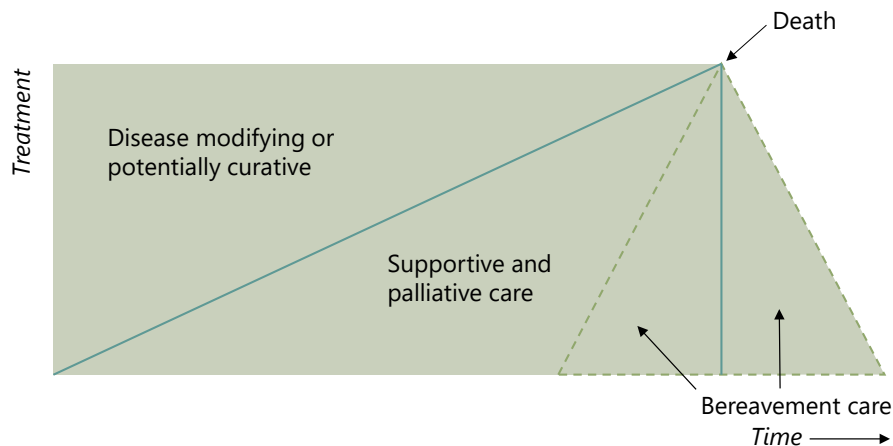


Figure 1.1 Lynn and Adamson's concept of palliative care

However, as a general model, this model does not differentiate between the trajectories that different types of life-threatening illnesses generally follow, as distinguished by Murray et al.<sup>4</sup> (figure 1.2):

- Patients with cancer generally start with a stable period, which is followed by a period of rapid decline until death.
- Patients with organ failure generally have a longer period of slow decline, in which acute exacerbations of their illness frequently occur. Death often occurs suddenly, during such an exacerbation.
- Patients with dementia, frailty and/or an accumulation of age-related issues generally decline slowly over a longer period of time.

In palliative care, timely discussion of end-of-life topics is crucial as it allows for the identification of and anticipation of both current and future wishes, expectations and palliative care needs.<sup>5</sup> Furthermore, making treatment decisions and discussing events before they occur (often as an acute incident), and before the patient loses the capacity to discuss them, reduces aggressive treatment and hospital admissions in the final phase of life, and improves compliance with the patient's wishes and quality of life.<sup>6,7</sup> But timely identification of patients requiring palliative care is challenging.<sup>8</sup> Although the overview of trajectories of life-limiting illness as depicted by Murray et al. may assist physicians in the timely identification of patients who could benefit from palliative care, there are some limitations. The time between diagnosis and death may vary greatly between patients, and finding the right time for these conversations remains difficult. Patients may not need extra care in the period after diagnosis, and may not realize or be ready to accept that they are suffering from a life-threatening illness. Other barriers for communication about palliative care include physicians' concerns about taking away hope, causing distress, or having insufficient time for these conversations.<sup>9</sup>

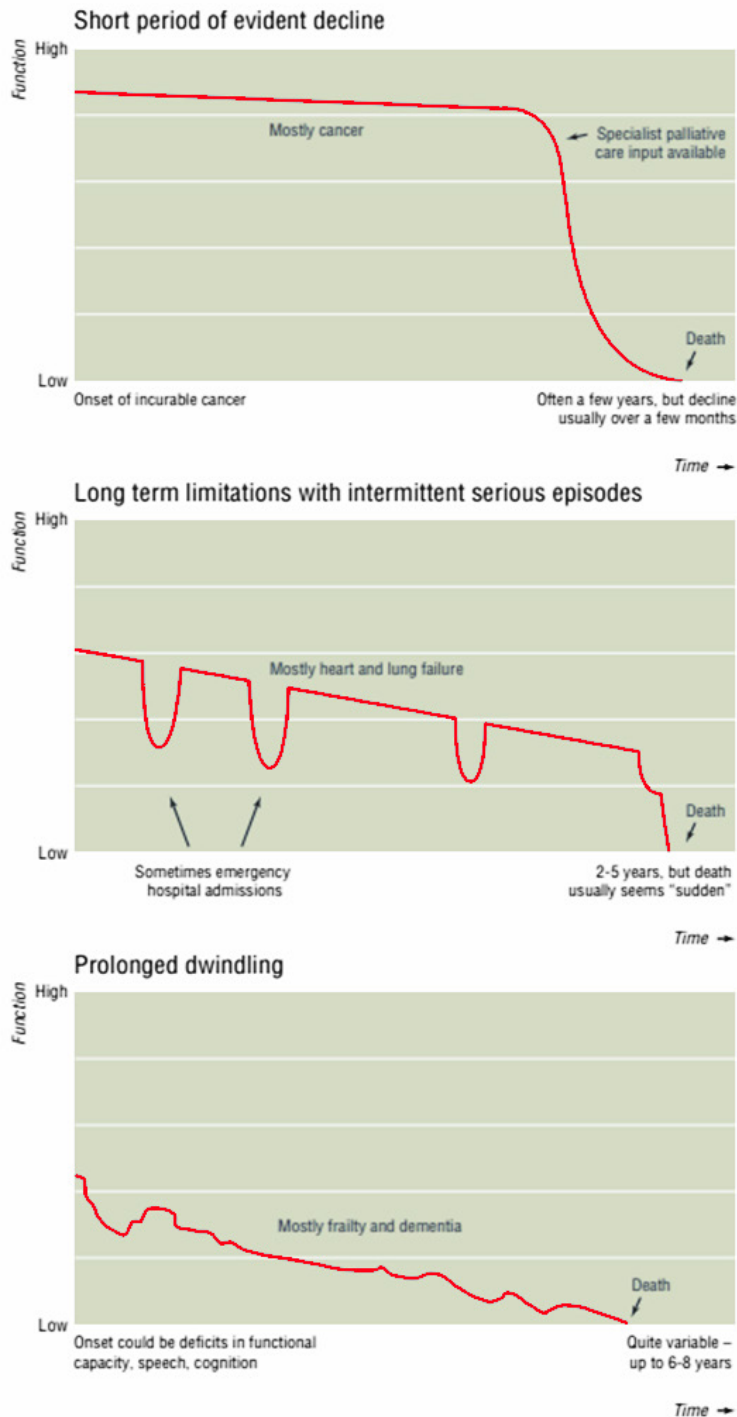


Figure 1.2 Murray's illness trajectories



Perhaps one of the most commonly used identification tools in palliative care is the Surprise Question (SQ: 'Would I be surprised if this patient died in the coming 6-12 months?').<sup>10</sup> The value of this tool should not be sought in its prognostic accuracy, but instead in its ability to identify patients who may benefit from palliative care.<sup>10,11</sup> If the answer to the question is 'no', a physician should be triggered to start a conversation about palliative care.

Another aspect of palliative care that can be seen from the WHO definition is that it is ideally multidimensional, focusing not just on physical but also on psychosocial *and* spiritual issues that arise when patients are facing a life-threatening illness. Psychosocial issues include themes like anger, depression, self-esteem and a changing role within society or the family<sup>12</sup>, while spiritual issues include themes like love and faith, hope and fear, meaning and purpose, and existential issues.<sup>13,14</sup> In practice however, the psychosocial and spiritual dimensions generally remain underserved,<sup>15,16</sup> and research into these domains of palliative care is scarce.

Another important notion is that the WHO explicitly states that palliative care requires a team approach. As it is virtually impossible for a single healthcare professional to address the often complex and multidimensional care needs of patients at the end of their lives, and their relatives, palliative care requires multidisciplinary cooperation. Ideally, one healthcare provider assesses the care needs of the patient and their relatives, and brings in other healthcare providers with expertise concerning the presented care needs as necessary.

## What is the Dutch policy on palliative care?

Dutch national policy states that palliative care should be available to all who need it, and that it should be provided by healthcare providers close to the patient, where possible in the primary care setting.<sup>17</sup> In the Netherlands, a generalist-specialist palliative care model is in place.<sup>18</sup> All Dutch healthcare providers are considered to be able to provide basic palliative care, and if patients have complex needs that exceed the healthcare providers' skills, they can be referred to specialist palliative care providers.<sup>17</sup> Palliative care is not recognized as a medical specialty, although physicians can receive additional formal training in palliative care (in Dutch: kaderopleiding palliatieve zorg); but only an estimated 10-15% do so.<sup>19</sup> In 2017, the Netherlands Comprehensive Cancer Organization in cooperation with Palliatief published a Quality Framework for Palliative Care<sup>20</sup> authorized by national healthcare associations such as the Dutch College of General Practitioners (NHG), the Association of Elderly Care Specialists (Verenso), the Dutch Nurses' Association (V&VN) and the Dutch Patient Federation (NPF). In this framework, the core values and principles of palliative care in the Netherlands are explained, and it provides guidelines for structuring the process of palliative care as well as criteria for palliative care in the physical, psychological, social and spiritual

dimensions. Finally, it provides guidelines and criteria for the provision of terminal and bereavement care, and insight into cultural, legal and ethical aspects of palliative care.<sup>20</sup>

## What is the role of GPs in primary palliative care?

Most patients in the Netherlands prefer to die at home.<sup>21,22</sup> In this setting, the GP is the primary healthcare provider, playing a central role in palliative care. Together with district nurses (DNs), they coordinate and provide palliative care in the primary care setting, assessing and addressing problems in all dimensions of palliative care. If needed, they can seek consultation with a palliative care consultation team or involve specialist palliative care providers, services or facilities, such as volunteers in palliative care, spiritual caregivers or hospices.

The WHO states that palliative care requires a team approach, implying that the provision of good quality palliative care requires communication and cooperation between healthcare providers. In the Dutch healthcare system, where market mechanisms have led to a proliferation of home care organizations, this can be particularly problematic in more urbanized regions. In some major cities, there are over one hundred home care organizations.<sup>23</sup> In addition, research has shown that there is only limited cooperation with other disciplines that can support the GP in the provision of multifaceted palliative care, such as physiotherapists, spiritual caregivers or volunteers in palliative care.<sup>24,25</sup> Potential explanations for these findings include the possibility that GPs are unaware of the opportunities to involve other disciplines in palliative care, are unable to develop close communication with other professionals<sup>26</sup> or that their workload hinders the cooperation with others.<sup>27</sup>






## What is PaTz?

In an effort to bolster cooperation and communication between GPs and DNs in the primary care setting, the PaTz method was introduced to the Netherlands by the former GP Bart Schweitzer. PaTz is a method aimed at improving palliative care in the primary care setting based on the British Gold Standards Framework.<sup>28</sup> The PaTz method has three basic principles<sup>i</sup>:

1. A PaTz group consists of local GPs and DNs, who meet at least six times a year to discuss their patients with a life-threatening illness.
2. The group identifies patients with potential palliative care needs and registers these patients in the PaTz register.
3. The group is supported by a palliative care consultant.

<sup>i</sup> PaTz groups are also required to participate in evaluation studies.

Table 1.1 PaTz-register colour coding scheme

Colour	Label	Description
	Stable	Patient has incurable illness or is frail. Stable situation and possibly on-going curative treatment
	On-going palliative care	End of life conversation has occurred and care in one of the dimensions has started
	Increasing care needs	Increasing care needs on one or more dimensions. Destabilizing situation.
	Intensive care needs	Intensive, urgent or complicated care or crisis situation.
	Deceased	Potential bereavement care

The previously mentioned Surprise Question is endorsed as a way of identifying patients who might benefit from a palliative care approach, but other tools such as the Supportive and Palliative Care Indicators Tool (SPICT) can also be used. The PaTz register provides an overview of all patients in the PaTz group with palliative care needs, and patients on the register can be coded with a colour code to indicate the urgency, intensity or complexity of their care needs. A light blue colour code indicates the patient is stable, possibly still undergoing curative treatment. Green indicates that care has started in one or more dimensions of palliative care, and yellow indicates increasing care needs on one or more dimensions of palliative care. A red colour code indicates an intensive, urgent and/or complicated care situation. Dark blue indicates that the patient has died and bereavement care might be necessary. PaTz meetings are supported by a palliative care consultant: a physician or nurse with formal training in palliative care. These experts provide advice and background information as requested.

The PaTz method started in 2010 with four groups in Amsterdam. Since then, the number of groups grew to 80 in 2016, and increased to 232 PaTz groups by January 2020. This growth may partly be explained by the promotional efforts of the PaTz foundation, and the practical support offered by the foundation in starting or running PaTz groups. Chairs of PaTz groups follow an introductory course and are guided in their role. The website of the PaTz foundation ([www.patz.nu](http://www.patz.nu)) provides readily accessible information supporting the start and functioning of a PaTz group, plus a tool that can assist in the identification of patients with palliative care needs or in the conversations on advance care planning. Also, many physicians who follow the formal additional training in palliative care start a PaTz group during their training as a project to improve palliative care in their practice. In any case, PaTz apparently fulfils a need. At the same time, this growth prompts



questions regarding the efficacy and added value of PaTz groups as well as questions regarding consistency in the implementation and practice.

A pilot study of the first four PaTz groups in the Netherlands showed the potential of the PaTz method in improving primary palliative care.<sup>29</sup> Participants reported that the PaTz group improved cooperation, leading to better continuity of care, more knowledge about palliative care in general, a better picture of the patient and more support in difficult situations regarding care.<sup>29</sup> Furthermore, a pre- and post-survey evaluation in 37 PaTz groups showed that identification of patients with palliative care needs improved dramatically and that identification of these patients was associated with improved communication about end-of-life topics and advance care planning.<sup>30</sup> In the Quality Framework for Palliative Care, PaTz groups are mentioned as the preferred method of cooperation in palliative care in the primary care setting.<sup>20</sup>

## Aim, research questions and outline of this thesis

Summarizing the background to this thesis: palliative care is principally provided in the primary care setting, where general practitioners and district nurses bear the main responsibility. Although they are equipped to provide basic palliative care, meeting the multidimensional palliative care needs of patients and their relatives may prove difficult. In addition, GPs may not have an overview of the multitude of services, facilities and additional healthcare providers that are available to assist in the provision of primary palliative care. The PaTz method may contribute to better palliative care through better cooperation between healthcare providers in the primary care setting and early identification of patients with palliative care needs. Insight is needed into what areas of primary palliative care can potentially be improved and whether PaTz groups can contribute to improvement in these areas of primary palliative care. **The overall aim of this thesis is therefore to investigate areas of improvement in primary palliative care and the role of PaTz groups in these improvements.**

Part 1 of this thesis addresses potential areas of improvement in primary palliative care, posing the following research questions:

- What are the experiences of the coordinating healthcare providers in their cooperation with the other palliative care services and facilities that are available? (Chapter 2)
- What is the role of spiritual caregivers in primary palliative care and how can they be involved more often? (Chapter 3)
- Is early identification of patients with palliative care needs positively associated with communication about palliative care and palliative care outcomes? (Chapter 4)



After establishing areas of improvement for primary palliative care, the potential role of PaTz in this will be described in Part 2. The research questions in Part 2 are:

- How do PaTz groups function in practice? (Chapter 5)
- Is participating in a PaTz group associated with palliative care outcomes and end-of-life communication? (Chapter 6)
- Is the integration of spiritual caregivers in PaTz groups feasible and valuable? (Chapter 7)

## Methods

The data for this thesis was derived from four studies: a mixed methods study on the needs and experiences of healthcare providers working in primary palliative care (Chapters 2, 3 and 6); the Sentinel study (Chapter 4); a prospective observational study on the practice of PaTz groups (Chapter 5); and the listening consultation service pilot (Chapter 7).

### Mixed methods study

In 2016, a mixed methods study was performed which aimed to explore the needs and experiences of healthcare providers providing palliative care in the primary care setting. For this purpose, a questionnaire was available online from 5 April 2016 until 5 August 2016. The invitation to fill in this questionnaire was sent through professional organizations such as the Dutch College of General Practitioners (NHG), the Advisory Board of General Practitioners on palliative care (PalHag), the Dutch Nurses' Association (V&VN), the Dutch Spiritual Caregivers' Association (VGvZ), and the Dutch Humanist League (HV). In total, 108 general practitioners, 258 district nurses and 31 spiritual caregivers participated. In addition, four homogenous online focus groups were formed to explore the insights from the questionnaire in greater depth; eight general practitioners, 19 nurses and nine spiritual caregivers participated in these focus groups.

### Sentinel study

The Sentinel study is a network of 53 general practices, designed and managed so as to be representative for the general population of the Netherlands with regard to age, socioeconomic status, ethnic composition and degree of urbanization. For the death of every patient who is registered with one of these practices, the GP fills in a standardized form on patient and care characteristics relevant to end-of-



life care. For this thesis, data was used on 1,464 patients who died between 2013 and 2018.

## Prospective observational study

To explore the functioning of PaTz groups in practice, a prospective observational study was performed in which ten PaTz groups recorded the content and activities of their meetings for a follow-up period of one year. The chairs of the PaTz groups recorded which patients were identified as definitely or potentially in need of palliative care (n=584), which patients were discussed (n=243), and what other topics were discussed during the meetings. In addition, two observation sessions were performed in each PaTz group.

## The listening consultation service pilot

In an effort to improve the provision of spiritual care in palliative care in the primary care setting, the PaTz foundation started a pilot in which spiritual caregivers were linked to three PaTz groups. They educated the members of the PaTz-groups in spirituality, spiritual issues and when to refer to a specialist, and the PaTz group members referred their patients with complex spiritual care needs to the spiritual caregivers. Interviews were performed with spiritual caregivers (n=5), PaTz group members (n=30) and patients (n=5) to assess the feasibility and added value of the listening consultation service in this form.

## Thesis outline

### Part 1 – Potential areas of improvement for primary palliative care

Chapter 2, 'Experiences of Dutch general practitioners and district nurses with involving care services and facilities in palliative care: a mixed methods study', describes the extent to which Dutch GPs and district nurses involve services and facilities that can aid them in the provision of palliative care. It also describes their experiences with these services and facilities, their reasons for not involving them and how they think the involvement of these services and facilities can be improved. This study reports on data from the mixed methods study.

Chapter 3, 'Spiritual care at the end of life in the primary care setting: experiences from spiritual caregivers - a mixed methods study', explores the role of spiritual caregivers in palliative care in practice and how spiritual caregivers think

they could become more involved in the primary care setting. This study draws on data from the mixed methods study.

Chapter 4, 'How are treatment aims at the end of life associated with advance care planning and palliative care outcomes: a mortality follow-back study in general practice', estimates how often patients in the final phase of life have curative, life-prolonging and/or palliative treatment aims. It also explores how these treatment aims are related to advance care planning, communication about end-of-life topics and palliative care outcomes. This study reports on data from the Sentinel study.

## Part 2 – the role of PaTz in improving palliative care

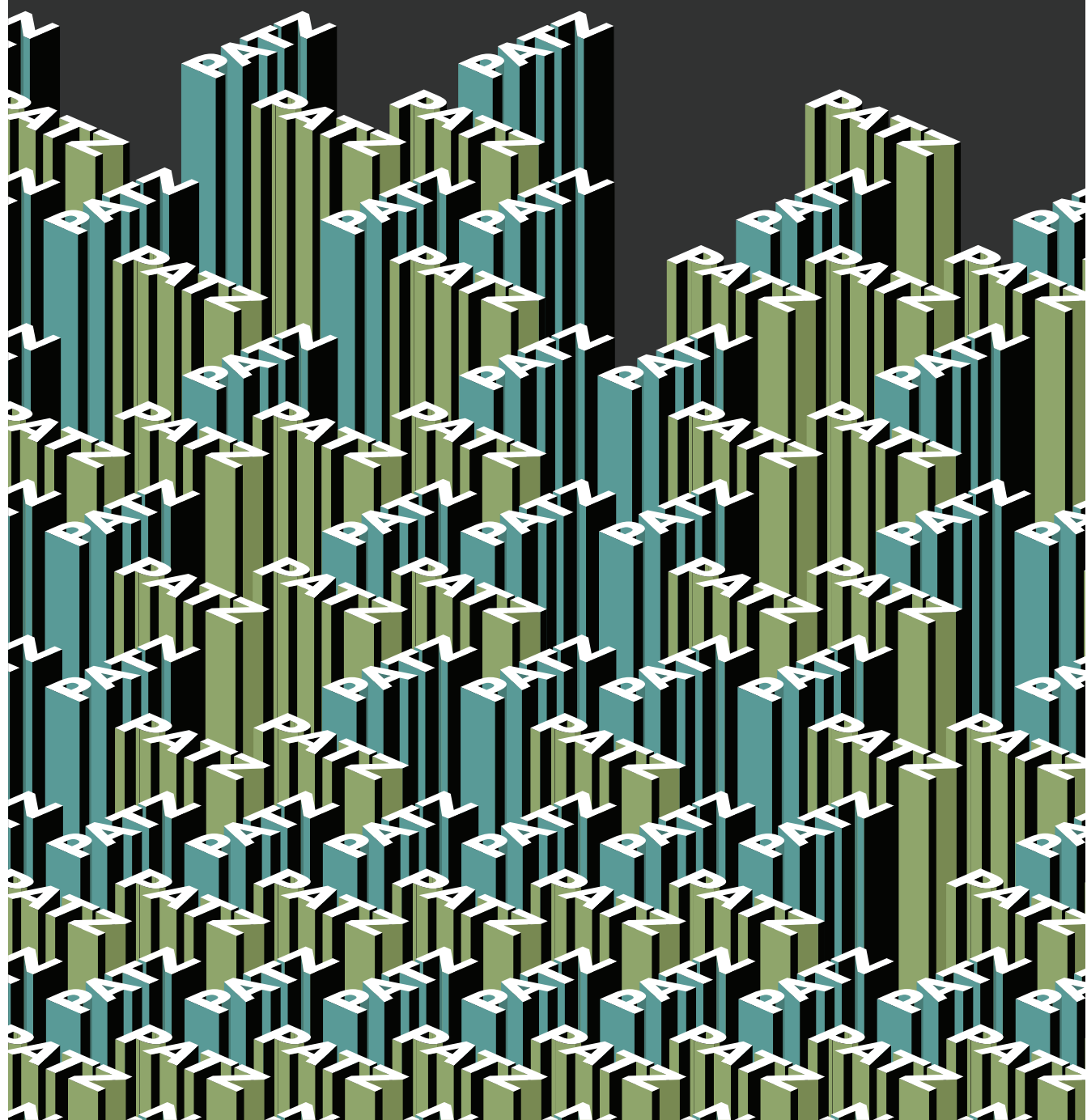
Chapter 5, 'Variation in the implementation of PaTz: a method to improve palliative care in general practice - a prospective observational study', describes the variation in the structure and practice of PaTz groups. This study reports on data from the prospective observational study.

Chapter 6, 'The association between PaTz and improved palliative care in the primary care setting: A cross-sectional survey', examines the perceived benefits of and barriers for participating in a PaTz group according to GPs and DNs. It also describes how PaTz participation is associated with improved communication about end-of-life topics and palliative care outcomes. This study reports on data from the mixed methods study.

Chapter 7, 'Strengthening the spiritual domain in primary palliative care through a listening consultation service: evaluation of a pilot', describes the feasibility and added value of a listening consultation service where spiritual caregivers joined PaTz groups to improve the provision of spiritual care in primary palliative care. This study reports on data from the listening consultation pilot.

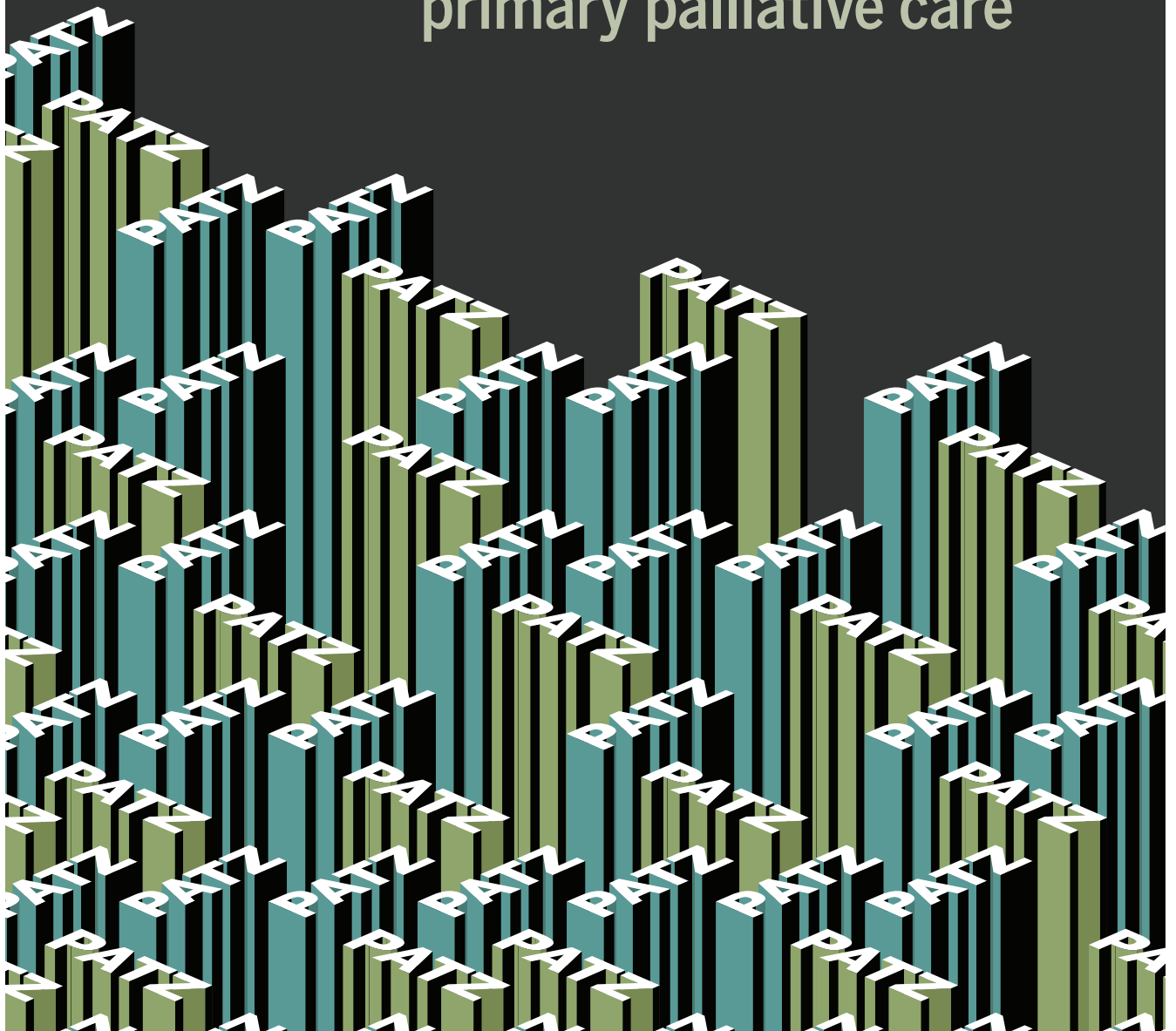
## General discussion

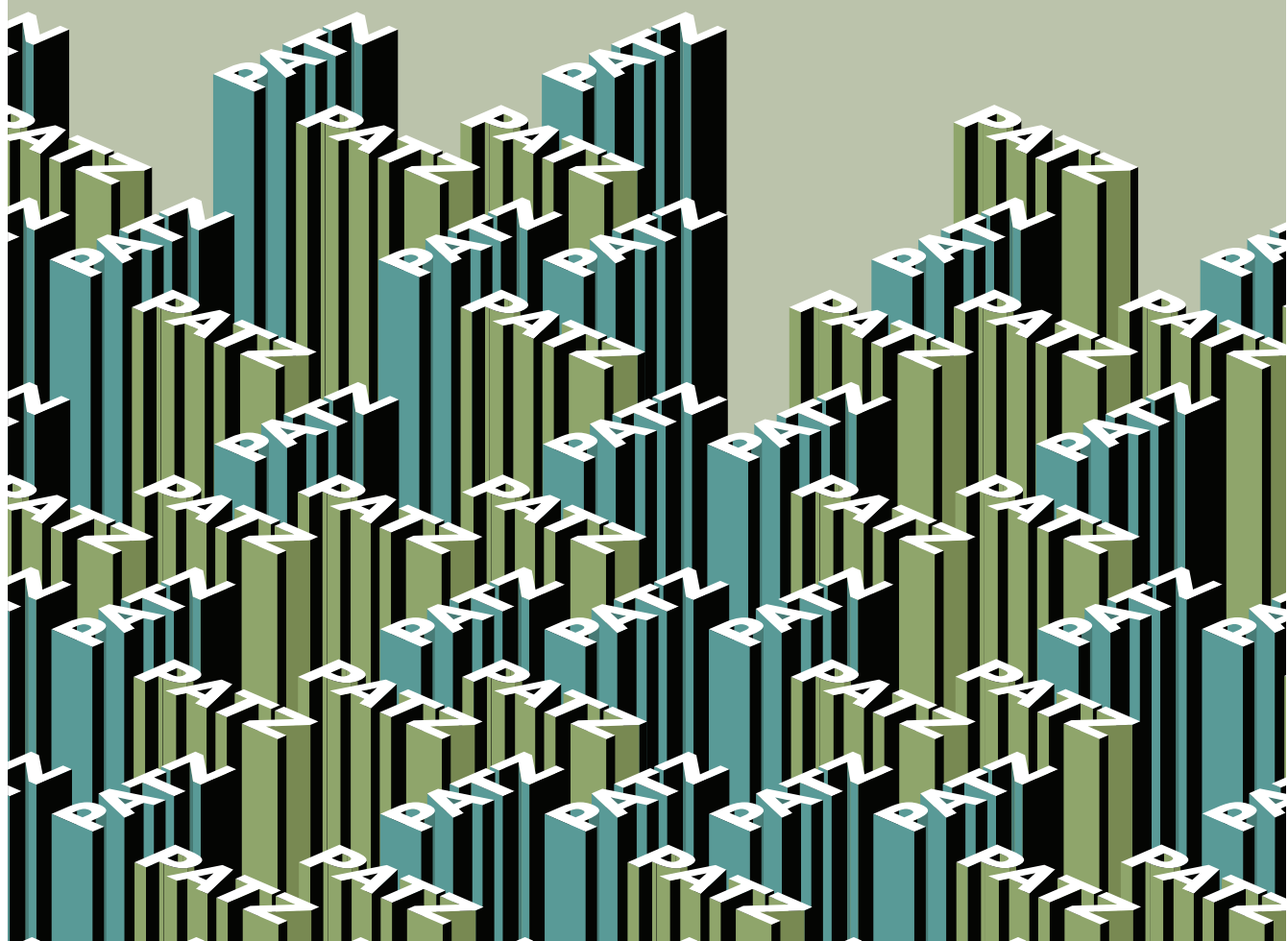
In this chapter, the main findings from the previous chapters are critically appraised, and implications and recommendations for research, practice and policy are discussed.



# Part 1

Potential areas of  
improvement for  
primary palliative care



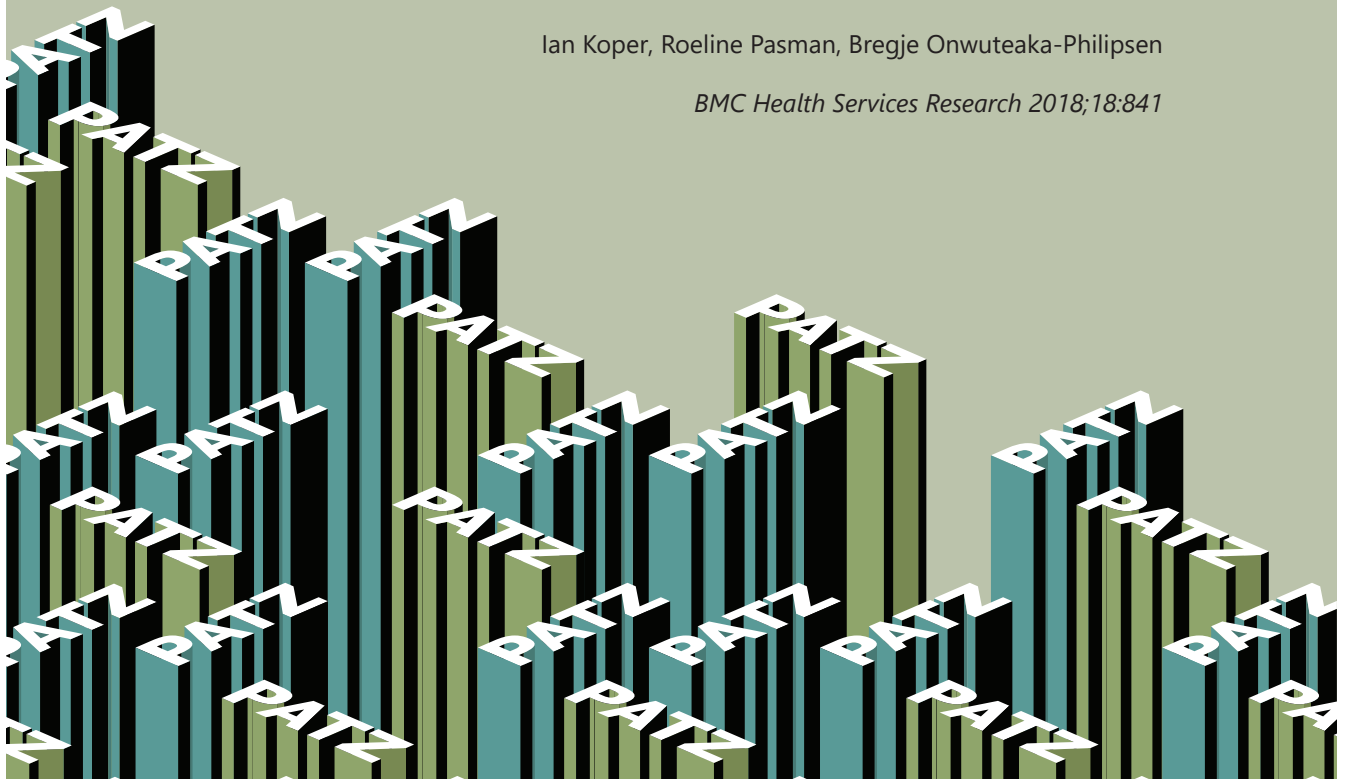


# Chapter 2

## **Experiences of Dutch general practitioners and district nurses with involving care services and facilities in palliative care: a mixed methods study**

Ian Koper, Roeline Pasman, Bregje Onwuteaka-Philipsen

*BMC Health Services Research 2018;18:841*





## Abstract

Background: General practitioners (GPs) and district nurses (DNs) play a leading role in providing palliative care at home. Many services and facilities are available to support them in providing this complex care. This study aimed to examine the extent to which GPs and DNs involve these services, what their experiences are, and how involvement of these services and facilities can be improved.

Methods: Sequential mixed methods consisting of an online questionnaire with structured and open questions completed by 108 GPs and 258 DNs, followed by three homogenous online focus groups with 8 GPs and 19 DNs, analysed through open coding.

Results: Most GPs reported that they sometimes or often involved palliative home care teams (99%), hospices (94%), and palliative care consultation services (93%). Most DNs reported sometimes or often involving volunteers (90%), hospices (88%), and spiritual caregivers (80%). The least involved services and facilities were psychologists and psychiatrists (51% and 50%) and social welfare (44% and 57%). Main reason for not involving services and facilities was 'not needing' them. If they had used them, most GPs and DNs (68%-93%) reported solely positive experiences. Hardly anyone (0%-3%) reported solely negative experiences with any of the services and the facilities. GPs and DNs suggested improvements in three areas: (1) establishment of local centres giving information on available services and facilities, (2) presentation of services and facilities in local multidisciplinary meetings, and (3) support organizations to proactively offer their facilities and services.

Conclusion: Psychological, social, and spiritual services are involved less often, suggesting that the classic care model, which focuses strongly on somatic issues, is still well entrenched. More familiarity with services that can provide additional care in these areas, regarding their availability and their added value, could improve the quality of life for patients and relatives at the end of life.

## Background

Palliative care is complex care, addressing physical, psychosocial, and spiritual problems at the end of life<sup>2</sup>. When faced with a life-threatening illness, most people in the Netherlands prefer to die at home<sup>21</sup>. Dutch national policy states that palliative care should principally be provided in the primary care setting<sup>31</sup>, where primary care professionals such as general practitioners (GPs, in some countries better known as family physicians) and district nurses (DNs, in some countries better known as community nurses) play a leading role in the care for patients with a life-threatening illness in the primary care setting<sup>32-35</sup>. In this coordinated care model<sup>18</sup>, the primary care physician provide general palliative care and can refer to specialist palliative care in case of complex problems. Similar to other countries like the UK, Australia and Canada<sup>36</sup>, general practitioners serve as gatekeepers to specialist care services.

In practice, meeting the multidimensional needs of patients and their relatives has proven to be difficult<sup>37-39</sup>. There are many services and facilities available that GPs and DNs can involve or refer to when providing palliative care in the primary care setting. While most studies on palliative care services focus on hospices, palliative care consultation services, and/or palliative home care teams<sup>40-45</sup>, there are also studies showing the added value of involving other services in palliative care such as psychologists, volunteers, and spiritual caregivers<sup>46-48</sup>. Little is known about how often these services are involved in palliative care by GPs and DNs in the Netherlands, and what the experiences are of GPs and DNs when using these services and facilities.

The first aim of this study was therefore to investigate how often GPs and DNs involve healthcare services and facilities in palliative care and what their experiences are with these services and facilities. The second aim was to investigate what reasons GPs and DNs have for not involving these services and facilities. Finally, we wanted to investigate how GPs and DNs think palliative care support by services and facilities can be improved, and how these improvements can be achieved.

## Methods

### Design

This mixed methods study had a sequential exploratory design<sup>49</sup>, consisting of two parts. The first part was an online questionnaire, investigating GPs' and DNs' use of and experiences with services and facilities in palliative care and their reasons for not involving them, which was available online from April 5, 2016 until Au-



gust 5, 2016. The second part of the study consisted of homogenous online focus groups in which the insights from the online questionnaire were explored more in-depth, with a focus on how palliative care support by services and facilities can be improved, and improvements in palliative care can be achieved. All focus groups were held within a three-month time frame: the first focus group started September 26, 2016 and the final focus groups finished December 6, 2016. In this study, palliative care was described as *'care for people with a life-threatening illness or age-related decline in the final phase of their life.'* The Medical Ethics Committee of the VUmc approved this study beforehand (METc VUmc 2016.320).

## Participants

Potential participants were invited to participate by professional organizations, the national organization of palliative care networks (Fibula) and regional care support networks (ROS) through newsletters and websites. Participating organizations were the Dutch College of General Practitioners (NHG), the Advisory Board of General Practitioners on palliative care (PalHag) and the Dutch Nurses' Association (V&VN). The inclusion criteria were: 1) working as a GP or DN in patient care, 2) having experience with palliative care, and 3) working in the Netherlands. Details of 108 GPs and 258 DNs from all over the Netherlands who participated in the online survey responded to the questions on services and facilities are shown in Table 2.1.

In the final question of the online questionnaire, participants were asked if they were interested in participating in a focus group aimed at further investigating points for improvement in palliative care. Participants who expressed an interest were invited to participate in an e-mail containing information on the procedure, discussion topics, and the ground rules. Twenty-two GPs were invited, 11 responded, 10 agreed to participate and 8 actually did so in practice. The equivalent figures for DNs were 24, 24, 20 and 19. Their details are shown in Table 2.1. Although the recruitment strategy does not allow for response rates to be calculated, characteristics of the sample can be compared to the national population. Nationwide, GPs are 48 years old on average, working 30 hours per week<sup>50</sup> while DNs are 45 years old and working 15 hours per week on average<sup>51</sup>. Respondents in our sample were of similar age, while working slightly more hours per week. Comparing the gender distribution of the respondents to national figures (nationwide, 51% of GPs and 92% of DNs are women), the proportion of female GPs in our sample is rather high.

**Table 2.1** Characteristics of participants in the online survey and online focus groups

	Online survey		Online focus groups		
	GP n=108	DN n=258	GP n=8	DN group 1 n=9	DN group 2 n=10
Age (mean (range))	49 (30-64)	46 (21-66)	51 (39-59)	42 (33-52)	50 (35-57)
Gender (female)	71%	94%	4	9	8
Mean working hours per week	33	26	35	33	26
Working experience (mean years(range))	17 (1-38)	13 (1-42)	18 (6-30)	10 (1-20)	17 (3-34)
Having received any training in palliative care	50%	59%	6	5	10



## Questionnaire

The questionnaire contained both open and structured questions. Participants were asked to say for nine specific services and facilities whether or not they involved these when providing palliative care. The services and facilities concerned were: hospices, palliative care consultation services, clinical pain specialists, palliative home care teams, case managers for palliative care/dementia, spiritual caregivers, psychologists/psychiatrists, social welfare, and volunteers in palliative care. The possible answers were: 'yes, often', 'yes, sometimes', and 'no'. If participants reported using a particular service or facility sometimes or often, they were subsequently asked to rate their experiences. The possible answers were: 'solely positive experiences', 'mixed experiences', and 'solely negative experiences'. If participants reported that they did not involve certain services or facilities, they were asked to indicate why they did not. The possible answers were that these service were 'unavailable' or 'not needed' (from their perspective), that the participants had 'bad experiences' in the past, perceived involving them as 'not my task', or 'other reason'. Participants who choose 'other reason' were asked to elaborate. Next, participants were asked in an open question how palliative care with regard to services and facilities could be improved.

## Online focus groups

The focus group discussions were held online<sup>52</sup>, on a website with an interface similar to an online chat room. Participants logged into the website using an account name (their code name) and password provided by a moderator (IK). There they

could respond under their code name to the questions posed by the moderator and to other respondents' comments. One question was posed each working day at 10.00 am, except on Wednesdays. The moderator sent an e-mail to all participants notifying them when a new question was available. This e-mail contained a link to the website as well as an encouragement to read and respond to earlier questions and comments by other respondents. The website was accessible 24 hours a day, from the moment the first question was presented until one week after the last question was presented. The participants could click on a question to read the question with its context, read earlier comments from other respondents and react to both the question and the earlier comments. If necessary, the moderator redirected the discussion with follow-up questions at any time. For instance, the moderator summarized previous comments and asked the participants to respond to the summary. Any personal information or information that identified specific individuals or organizations was depersonalized by the moderator. In order to explore the insights from the questionnaire related to services and facilities in more depth, two of the questions for the online focus groups were on this topic: 1) *how can the accessibility of services and facilities such as hospices, spiritual caregivers, and volunteers be improved?* and 2) *how can the availability of services and facilities be made more widely known to healthcare providers as well as patients and relatives?*

## Data analysis

Data from the structured questions was analysed using IBM SPSS Statistics software (Version 20.0). Descriptives were used to analyse the participant characteristics, involvement of services and facilities, and the respondents' experiences and reasons for not involving them. Differences between GPs and DNs in their involvement of services and facilities were tested for statistical significance using Fisher's Exact Test.

Data from the open question on improvements regarding services and facilities and the online focus groups was analysed (separately) using open coding.<sup>53</sup> The codes were derived from the data rather than being determined beforehand. IK analysed and coded the data, after which the codes were checked by RP and discussed with RP and BO. During this process, codes underwent content and definition changes as the analysis progressed and relations between codes became apparent. We coded thirteen subcategories that could be grouped into three overarching categories: 1) availability of services and facilities, 2) referrals to services and facilities, and 3) other improvements.

## Results

### Involvement of services and facilities in palliative care.

The services and facilities that most GPs used sometimes or often were palliative home care teams (99%), palliative care consultation services (95%), and hospices (94%). DNs most frequently mentioned involving volunteers (90%), hospices (90%), and spiritual caregivers (80%) sometimes or often. Furthermore, 75% of the GPs and 61% of the DNs said that they sometimes or often involved a pain specialist, 69% and 53% a case manager, 51% and 50% a psychologist or psychiatrist and 44% and 57% social welfare. All differences between GPs and DNs were statistically significant, except for the differences in involving hospices and psychologists or psychiatrists. An overview is shown in table 2.2.

**Table 2.2** Extent to which GPs and DNs involve services and facilities when providing palliative care (% sometimes or often)

	GP# N=108 %	DN# N=258 %
Palliative home care team*	99	67
Palliative care consultation services*	95	74
Hospice	94	90
Volunteers in palliative care*	82	90
Clinical pain specialist*	75	61
Case manager for palliative care/dementia*	69	54
Psychologist/psychiatrist	51	50
Spiritual caregiver*	50	80
Social welfare*	44	57

# Less than 5% missing for all rows

\* Statistically significant difference between GPs and DNs ( $p < 0.05$ )

### Experiences with services and facilities and reasons for not involving them

The majority of the GPs and DNs who used services and facilities in palliative care reported solely positive experiences with these services and facilities, with percentages ranging from 91% of GPs and 93% of DNs for hospices, palliative care consultation services, and palliative home care teams to 68% and 74% for pain

specialists. The percentage of participants reporting mixed experiences – i.e. both positive and negative – with services and facilities ranged from 6% and 9% for palliative consultation services to 32% and 25% respectively for clinical pain specialists. Hardly anyone (0%-3%) reported solely negative experiences with any of the services and the facilities. An overview is shown in table 2.3.

**Table 2.3** Experiences of GPs and DNs district nurses with services and facilities in palliative care (row %)

	General practitioners <sup>#</sup>				District nurses <sup>#</sup>			
	N	Solely positive %	Mixed %	Solely negative %	N	Solely positive %	Mixed %	Solely negative %
Palliative home care team	105	92	8	.	146	91	9	.
Palliative care consultation services	98	93	6	1	168	91	9	.
Hospice	101	92	8	.	217	93	7	.
Volunteers in palliative care	79	80	20	.	216	87	12	1
Clinical pain specialist	74	68	32	.	143	74	25	1
Case manager for palliative care	70	70	27	3	122	81	19	.
Psychologist/psychiatrist	51	82	16	2	115	71	27	2
Spiritual caregiver	53	83	17	.	193	87	12	1
Social welfare	43	74	26	.	126	75	25	.

<sup>#</sup> Less than 5% missing for all rows

GPs and DNs who reported not involving certain services and facilities were asked to indicate why they did not. For most services and facilities, GPs and DNs mentioned 'not needed' as the main reason not to involve those services and facilities. The exceptions for GPs concerned palliative care/dementia case managers ('unavailable'), spiritual caregivers ('not my job'), and volunteers in palliative care ('don't know them/where to find them'). For DNs the only exception concerned clinical pain specialists ('not my job'). Services and facilities being unavailable, not knowing them or how to find them, or not considering it their job were mentioned less often as reasons for not involving those services and facilities. Having bad experiences with services and facilities in the past was rarely given as a reason not to involve them. A detailed overview can be found in table 2.4.

**Table 2.4** GPs' and DNs' reasons for not involving services and facilities (absolute numbers and %\*)

Service/facility <sup>#</sup>		N	Not needed	Not my job	Don't know them/where to find them	Unavailable	Bad experiences	Other/no reason specified
Clinical pain specialist	GP	27	15	0	1	0	6	5
	DN	93	37 (40%)	44 (47%)	6 (6%)	2	0	4
Case manager for palliative care	GP	34	8	0	5	16	1	4
	DN	116	56 (48%)	12 (10%)	10 (9%)	18 (16%)	1	19 (16%)
Spiritual caregiver	GP	54	16 (30%)	23 (43%)	9 (17%)	4 (7%)	0	2
	DN	51	23 (45%)	7 (14%)	3 (6%)	3 (6%)	1	14 (27%)
Psychologist/psychiatrist	GP	52	39 (75%)	0	1	2	1	9 (17%)
	DN	123	57 (46%)	35 (28%)	4	2	1	24 (20%)
Social welfare	GP	61	40 (66%)	0	2	1	4 (7%)	14 (23%)
	DN	103	62 (60%)	15 (15%)	1	3	1	21 (20%)

\* Percentage shown if total N &gt; 50

<sup>#</sup> We excluded palliative home care teams, palliative care consultation services, hospices, and volunteers in palliative care as the vast majority of GPs and DNs said that they used these services and facilities sometimes or often

## Improving the involvement of services and facilities in palliative care

We asked the participants how palliative care with regard to services and facilities could be improved, and 144 participants (104 DNs and 40 GPs) mentioned one or more areas of improvement, which can be clustered in three different categories. Improvement in the availability of services and facilities was mentioned by 84 respondents. These included comments on the availability and capacity of hospices, and the availability and faster provision of tools (e.g. morphine pumps and adjustable beds) and medication. Improvements in referrals to services and facilities were mentioned by 29 respondents, commenting that spiritual caregivers, volunteers, and respite care should be called in more often. Other improvements, such as better information about and improved funding for the available services and facilities was also mentioned by 31 respondents. Quotes illustrating the suggestions can be found in Table 2.5. Sixty-three participants (24 GPs and 39 DNs) indicated that no improvements were necessary in the services and facilities in their area, or had no ideas for improvements.



Table 2.5 Quotes illustrating three categories of areas of improvement.

Availability of services and facilities
<i>"Intensive home care in particular in the final phase, which often comes unexpectedly, is not always available, because the [health insurance (ed.)] allowance is running out and some things can't always be predicted." (GP650)</i>
<i>"There is no hospice [in our area]. A respite care facility is coming, possibly with palliative beds. A palliative ward in a nursing home has recently been opened and modernized. I don't know the details." (GP619)</i>
Referrals to services and facilities
<i>"In institutions, spiritual caregivers are available. In the home setting people have to arrange this themselves, sometimes in emergency situations, as well as tussle with the health insurers. And where can they find someone that they get on with as well? Obviously this rarely happens, even though I see a great need. Professional caregivers can deal with this to some extent, but they are restricted in their possibilities. As people increasingly want to die at home, I feel that every healthcare supplier should offer a spiritual caregiver or counsellor." (DN 318)</i>
<i>"With long-term palliative care recipients, there is a need for options for structural night care, for instance twice a week, so the relatives can get a proper night's sleep." (DN277)</i>
Other improvements
<i>"It would be nice if there was a write-up of where people are best off ordering things, it would be nice if we had a brochure that we could hand out." (DN 257)</i>
<i>"Involving a palliative care nursing specialist in our area is not always possible. Sometimes because the insurance company doesn't have a contract with our organization, sometimes because another healthcare provider organization doesn't have a nursing specialist but can't or doesn't want to involve me. Ascetic drainage at home still isn't funded properly and there is no regional coverage, so it is not available to all patients." (DN 820)</i>

Nineteen DNs and eight GPs participated in three homogenous online focus groups, where we asked how improvements in the availability of services and facilities could be achieved. Analysis of the focus group data revealed two key ways to achieve this. First, a central point of contact was suggested that can provide healthcare providers as well as patients and relatives with information on the available services and facilities. This point of contact could be a person (e.g. a district nurse) or a regional centre, and should be connected to the regional palliative care network, ensuring familiarity with all local services and facilities. Healthcare providers caring for a patient with a life-threatening illness could then approach this point of contact to get in touch with the necessary services or facilities.

Second, it was suggested that services such as spiritual caregivers, volunteers in palliative care and social welfare should play a more active role in promoting themselves to improve the familiarity of GPs and DNs with these services and facilities. For example, services and facilities should be given the opportunity to introduce themselves and make their availability known in local multidisciplinary meetings or in locally organized training sessions.

## Discussion

Our results show that most GPs and DNs in our sample sometimes or often involve hospices, consultation services, palliative home care teams, and volunteers in palliative care. Fewer GPs and DNs involve psychologists or social welfare when providing palliative care. The majority of GPs and DNs reported mainly positive experiences with the services and facilities they used. 'Not needing' services or facilities in their perspective was often reported as a reason for not involving them.

According to GPs and DNs, there should be more referrals to services and facilities. The availability of services and facilities is also mentioned as a point of improvement. A central desk providing information on services and facilities in the area, and actively promoting services among GPs and DNs to increase their awareness and familiarity could reduce barriers to using these services and facilities in palliative care.



### Reflections on level of involvement of services and facilities in palliative care

We found that most services and facilities were involved sometimes or often by at least two thirds of GPs and DNs. These findings differ from studies on palliative care service use from the patient perspective. One study showed that 29% of patients in the Netherlands received specialist palliative care (i.e. involvement of hospices, consultation services or palliative home care teams) in the last three months of life<sup>19</sup>. Another study showed that in 27% of all cases of patients who had died a non-sudden death, one or more supportive caregivers (i.e. palliative care consultants, pain specialists, psychologists or spiritual caregivers) had been involved in the care in the last month of life<sup>25</sup>. It is therefore crucial to realize that even if all healthcare providers were to report 'sometimes or often' involving services or facilities, this would not mean that all patients receive this additional care. At the same time it is important to realize that not all available services or facilities have to be involved in every case<sup>54</sup>. According to the Dutch national palliative care policy, palliative care is supposed to be delivered by generalists, supported where necessary by healthcare providers with expertise in palliative care<sup>31</sup>. If the generalist can fulfil the needs of the patient on their own, or if a patient does not want additional healthcare providers to be involved, the involvement of additional services and facilities is unnecessary. Still, our finding that around half of the GPs never involves a psychologist, spiritual caregiver or social welfare is concerning.

## Reflections on reasons for not involving services and facilities

The main reason GPs give for not involving a clinical pain specialist is that it is 'not needed'. As somatic issues like pain are traditionally the focus of treatment, and patients' physical needs at the end of life are often met<sup>37</sup>, this reason may be justified. As mentioned above, if generalists can meet the needs of their patient, the involvement of specialists may not be necessary. Furthermore, GPs have been shown to discuss difficulties in managing pain in their patients with palliative care consultation services<sup>55</sup>.

The main reason GPs do not involve palliative care case managers is that they are unavailable. We know from research that while case managers are indeed not available in every part of the country, GPs and DNs are not always aware of their availability in regions where they *are* available<sup>56,57</sup>. DNs mainly reported not needing a case manager as the reason for not involving them. This may be related to DNs (either formally or informally) taking on the role of case manager themselves<sup>58</sup>. While 80% of the DNs reported sometimes or often involving spiritual caregivers, only half of the GPs reported doing so. The main reason for GPs not referring to spiritual caregivers was 'not my task'. Some GPs elaborated on this reason, commenting that they leave it up to the patient to seek spiritual care if they need it. However, lack of awareness and lack of physician referrals have been shown to be important barriers for patients in the use of palliative care services in general<sup>59</sup>. Furthermore, as spiritual support at the end of life is associated with better quality of life<sup>60-62</sup>, and GPs struggle to provide spiritual care to patients for various reasons<sup>63,64</sup>, a more proactive approach from GPs may be appropriate here.

Regarding the decision not to involve a psychologist or psychiatrist, both GPs and DNs mainly reported that these services were not needed. Psychological issues such as anxiety, depression, and delirium are not uncommon in patients with a life-threatening illness and their relatives, and previous research has shown that the psychosocial needs of patients and relatives are often unmet<sup>37,65-67</sup>. In some of these cases, the involvement of a psychologist or psychiatrist may prove valuable. GPs and DNs may be unaware of the potential value of involving psychologists in palliative care for patients and their relatives alike. The same might be the case for the potential value of involving social welfare<sup>68</sup>, another service where both GPs and DNs gave 'not needed' as the main reason for not involving this service.

## Improving services and facilities in palliative care

GPs and DNs mentioned two major points for improvement: the availability of tools and services such as hospice beds, and more referrals to certain services and facilities. In the online focus groups, GPs and DNs discussed how these improve-

ments can be achieved. The suggested solution has two elements. The first is the establishment of well-publicized central points of contact that can be approached by healthcare providers and patients alike to get information on the available services and facilities. This may indeed be a solution when unavailability or not knowing how to reach services and facilities is the main reason not to use them. This element alone, however, may not be enough. 'Not needing' services was a major reason for not involving them, and this reason may partly be related to a lack of awareness of the added value of these services. This emphasizes the need to educate healthcare providers on the availability and value of services and facilities. A way to achieve this was suggested in the online focus groups as the second element of the solution: enabling services and facilities to present themselves to groups of GPs and DNs in local multidisciplinary meetings. These proactive presentations may improve familiarity with those services and facilities, giving otherwise unaware GPs and DNs more insight into the added value of these services.



## Implications from an international perspective

The Netherlands is one of the few countries with generalist-plus-specialist palliative care<sup>18</sup>, while in many countries such as the US, the UK, Canada, Australia, palliative care is a medical specialty<sup>69</sup>. Still, similar to the Netherlands, in most countries the majority of palliative care is provided by generalist practitioners<sup>19,70-73</sup>. Earlier research showed that in Belgium, Italy and Spain specialist palliative care services such as palliative home care teams, volunteers, social workers and psychologists were involved in 39-47% of patients in the last three months of life<sup>19</sup>. In Australia around 30% of decedents had received palliative care services at home<sup>74</sup> and a recent study in Canada showed that 52% of decedents with cancer had received at least one home palliative care service<sup>75</sup>. It would be interesting to see if in these countries, including the Netherlands, increased awareness of healthcare providers on the availability and the added value of services and facilities in palliative care in other countries indeed improves patients' access to these services, as the respondents in the online focus group suggest. This is important for the sustainability of palliative care for all people who need it.<sup>18</sup>

## Strengths and limitations

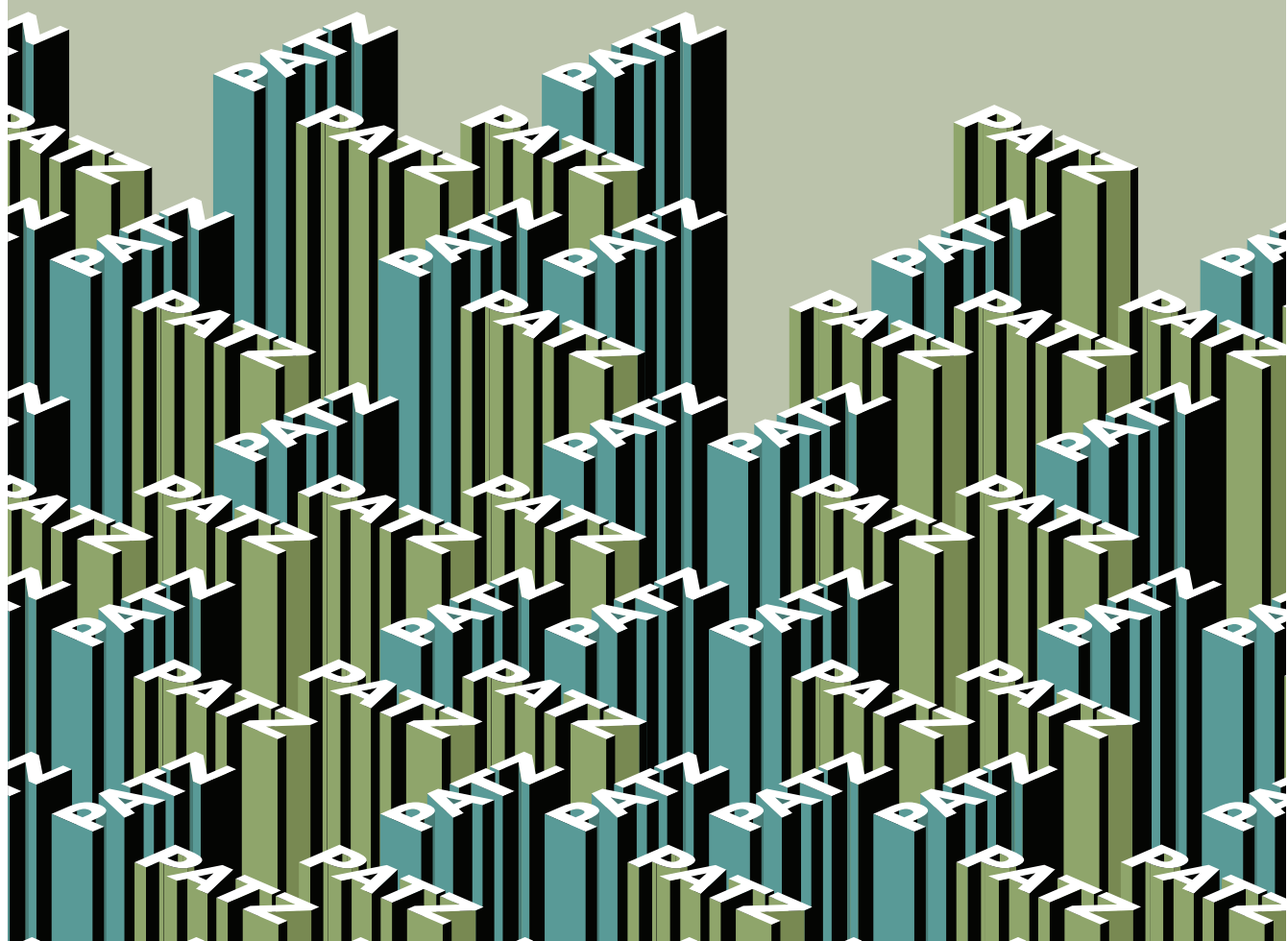
A strength of this study lies in the mixed methods design, allowing us to elaborate on findings from the quantitative data in a qualitative way. Also, the accessibility of the online questionnaire enabled GPs and DNs from all over the country to participate, potentially providing a nationwide view on palliative care services. Still, it is

possible that responders were GPs and DNs who are more interested and involved in palliative care. The finding that our sample on average worked more hours and contained a higher proportion of female GPs may be related to that <sup>76</sup>. This may have led to an overestimation of the involvement of services and facilities in palliative care. On the other hand, it would decrease the chance that respondents indicated a service was unavailable while such a service, unbeknownst to the respondent, was actually available. Yet, the reasons not to involve services or facilities are reported from the healthcare provider's perspective. Thus, when they reported to not involve or make use of a service or facility because it is 'unavailable' or 'not needed', it is impossible for us to know if this is actually the case and not caused by unawareness of availability or added value.

## Conclusion

Services and facilities in palliative care can help meet the multidimensional needs of patients and relatives. Our finding that psychological, social, and spiritual services are involved less often suggests that the classic care model, with the primary focus on somatic issues, is still well entrenched. While involvement of all available services and facilities is certainly not always needed or desired by patients and relatives, it may be beneficial to involve these services more often. More familiarity with services that can provide additional healthcare in these areas, both with regard to availability and added value, could improve the quality of life for patients and relatives at the end of life.



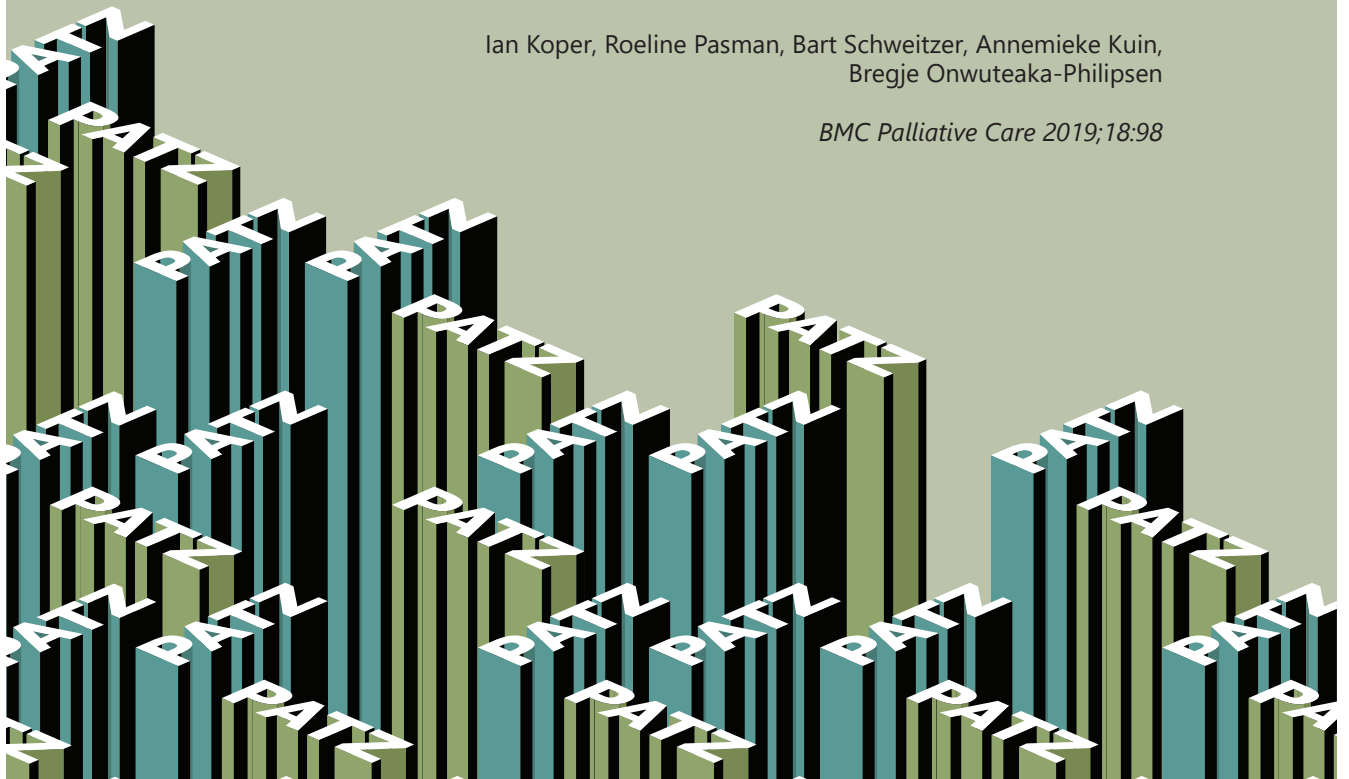


# Chapter 3

## **Spiritual care at the end of life in the primary care setting: experiences from spiritual caregivers - a mixed methods study**

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## Abstract

**Background:** Spiritual care is an important aspect of palliative care. In the Netherlands, general practitioners and district nurses play a leading role in palliative care in the primary care setting. When they are unable to provide adequate spiritual care to their patient, they can refer to spiritual caregivers. This study aimed to provide an overview of the practice of spiritual caregivers in the primary care setting, and to investigate, from their own perspective, the reasons why spiritual caregivers are infrequently involved in palliative care and what is needed to improve this.

**Method:** Sequential mixed methods consisting of an online questionnaire with structured and open questions completed by 31 spiritual caregivers, followed by an online focus group with 9 spiritual caregivers, analysed through open coding.

**Results:** Spiritual caregivers provide care for existential, relational and religious issues, and the emotions related to these issues. Aspects of spiritual care in practice include helping patients find meaning, acceptance or reconciliation, paying attention to the spiritual issues of relatives of the patient, and helping them all to say farewell. Besides spiritual issues, spiritual caregivers also discuss topics related to medical care with patients and relatives, such as treatment wishes and options. Spiritual caregivers also mentioned barriers and facilitators for the provision of spiritual care, such as communication with other healthcare providers, having a relationship of trust and structural funding. In the online focus group, local multidisciplinary meetings were suggested as ideal opportunities to familiarize other healthcare providers with spirituality and promote spiritual caregivers' services. Also, structural funding for spiritual caregivers in the primary care setting should be organized.

**Conclusion:** Spiritual caregivers provide broad spiritual care at the end of life, and discuss many different topics beside spiritual issues with patients in the palliative phase, supporting them when making medical end-of-life decisions. Spiritual care in the primary care setting may be improved by better cooperation between spiritual caregiver and other healthcare providers, through improved education in spiritual care and better promotion of spiritual caregivers' services.

## Background

Spiritual care, an intrinsic aspect of palliative care,<sup>2</sup> is a broad concept for which many definitions exist.<sup>62,77-79</sup> In 2011, the EAPC taskforce on spirituality adjusted a preceding North American consensus definition<sup>80</sup> and defined it as 'the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.'<sup>13</sup> The Netherlands Comprehensive Cancer Organisation adopted this definition in their recently revised guideline on spiritual care in palliative care.<sup>81</sup> While religious spirituality, in which religion provides identity, morals and faith in a higher power, may be distinguished from secular spirituality, which emphasises on unity, integrity, holism and individuality<sup>82</sup>, this definition comprises both.

Receiving spiritual care is associated with better quality of life for patients with a life-threatening illness.<sup>60-62,64</sup> As in other countries, a pastor or chaplain used to be the designated spiritual care provider in primary care in the Netherlands, but due to progressing secularisation in the population,<sup>83,84</sup> only a minority of patients is member of a religious society. Currently, in the Dutch coordinated care model of providing palliative care,<sup>18</sup> it initially falls to general practitioners and district nurses to assess and address spiritual needs in their patients.

In recent years, a number of international studies have identified a variety of unmet spiritual needs in patients with a life-threatening illness.<sup>85-89</sup> Even though patients are willing to talk about end-of-life issues and spirituality with their healthcare providers,<sup>90-92</sup> physicians and nurses struggle to provide it.<sup>93-96</sup> Institutional factors such as high workload and low staffing, personal factors such as lacking attention for spirituality or perceiving a patient's spirituality as a personal matter, and cultural factors such as religious discordance impede provision of spiritual care.<sup>64,96-99</sup> Lack of training and care providers not perceiving it as their task have also been shown to be negatively associated with spiritual care provision.<sup>63</sup> When a lack of knowledge, skills or time, or the mere complexity of spiritual issues hampers healthcare professionals in providing adequate spiritual care, they have the option of referring patients to professional spiritual caregivers. In the Dutch primary care setting however, such referral is rare. A study on the involvement of supportive care professionals in the Netherlands found that, in this setting, spiritual caregivers were involved in the care of less than 13% of the patients in the last month of life.<sup>25</sup>

Although research explaining the low number of consistent referrals of patients with spiritual issues to spiritual caregivers in the Netherlands is scarce, a recent study showed that physicians and nurses refrain from referring to spiritual caregivers because they do not perceive it as their task or see no added value in



their involvement.<sup>100</sup> Research from other countries showed that the unfamiliarity of healthcare providers with spiritual care and spirituality can be an important barrier to referral.<sup>95,101</sup> For many healthcare providers what the spiritual dimension entails is unclear, as is the role of a spiritual caregiver and how to find one. Improving the understanding of the role of the spiritual caregiver in the primary care setting can lead to more referrals, and ultimately, to better palliative care.<sup>60,61,64</sup> So, rather than trying to formulate a clear and concise definition of spiritual care, we believe that describing in concrete terms what care provided by spiritual caregivers looks like, may help healthcare providers understand the role of such a caregiver. The primary aim of this study was therefore to investigate and describe the practice of spiritual caregivers in the primary care setting. The secondary aim was to investigate, from their own perspective, the reasons why spiritual caregivers are infrequently involved in palliative care and what they think is needed to improve this.

## Methods

### Design

This study is part of a larger project aimed at improving palliative care in the primary care setting with a sequential mixed methods design. A two-step needs assessment among healthcare providers in the primary care setting was performed. This study focusses on the responding spiritual caregivers within the project.

The first part of the needs assessment was an online questionnaire that was available online from the 5<sup>th</sup> of April 2016 until the 5<sup>th</sup> of August 2016, containing open and structured questions on the participants' most recent case of palliative care. The second part consisted of an online focus group in which the insights from the online questionnaire were explored more in-depth. The online focus group was held on a website with an interface similar to an online chat room. Participants logged into the website, using a code name and password provided by a moderator (IK), where they responded to the questions posed by the moderator and other respondents' reactions. The website was accessible 24 hours a day, from the moment the first question was presented until a week after the last question was presented. When participants clicked on a question, they could read it with its context, read any earlier comments from other respondents and write a response. Any personal information, or information that identified specific individuals or organisations was depersonalised by the moderator.

## Participants

Participants in the online questionnaire were recruited through two professional associations for spiritual caregivers: the Spiritual Caregivers Association (VGvZ), and Humanistic Covenant (HV). Inclusion criteria were: 1) working as a spiritual caregiver in the Netherlands, 2) working in the primary care setting, and 3) having experience with providing palliative care. The professional associations sent the call to participate to 112 and 110 of their members respectively, whom they knew were involved in palliative care in the primary care setting. But as it is likely that these numbers overlap, the actual number of eligible spiritual caregivers that received the call is uncertain. There is also no data available on the number of spiritual caregivers practicing in primary care settings in the Netherlands. In total, 31 spiritual caregivers described the most recent case in which they had provided palliative care. In the final question of the online questionnaire, participants were asked to leave their contact details if they were interested in participating in a focus group aimed to further investigate points of improvement in palliative care. Participants who did, were invited to participate through an e-mail containing information on the procedure, subjects of discussion and the ground rules. In total, 26 were invited, and 16 responded of whom 7 declined. Finally, 9 spiritual caregivers participated in the online focus group.

## Data collection

After some structured questions on the characteristics of their most recent case of palliative care, participants in the questionnaire were prompted to describe their case through three open questions: 1) *Can you describe the situation and the palliative care you provided*, 2) *Can you describe what went well in this case*, and 3) *Were there things that could have gone better*. They were also asked to report on eight end-of-life topics whether they had discussed these and if so, with whom. These topics were 'life expectancy', 'complications', 'treatment options', 'hospital admissions', 'palliative sedation', 'preferred place of death', 'spiritual issues' and 'euthanasia'.

Following the questionnaire, eight questions were posed over the course of two weeks in the online focus group. In this paper we focus on two: 1) *What causes spiritual caregivers to be infrequently or untimely involved in palliative care*, and 2) *In what way can spiritual caregivers contribute to more frequent and earlier involvement*.

## Data analysis

The data from the online questionnaire was analysed through open coding<sup>53</sup>: codes were derived from the data rather than determined beforehand. First, the data was analysed and coded by IK. Second, the codes were discussed with HP, and finally, with all other authors. During this process, codes underwent content and definition changes as the analysis progressed and relations between codes became apparent. From the data, codes in three categories were identified: (1) aspects of care (i.e. the practice of spiritual caregivers), (2) dimensions that are covered (i.e. the dimensions in which care is provided), and (3) barriers and facilitators for the provision of spiritual care.

## Results

### Characteristics of spiritual caregivers

Table 3.1 provides an overview of the characteristics of the participants, including the subgroup of the online focus group. The majority was female and was working part-time. The participants had a broad range of age and years in practice. While every participant worked in at least one primary care setting (home, care home or hospice), half (16/31) worked in more than one, including hospitals and other settings such as psychiatric wards, institutions for the mentally impaired and rehabilitation centres.

More than half (19/31) of the participants had a Christian denomination, while nine had a humanistic and one a Buddhist denomination. Eight had no institutional affiliation. Almost half of the participants indicated they had received education in palliative care. The average number of patients at the end of life they cared for in the last year was 27, with a considerable range (0-120).

## Online questionnaire: results from the case descriptions

### Patient characteristics

Thirty-one spiritual caregivers described their most recent case in which they had provided spiritual care. Table 3.2 provides an overview of the patients' and care characteristics of the described cases. The mean age of the described patients was 72 years, and half were female. Most patients were diagnosed with cancer (n=24), eight suffered from organ failure and seven from frailty or dementia. Fifteen patients remained at home while a minority remained in a hospice (n=5) or a residential home (n=3). As some participating spiritual caregivers also worked in other settings (table 3.1), and they were asked to describe their most recent case, some of the cases concerned patients in secondary care (n=4), or another setting (n=2).

From the case descriptions, we derived aspects and dimensions of spiritual care as well as barriers and facilitators for the provision of spiritual care in the primary care setting. Table 3.3 provides three exemplifying case descriptions in full. An overview of aspects and dimensions of spiritual care with exemplifying quotes can be found in table 3.4.

**Table 3.1** *Characteristics of spiritual caregivers participating in the online questionnaire and online focus group*

	Online questionnaire (N=31)	Online focus group (N=9)
<b>Age (years), mean (range)</b>	54 (27-74)	50 (35-63)
<b>Gender</b>	22 F 9 M	8 F 1 M
<b>Working part-time (mean hours)</b>	25 (22)	7 (23)
<b>Years in practice, mean (range)</b>	13 (1-30)	12 (1-30)
<b>Setting<sup>1</sup></b>		
Home	13	4
Hospice	10	3
Residential home	8	2
Secondary care setting	17	6
Elsewhere	8	0
<b>Denomination<sup>2</sup></b>		
Christian	19	7
Humanistic	9	3
No institutional affiliation	8	3
Other	1	0
<b>Education in palliative care</b>	15	5
<b>Number of patients cared for in last year, mean (range)</b>	27 (0-120)	34 (2-100)

<sup>1</sup> Participants could work in more than one setting; other settings included: psychiatric ward, rehabilitation ward, care hotel, monastery, institute for the mentally-impaired.

<sup>2</sup> Participants could have more than one denomination; Christian denominations included: catholic, protestant, oecumenical; other denomination: Buddhist.

Table 3.2 Patient characteristics, N = 31

Age, mean (range)	72 (29-91)
Gender	15 F 15 M
Diagnosis <sup>1</sup>	
Cancer	24
Organ failure	8
Frailty/dementia	7
Unknown	1
Setting <sup>2</sup>	
Home	15
Hospice	5
Residential home	3
Secondary care setting	4
Elsewhere <sup>3</sup>	2

<sup>1</sup> Patients could have more than 1 diagnosis

<sup>2</sup> Missing data for 2 patients

<sup>3</sup> Care hotel or institute for the mentally impaired

Table 3.3 Exemplifying case descriptions by spiritual caregivers. Cases are anonymized

#### R15

**Case:** 'Mr. A. needed reflection in the form of conversations about his life. Since his incurable illness many questions arose about the purpose and meaning of life and how he could be significant in this stage of life.'

**What went well:** 'A good connection led to strong relationship of trust. Because of this, Mr. A. could openly talk about his life, his questions and his doubts.'

**What could have gone better:** 'There was no communication between me and the general practitioner and I missed that in being able to adjust to each other.'

#### R11

**Case:** 'Mr. B. was bedridden, and had a lot of visitors. I listened to his stories a lot, which went further than daily worries and occurrences.'

**What went well:** 'He enjoyed talking about more serious topics now and then. He slowly came to some sort of acceptance of what was happening to him.'

**What could have gone better:** 'Sometimes he wanted to speak freely, and sometimes just a short visit. I could have realized that last part a bit better so I wouldn't have stayed too long and have the nurse telling me I should visit less often.'

#### R09

**Case:** 'Mr. C. had attacks of severe pain, itch and dyspnoea. He didn't want this anymore and talked with the general practitioner about euthanasia, but couldn't make a decision, because of an inner conflict with his religious values. In conversation with Mr. C., his partner and daughter, I clarified the situation, values and (religious) coping style of Mr. C., after which he could come to an informed decision.'

**What went well:** 'The opinions and values of Mr. C. were openly discussed, without any pressure into a certain direction. As well as the concern for his wife and daughter, and the burden Mr. C. thought to be, as a possible factor in the decision-making process. Also, good communication with the general practitioner.'

**What could have gone better:** 'Prior information on an alternative, palliative sedation, could have been more clear.'

**Table 3.4** Aspects and dimensions of care provided by spiritual caregivers

Category 1: Aspects of spiritual care and exemplifying quotes
<p><b>Helping to find meaning, acceptance or reconciliation</b></p> <ul style="list-style-type: none"> <li>• She accepted the fact she was going to need increasingly more help and that she eventually was going to die. (R10)</li> <li>• He felt heard and had the specific question for me to help him learn to pray again. Additionally, I helped him realize he wanted to ask forgiveness from his wife and son for his alcohol abuse in the past. (R26)</li> </ul>
<p><b>Attention for patient's relative(s)</b></p> <ul style="list-style-type: none"> <li>• In separate conversations with the patient and his spouse, it turned out that the patient's demise was a difficult subject. I facilitated a conversation between patient and wife about the coming death. (R14)</li> <li>• The children disagreed about the treatment plan. We talked about their thoughts, expectations and fears and the underlying pain and grief from the death of their other parent 16 years ago. Taking time for their suffering. (R25)</li> </ul>
<p><b>Performing a (farewell-)rite</b></p> <ul style="list-style-type: none"> <li>• Good guidance, a farewell-ritual with children. Let go of life and died three days later. (R04)</li> <li>• Only one granddaughter was present at the time of the farewell rite. Based on the son's description of his mother, I read a poem about saying farewell, a prayer of Mary and I asked the granddaughter to tell her grandmother what she was grateful for. Finally, we prayed. Madam seemed unconscious for the greater part of the rite, but at the end of the prayer she said a heartfelt 'amen'. (R17)</li> </ul>
<p><b>Helping to say farewell</b></p> <ul style="list-style-type: none"> <li>• She opened up, was able to enjoy things and she said goodbye to her family and friends very consciously. In the end there was surrender and faith that everything was alright. (R08)</li> <li>• I began visiting him weekly where we spoke about the end of life, saying farewell, and ways to inform loved ones et cetera. (R20)</li> </ul>
<p><b>Acknowledgement (n=5)</b></p> <ul style="list-style-type: none"> <li>• He felt recognized and heard because of the respectful and reticent position I took regarding my own way of thinking. (R27)</li> <li>• Being around him, connecting to his world, talking about the place after the end of this life. Offering encouragement and trust. Comradery, ganging up together. (R01)</li> </ul>
<p><b>(Help) organizing the funeral</b></p> <ul style="list-style-type: none"> <li>• I discussed preparations for the funeral with him and organized it along with the children. (R21)</li> <li>• I met the family and talked to them. It was nice to be able to do the funeral in cooperation with the companies, wife and family. (R05)</li> </ul>
<p><b>Spiritual counselling (not specified)</b></p> <ul style="list-style-type: none"> <li>• She and her son wanted counselling on a spiritual level and I was able to provide this. (R07)</li> <li>• I guided him spiritually and I had conversations with him about his life and its conclusion, and his wishes and expectations. (R16)</li> </ul>



Table 3.4 Continued

Category 2: Dimensions of care and exemplifying quotes	
48	<b>Existential</b> <ul style="list-style-type: none"><li>• I came to talk with them about the illness of the husband, what it meant for him, what he still wanted in life. And also for the wife: how to spend time together, how to say goodbye etcetera. (R12)</li><li>• I guided the patient in looking back on her life, existential questions and in the terminal phase by being there and conversing and supporting the caregiver and her family. (R24)</li></ul>
	<b>Relational</b> <ul style="list-style-type: none"><li>• The patient was very concerned with the future of her partner, at first this eclipsed her own process of dying. I had weekly conversations with her, and later also with her daughter and granddaughter. (R19)</li><li>• She wanted to be eligible for euthanasia in order to not be a burden for her children, and because of her fear of pain and death. When her wish was declined, I assisted her in accepting that. There were also some feelings of anger and resentment towards her son-in-law, the husband of her deceased daughter. I assisted her in managing this. (R31)</li></ul>
	<b>Religious</b> <ul style="list-style-type: none"><li>• Madam used to be member of a church denomination that ended in the previous century and she found out her belief system didn't work anymore. This increased her anxiety. As spiritual caregiver I provided her a listening ear and understanding. I could also assist her in her way of seeking religious answers. These conversations gave her consolation. (R31)</li><li>• He became a Buddhist in the final five years of his life. I guided him in his existential questions which he approached either from the more traditional Christian framework from his 'former' life or from his recent search for Buddhist answers. (R27)</li></ul>

Table 3.5 Reasons spiritual caregivers are infrequently involved in primary care and suggestions for improvement

Reasons spiritual caregivers are infrequently involved
1. Other healthcare providers have insufficient knowledge of spiritual care
2. Other healthcare providers do not know spiritual caregivers or how to find one
3. Spiritual care is not funded in primary care
Suggestions to improve involvement of spiritual caregivers
4. Training of healthcare providers in primary care in recognizing spiritual distress
5. Active promotion of spiritual caregiver services in primary care to increase awareness of their availability
6. Organise structural funding / insurance coverage in primary care

Aspects of spiritual care

In most case descriptions, we found more than one aspect of spiritual care in practice. In total, we distinguished six separate aspects of spiritual care from the case descriptions. These aspects were: (1) helping the patient to find meaning, acceptance or reconciliation, (2) having attention for relatives of the patient, and (3) performing a (farewell) rite to be part of the spiritual care they provided. (4)

Helping to say farewell, (5) acknowledgement, and (6) organizing the funeral were also described as part of provided care. Also, some spiritual caregivers stated they had provided spiritual care, but did not go into detail.

### Dimensions of spiritual care

From the data we distinguished three dimensions covered by spiritual care. Similar to the aspects, we found that in most cases the provided care covered more than one, due to the multidimensional issues of the patient. The descriptions that spiritual caregivers gave of their care were distinguished by us in tending to their patient's (1) existential issues, concerning for example hope, suffering or the meaning of life and illness to oneself, (2) relational issues, concerning (still) being of value to or the significance of relatives and (3) religious issues in their patient, concerning one's beliefs and practices or (a loss of) faith in God or a higher power. In addition, spiritual caregivers described tending to the emotions patients experience related to the existential, relational or religious issues they face.

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### End-of-life topics discussed

We also asked the participants to indicate whether they discussed eight specific end-of-life topics with the patients and/or their relatives. Figure 1 provides an overview of these topics. While spiritual issues and life expectancy are discussed with almost all patients and the majority of relatives, all other topics are also addressed regularly. Spiritual caregivers discussed topics related to medical care and treatment, such as treatment options, complications and hospital admissions with their patients and to a lesser extent with their relatives.

### Barriers and facilitators for the provision of good spiritual care

Besides the aspects and dimensions of care, we also derived other factors relevant to spiritual care provision from the data. These issues, sometimes mentioned as something that went well, sometimes as something that could have gone better, facilitated or hampered spiritual caregivers in the provision of care, but were not described as part of the provided care.

Facilitators that were mentioned included communication with other health-care providers, a relationship of trust with the patient and communication with the patient, while the absence of structural funding, the lack of knowledge of spiritual care in other healthcare providers, being involved too late were referred to as barriers. Another factor the participants indicated to play a role in the provision of spiritual care was dosage of care (adjusting the amount of time spent with the patient to his or her wishes).

## Online focus group: reasons spiritual caregivers are not involved and how to improve involvement.

In the online focus group, we asked the participants why spiritual caregivers in general are infrequently involved in palliative care in the primary care setting, and what they can do to be involved more often, and in time. Table 3.5 provides an overview of the reported reasons and suggestions for improvement.

Participants in the online focus group indicated that, according to them, other healthcare providers have insufficient knowledge of and attention for spiritual care and do not know spiritual caregivers in person or how to find one. They suggested a twofold solution: healthcare providers should be better trained in recognizing spiritual distress and when to refer, while spiritual caregivers should promote their services better and making their availability more widely known. Participating in multidisciplinary meetings was suggested as a way to do so. The lack of funding for spiritual caregivers in primary care was also raised as an issue, with an apparent solution: organising insurance coverage.

## Discussion

### Reflections on the aspects and dimensions of spiritual care

This is, to our knowledge, the first empirical study describing the practice of spiritual caregivers for patients at the end of life in the primary care setting from their perspective. Spiritual caregivers provide care in several dimensions, including care for existential, relational and religious issues. We identified a wide variety aspects of this care in practice, including helping patients find meaning, acceptance or reconciliation, paying attention to the spiritual issues of relatives of the patient, and helping them all to say farewell. Other aspects we identified were performing rites, helping with the funeral or just simply 'being there'.

In a recent study on the practice of spiritual caregivers working in palliative care in hospitals in the US, similar aspects of spiritual care were found.<sup>102</sup> Spiritual caregivers in that study provided spiritual care in many ways, including providing ritual support, caring for relatives, facilitating communication between patient/families and care teams and addressing familial conflicts. Still there was one notable difference in that the US chaplains emphasized religious distress more than the participants in our study. This may be explained by the fact that religion plays a larger role in the US than it does in the Netherlands.<sup>84,103</sup>

Regarding the dimensions of spiritual care, earlier research by The EAPC Task Force on spiritual care stated that spirituality comprises three dimensions: (i) existential questions, (ii) religious considerations, and (iii) value-based considerations

(i.e. (inter)relational issues).<sup>13</sup> Although the European Organisation for Research and Treatment of Cancer (EORTC) Quality of life group phrased the latter differently, it mentioned the same three dimensions of spiritual well-being.<sup>104</sup> In our data, we found that spiritual caregivers also deal with their patients' emotional issues. But rather than proposing emotional issues as a fourth dimension, we feel that these emotions like anger, anxiety, and grief are intertwined with the three dimensions and cannot be seen as separate.

## Reflections on topics of discussion.

The participating spiritual caregivers indicated for eight topics whether they discussed these, showing the wide range of topics that spiritual caregivers talk about with patients and their relatives. Similar to the aspects of spiritual care in practice, the topics discussed are diverse. Naturally, spiritual issues are discussed, but other topics like life expectancy, treatment options and preferred place of death are also discussed regularly. As other healthcare providers are also likely to talk about these topics with patients at the end of their lives, it would be interesting to study the added value of discussing these from a different vantage point.

## Reflections on barriers and facilitators

Spiritual caregivers also mentioned barriers and facilitators for the provision of spiritual care, such as communication with other healthcare providers, having a relationship of trust and communication with the patient. Some of these factors are mentioned as conditions for the provision of spiritual care in the Dutch guideline on spiritual care in palliative care.<sup>81</sup> The guideline recommends healthcare providers to take time for the spiritual issues of their patient, be open, build a relationship of trust and compassion and respect their own limitations. Similarly, in the previously mentioned study on the practice of chaplains in the US, building relationships was found to be the primary activity.<sup>102</sup>

Although the guideline on spiritual care provision recommends that healthcare providers refer to specialist spiritual caregivers in case of suspected existential or spiritual crises,<sup>81</sup> earlier research in the Netherlands which showed that general practitioners and spiritual caregivers rarely cooperate in palliative care.<sup>24</sup> Communication between healthcare providers as mentioned by the spiritual caregivers in our study, unfortunately remains unaddressed in the guideline, even though it could be critical in the shift from multidisciplinary to interdisciplinary care.

## Reflections on suggestions to improve referral.

The spiritual caregivers in the online focus group mentioned that more familiarity of other healthcare providers with spirituality and spiritual caregivers is likely to lead to more referrals. Local multidisciplinary meetings were suggested as ideal opportunities to familiarize other healthcare providers with spirituality and promote spiritual caregivers' services. Interestingly, in the guideline on spiritual care, healthcare providers are encouraged to invite a spiritual caregiver to permanently join their multidisciplinary meetings to ensure attention for the spiritual dimension of palliative care.<sup>81</sup> The recent establishment of regular funding the structural engagement of spiritual caregivers in primary care, both directly with patients and indirectly through multidisciplinary meetings,<sup>105</sup> will arguably make this more feasible. Future research should examine whether this development indeed leads to an improvement in spiritual care provision to patients.

The participating spiritual caregivers also mentioned that training other healthcare providers in recognizing spiritual care needs can lead to adequate referral. This is in line with results from a recent study, which showed a positive effect of spiritual care training on the attitudes and competencies of Dutch hospital staff, including an increase of referrals to spiritual care specialists.<sup>106</sup> Still, this effect may be smaller in the primary care setting, where healthcare providers do not work in the same institution and thus may have more difficulty finding each other.

## Strengths and limitations

A strength of this study is that we asked the field to describe their practice and we used their descriptions to derive a variety of important aspects of and conditions for spiritual care. A limitation of this study is that although we feel that the study provides a relevant overview of spiritual care in the primary care setting, it is uncertain whether we reached data saturation. Firstly, as we derived the case descriptions from a questionnaire, we could not ask probing questions regarding a specific case. Secondly, we were only able to include spiritual caregivers with a North-western European understanding of spirituality. As the Netherlands is a multicultural society, harbouring people with various understanding of spirituality, this description of spiritual care in the Netherlands may be incomplete. For instance, as the Islamic view on life and death differs greatly from the Western biomedical view,<sup>107</sup> spiritual care for Islamic patients may have a different approach, with different aspects playing a role and different topics being discussed at the end of life.<sup>108,109</sup> We recommend extra attention to minority groups in future research on spiritual care in the Netherlands.

## Practical implications

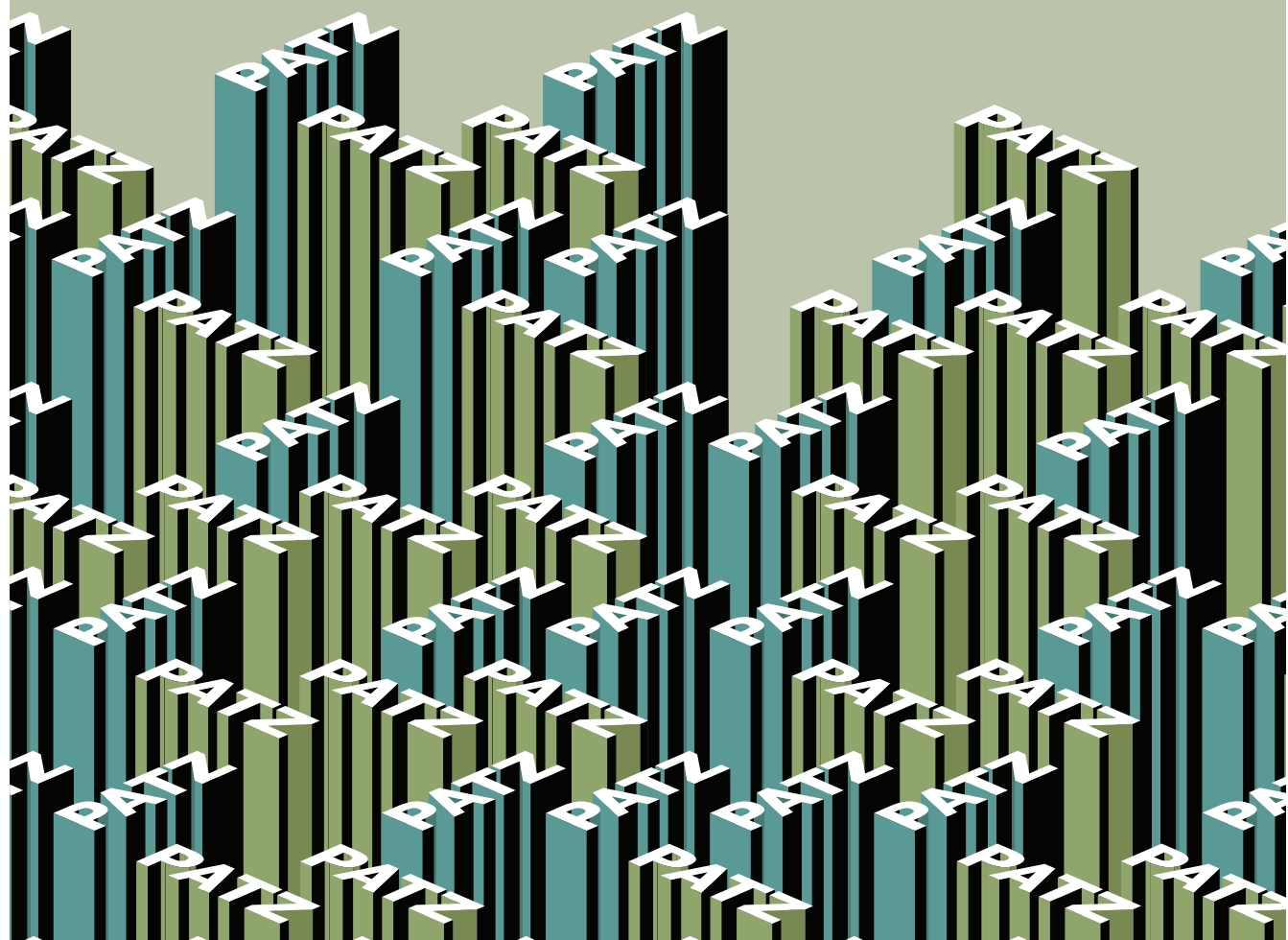
Although patients have unmet spiritual needs at the end of life, spiritual caregivers are infrequently involved in the primary care setting, due to unfamiliarity of healthcare providers with spirituality and the role of spiritual caregivers in palliative care. The overview of the practice of spiritual caregivers in this paper may provide healthcare providers such as general practitioners and district nurses with insight in the practice of spiritual caregivers. This may lead to better understanding of the added value of a spiritual caregiver in a particular patient, possibly leading to more appropriate palliative care for patients with spiritual care needs. In addition, this paper identifies opportunities to increase (timely) referrals in patients with spiritual distress. According to the field, better training of other healthcare providers in recognizing spiritual needs and a more proactive approach in the promotion of their services is needed, and spiritual caregivers joining local multidisciplinary meetings may be a good way to achieve this. The information derived from this study is used in a current study on the feasibility of involving spiritual caregivers in PaTz-groups<sup>29</sup>, local multidisciplinary groups in the Netherlands aimed at improving palliative care in the primary care setting.

Finally, while the role of spiritual caregivers in this setting became more important as secularisation progressed, their funding has, until lately, been overlooked. Time will tell whether recent funding developments<sup>105</sup> will improve the involvement of spiritual caregivers, and the provision of spiritual care for patients in the primary care setting.

## Conclusion

Spiritual caregivers provide broad spiritual care at the end of life and may have added value in palliative care. In order to provide adequate spiritual care in palliative care, better cooperation between spiritual caregivers and other healthcare providers in the primary care setting is needed. This requires further promotion of spiritual caregivers' services and more education in spiritual care for other healthcare providers. Recent funding developments to improve the engagement of spiritual caregivers in the primary care setting may be supportive in this respect.



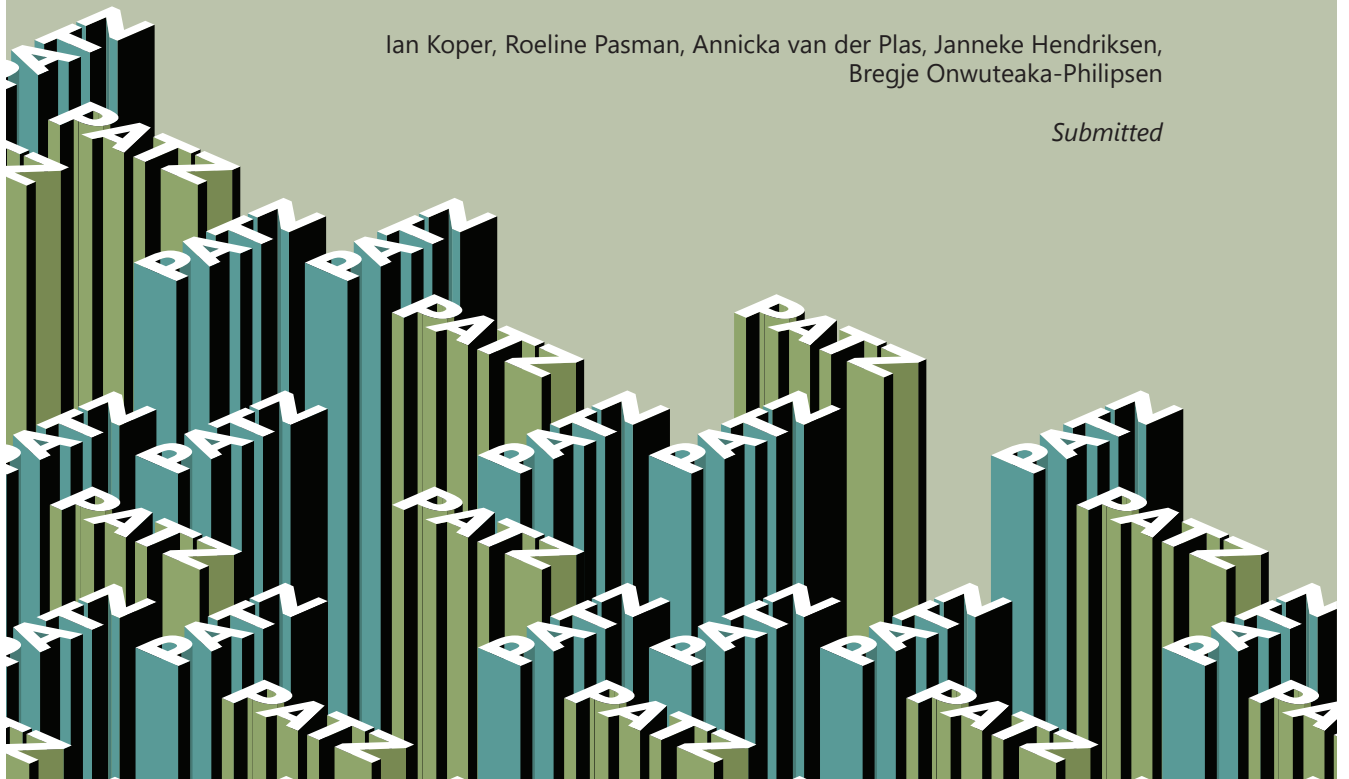


# Chapter 4

**The association of treatment  
aims at the end of life with  
advance care planning and  
palliative care outcomes:  
a mortality follow-back study in  
general practice**

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*Submitted*





## Abstract

**Background:** Timely palliative care has been shown to improve care outcomes, advance care planning and communication in care settings where palliative care is a medical specialty. Timely aiming for palliation may facilitate advance care planning, communication on end-of-life topics and improve care outcomes in general practice as well. This study aims to examine the treatment aims of patients in general practice in the final phase of life and the association between these treatment aims and palliative care outcomes.

**Methods:** A mortality follow-back study was conducted in a dynamic cohort in Dutch primary care practices. All adults who died between 2013 and 2018 in the primary care setting, where their general practitioner was responsible for the provision of palliative care, were included.

**Results:** We included 1464 patients for analysis. Most patients (77%) had a palliative treatment aim throughout the final three months. Just over half (51%) did not aim for cure or life prolongation throughout the final three months, only for palliation. Having a palliative treatment aim in this period was associated with improved advance care planning and communication on end-of-life topics. Having a palliative treatment aim only, compared to having coexistent treatment aims, was associated with improved care outcomes, such as decreased hospital admissions, increased acceptance of death and dying in the preferred place.

**Conclusion:** The results indicate the importance of a timely transition to palliative care in the primary care setting.

## Introduction

Palliative care aims to improve quality of life in patients suffering from a life-threatening illness and their families, and does not intend to hasten or postpone death.<sup>2</sup> Early identification of patients who could benefit from palliative care is considered essential<sup>2</sup>, as it provides opportunities to assess patients' needs and wishes and plan care accordingly. Several studies showed that, in the hospital setting, timely palliative care interventions improve quality of life in patients with a life-threatening illness and reduces unnecessary aggressive treatment, and depression.<sup>110-114</sup> Research on home-based specialized palliative care has shown similar results in the primary care setting.<sup>115-117</sup>

In the Netherlands, a generalist palliative care model<sup>18</sup> is in place, and palliative care is not recognized as a medical specialty.<sup>69</sup> National policy states that palliative care should principally be provided by primary care providers close to the patient.<sup>31</sup> For patients remaining at home, general practitioners (GPs) are primarily responsible for the coordination and provision of palliative care, and they can consult with specialist palliative care services when needed.<sup>25</sup> In the model proposed by Lynn and Adamson<sup>3</sup>, palliative care is considered a continuum in which curative and life-prolonging treatment is gradually replaced by palliative treatment rather than abruptly switching to palliative care the moment curative options are exhausted. Consequently, from the moment of diagnosis, curative, life-prolonging and palliative treatment aims may coexist. However, in a qualitative study on identifying palliative care needs, Dutch GPs stated that they tend to avoid talking about palliative care with their patients as long as cure is still an option<sup>118</sup>, and the information from a medical specialist that curative treatments have been exhausted was mentioned as the main stimulus for GPs to start palliative care.<sup>118</sup> Timely aiming for palliation may facilitate advance care planning and improve care outcomes in this specific setting as well, but research in this area is limited.<sup>119,120</sup> Research has shown that the majority of Dutch patients in the primary care setting have a palliative treatment aim three months before their death, both in coexistence with a curative or life-prolonging treatment aim<sup>121</sup>, but the proportion of patients with only a palliative treatment aim remains unclear. Moreover, it is unclear whether having only a palliative treatment aim rather than having a coexistent palliative treatment aim is associated with different palliative care outcomes.

Thus, in this study, we aimed to investigate the following questions: what are treatment aims for Dutch patients in the primary care setting in the last three months of life? Is a palliative treatment aim throughout the last three months associated with improved advance care planning, communication on end-of-life topics and palliative care outcomes for these patients? And is there a difference in these outcomes between patients with only a palliative treatment aim throughout the last three months and patients with a palliative treatment aim coexistent to a curative or life-prolonging treatment aim?

## Methods

### Design and study population

This study had a retrospective observational design, and was based on data from a nationally representative subgroup of 53 GP-practices, the Dutch Sentinel Network Study.<sup>122</sup> For each patient that passed away while registered to their practice, GPs were asked to fill out a standardized digital form on patient and care outcomes relevant in end-of-life care. For this paper we used data from patients who died between 1<sup>st</sup> January 2013 and 31<sup>st</sup> December 2018, and we applied the following exclusion criteria:

- The patient's death was sudden and unexpected, according to the GP.
- The patient was younger than 18 at the time of death.
- The patient did not reside in the primary care setting in the last year of life, where the GP is responsible for end of life care: home, residential care home, and hospice.
- The information on the patient's treatment aims throughout the final three months of life was missing.

A flow-chart of patient inclusion is shown in figure 4.1.

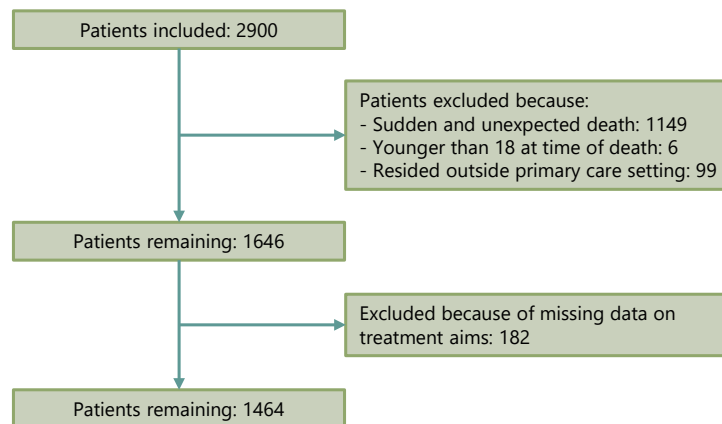


Figure 4.1 Flow chart of patient inclusion

## Measures

### Treatment aims at the end of life

In the questionnaire, GPs were asked to rate the importance of cure, life prolongation and palliation as treatment aims in the last 2-3 months; the last 2-4 weeks; and the last week before death, on a Likert scale, ranging from 1 (totally unimportant) to 5 (very important). For each treatment aim, at each time, a binomial variable was constructed in which cases with a 4 or 5 on the Likert scale were considered to have that treatment aim at that time, and cases with a score of 1 to 3 were not. Patients who had palliation as treatment aim at each point in time were labelled as having a palliative treatment aim throughout the last three months of life. Within this group, patients who also had a curative or life-prolonging treatment aim at any of the three time-points, were labelled as having a coexistent palliative treatment aim, while the patients with no curative or life prolonging treatment aim throughout the final three months were labelled as having only a palliative treatment aim.



### Advance care planning and communication on end-of-life topics.

Advance care planning is defining goals and preferences for future treatment and care, and discussing these between healthcare providers, patients and relatives<sup>123</sup>. In this study, advance care planning was measured by asking GPs whether patients had expressed end-of-life treatment preferences, whether patients appointed a surrogate decision maker in case of mental incompetency, and whether the GPs were aware of the preferred place of death of the patient. Regarding communication, they were also asked to report on seven end-of-life topics whether or not they had discussed these topics with the patient and/or a relative. These seven topics were: diagnosis; prognosis/course of illness; end of life; treatment pros and cons; palliative care options; psychosocial problems; and spiritual problems.

### Palliative care outcomes.

GPs were asked to report on several care outcomes considered to be quality indicators in palliative care<sup>79,124-127</sup>. These outcomes included dying in the preferred place as well as hospital admissions and emergency department visits in the last month of life. Additionally, GPs were asked whether they thought the patient died peacefully, whether the patient had accepted death and whether they had provided bereavement care for relatives after the death of the patient.

## Data analysis

We assessed the personal characteristics of patients using descriptive statistics. We used Pearson's chi square and ANOVA to assess differences between the groups. We performed multivariable logistic regression with Generalized Estimating Equations (GEE) to analyse the association between patient groups (no palliative aim vs palliative aim, and coexistent aims vs only palliative aim) as independent variable and outcomes (advance care planning, communication on end-of-life topics, and care outcomes) as dependent variable. GEE accounted for potential clustering of patient data on GP-practice level. In each separate GEE analysis we included age, sex, place of residence, year of death, primary diagnosis and dementia status as fixed effect. Cases with missing data were excluded from analysis. In addition, we performed sensitivity analyses with a cut-off point at 3 rather than at 4 as described above under *treatment aims at the end of life*, showing results similar to the original analyses presented in the results section below. SPSS version 26 was used for all statistical analyses.

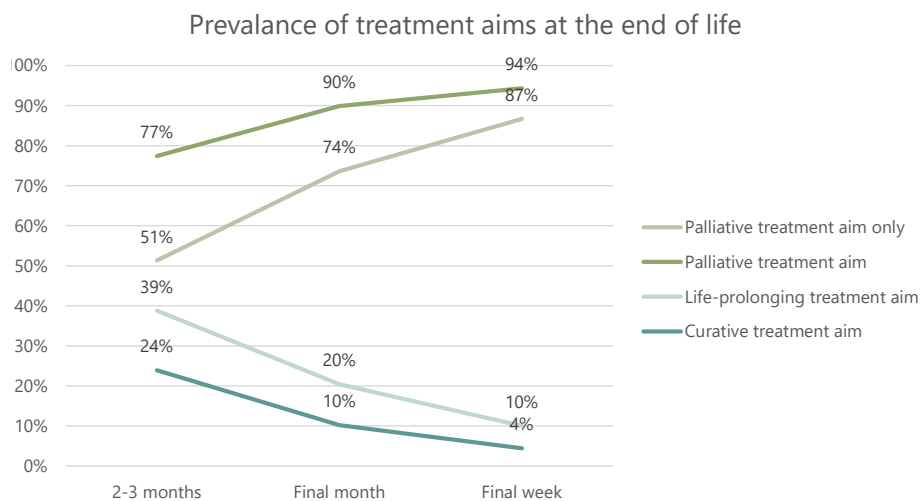
## Ethical approval

The Sentinel Network Study is exempt from official ethical approval, as posthumous collection of anonymous patient data is allowed under Dutch Law.

## Results

### Treatment aims at the end of life

An overview of the reported treatment aims can be found in figure 4.2. The proportion of patients with a palliative treatment aim increased from 77% in the last 2-3 months to 96% in the last week before death. The proportion of patients with life-prolonging or curative treatment aims steadily declined from 39% and 24% at 2-3 months before death to 10% and 5% respectively in the last week. Just over half of all patients had only a palliative treatment aim throughout the last 3 months of life, increasing to 88% in the last week.



**Figure 4.2** Prevalence of treatment aims at the end of life

## Patient characteristics

The included patients (n=1464) were approximately 77 years old at the time of their death, and 51% were male. The majority of patients was living at home (81%) and most died of cancer (59%). Seven percent of all patients were diagnosed with severe dementia. Within the group of patients with a palliative treatment aim in the last three months (n=1133) we found that the patients with only a palliative treatment aim were older, less often stayed at home, less often died from cancer, and more often were diagnosed with (severe) dementia. A detailed overview of their characteristics can be found in table 4.1.

## Advance care planning and communication of end-of-life topics

An overview of the association between having a palliative treatment aim throughout the last three months of life and advance care planning and communication on end-of-life topics is presented in table 4.2. We found that patients with a palliative treatment aim were more likely to have expressed end-of-life treatment preferences than patients without a palliative treatment aim (OR = 1.73, 95%CI = 1.28-2.35), and were also more likely to have appointed a surrogate decision maker (OR = 1.58, 95%CI = 1.20-2.06). Further, for all end-of-life topics we found that GPs were more likely to have discussed these with patients with a palliative treatment aim than with patients without a palliative treatment aim. We also found for several end-of-life topics that GPs were more likely to discuss these with the relatives of a patient with a palliative treatment aim.

Within the group of patients with a palliative treatment aim we found that patients with only a palliative treatment aim were more likely to have expressed their preferred place of death (OR = 2.44, 95%CI = 1.51-3.93). We also found for some end-of-life topics that GPs had more often discussed these with patients with only a palliative treatment aim.

### Palliative care outcomes

Table 4.3 provides an overview of the associations between having a palliative treatment aim throughout the last three months and end-of-life care outcomes. We found that patients with a palliative treatment aim had significantly lower odds to be admitted to a hospital (OR=0.48, 95%CI = 0.37-0.63) and to visit the emergency department in the last month (OR=0.51, 95%CI = 0.39-0.68) compared to patients without a palliative treatment aim. Further, they were also more likely to have died peacefully (OR = 1.47, 95%CI = 1.09-1.97) and to have accepted their death, according to their GP (OR = 1.66, 95%CI = 1.17-2.35).

Next, within the group of patients with a palliative treatment aim, we found that patients with only a palliative treatment aim had significantly lower odds for a hospital admission (OR = 0.30, 95%CI = 0.23-0.40) and an emergency department visit in the last month (OR = 0.33, 95%CI = 0.24-0.46) than patients with a coexistent palliative treatment aim. Further, they were more likely to have died at their preferred place of death (OR = 3.52, 95%CI = 2.05-6.04), to have died peacefully according to their GP (OR = 1.70, 95%CI = 1.25-2.33) and to have accepted death according to the GP (OR = 3.64, 95%CI = 2.43-5.46).

The significant differences found in the latter analyses led us to believe that the differences between the group with and without a palliative treatment aim could mainly be attributable to the group with only a palliative treatment aim. To examine this, we performed additional analyses estimating the association between having a coexistent palliative treatment aim throughout the last three months of life and end-of-life care outcomes. Interestingly, we found no significant differences in these outcomes between the group without a palliative treatment aim and the group with a coexistent palliative treatment aim. An overview can be found in table 4.4.

**Table 4.1** Patient characteristics of deceased patients in 2013-2018 with and without a palliative treatment aim throughout in the last three months

	Total N = 1464	No palliative treatment aim N = 331 (23%)	Palliative treatment aim N = 1133 (77%)	Palliative treatment aims N = 1133			
				p- value <sup>a</sup>	Coexistent palliative treatment aim N=393 (35%)	Only a palliative treatment aim N = 740 (65%)	p- value <sup>a</sup>
	N (%)	N (%)	N (%)				
<b>Age</b> (mean, sd) <sup>b</sup>	77.1 (13.0)	75.1 (13.4)	77.7 (12.9)	<b>0.001</b>	75.0 (13.0)	79.2 (12.6)	<b>&lt;0.001</b>
<b>Gender</b> (male)	750 (51)	185 (56)	565 (50)	0.054	201 (51)	364 (49)	0.531
<b>Longest place of residence in the last year of life</b>							
Home/with family	1190 (81)	283 (85)	907 (80)	0.081	341 (87)	566 (76)	<b>&lt;0.001</b>
Residential care home	261 (18)	46 (14)	215 (19)		47 (12)	168 (23)	
Hospice	13 (1)	2 (1)	11 (1)		5 (1)	6 (1)	
<b>Cause of death</b>							
Cancer	868 (59)	199 (60)	669 (59)	0.432	257 (65)	412 (56)	<b>0.002</b>
Organ failure	345 (24)	83 (25)	262 (23)		82 (21)	180 (24)	
Frailty/dementia	207 (14)	38 (12)	169 (15)		40 (10)	129 (17)	
Other	44 (3)	11 (3)	33 (3)		14 (4)	19 (3)	
Severe dementia diagnosed	106 (7)	13 (4)	93 (8)	<b>0.008</b>	15 (4)	78 (11)	<b>&lt;0.001</b>

<sup>a</sup> Test for differences, Pearson's chi-square.<sup>b</sup> Test for differences, ANOVA. No missing data for these variables.



Table 4.2 Association between having a palliative treatment aim throughout the last three months and advance care planning and communication on end-of-life topics

	No palliative treatment aim N = 331	Palliative treatment aim N = 1133	Palliative treatment aim N = 1133					
			OR (95% CI)	p-value	Coexistent palliative treatment aim N = 393	Only palliative treatment aim N = 740	OR (95% CI)	p-value
Advance care planning								
End-of-life treatment preferences expressed <sup>1</sup>	212 (70)	841 (78)	1.73 (1.28-2.35)	<0.001	288 (77)	553 (79)	1.45 (1.04-2.00)	0.028
Surrogate decision-maker appointed <sup>2</sup>	150 (52)	638 (61)	1.58 (1.20-2.06)	0.001	228 (61)	410 (61)	1.12 (0.85-1.47)	0.425
Preferred place of death known <sup>3</sup>	296 (90)	1058 (94)	1.52 (0.98-2.37)	0.064	356 (91)	702 (95)	2.44 (1.51-3.93)	<0.001
Topics discussed with the patient <sup>4</sup>								
Diagnosis	264 (80)	944 (83)	1.86 (1.28-2.72)	0.001	341 (87)	603 (82)	1.07 (0.70-1.63)	0.755
Course of illness/prognosis	273 (83)	953 (84)	1.66 (1.13-2.43)	0.010	345 (88)	608 (82)	1.02 (0.66-1.58)	0.915
End of life	267 (81)	947 (84)	1.55 (1.09-2.21)	0.016	328 (84)	619 (84)	1.56 (1.04-2.32)	0.030
Treatment pros and cons	220 (67)	813 (72)	1.60 (1.19-2.15)	0.002	293 (75)	520 (70)	1.13 (0.82-1.55)	0.465
Palliative care options	222 (67)	806 (71)	1.38 (1.04-1.82)	0.024	277 (71)	529 (72)	1.36 (1.02-1.83)	0.037
Psychosocial problems	170 (51)	656 (58)	1.64 (1.25-2.14)	<0.001	229 (58)	427 (58)	1.39 (1.05-1.84)	0.023
Spiritual problems	118 (36)	501 (44)	1.64 (1.26-2.15)	<0.001	166 (42)	335 (45)	1.40 (1.07-1.84)	0.014
None	34 (10)	83 (7)	0.44 (0.26-0.74)	0.002	25 (6)	58 (8)	0.70 (0.37-1.34)	0.285

Table 4.2 Continued

	No palliative treatment aim N = 331	Palliative treatment aim N = 1133	Palliative treatment aim N = 1133			
			Coexistent palliative treatment aim N = 393	Only palliative treatment aim N = 740	OR (95% CI)	p-value
<b>Topics discussed with the relative<sup>4</sup></b>						
Diagnosis	247 (75)	914 (81)	318 (81)	596 (81)	1.09 (0.78-1.51)	0.633
Course of illness/prognosis	268 (81)	942 (83)	318 (81)	624 (84)	1.30 (0.93-1.83)	0.127
End of life	262 (79)	940 (83)	309 (79)	631 (85)	<b>1.64 (1.17-2.30)</b>	<b>0.004</b>
Treatment pros and cons	222 (67)	804 (71)	272 (69)	532 (72)	1.22 (0.93-1.62)	0.155
Palliative care options	244 (74)	891 (79)	316 (81)	575 (78)	1.03 (0.75-1.42)	0.858
Psychosocial problems	147 (44)	601 (53)	210 (54)	391 (53)	1.14 (0.88-1.48)	0.311
Spiritual problems	84 (25)	389 (34)	135 (34)	254 (34)	1.07 (0.82-1.41)	0.603
None	25 (8)	56 (5)	24 (6)	32 (4)	0.66 (0.38-1.16)	0.150

OR = Odds Ratio; CI = confidence interval; statistically significant values in bold. Logistic regression analysis performed using Generalised Estimating Equations. Adjusted for age, sex, residence, year of death, primary diagnosis and dementia status. Missing values: 16% 39% 30.2% 40.1%

Table 4.3 Association between having a palliative treatment aim throughout the last three months and palliative care outcomes

	No palliative treatment aim N = 320	Palliative treatment aim N = 1144	Palliative treatment aim N = 1144			
			Coexistent palliative treatment aim N = 393	Only palliative treatment aim N = 751	OR (95% CI)	p-value
Hospitalisation in last month <sup>1</sup>	167 (51)	348 (31)	193 (49)	155 (21)	<b>0.48 (0.37-0.63)</b>	<b>&lt;0.001</b>
ED visit in last month <sup>1</sup>	107 (32)	208 (18)	1221(31)	87 (12)	<b>0.51 (0.39-0.68)</b>	<b>&lt;0.001</b>
Died at PPOD <sup>2</sup>	270 (91)	1001 (95)	320 (90)	681 (97)	1.60 (0.98-2.59)	0.058
Patient died peacefully <sup>1</sup>	240 (73)	911 (81)	291 (74)	620 (84)	<b>1.47 (1.09-1.97)</b>	<b>0.011</b>
Patient had accepted death <sup>3</sup>	241 (80)	937 (87)	285 (77)	652 (93)	<b>1.66 (1.17-2.35)</b>	<b>0.004</b>
Bereavement care for relatives after death of patient <sup>1</sup>	280 (85)	988 (87)	342 (87)	646 (88)	1.38 (0.96-1.98)	0.079

OR = Odds Ratio; CI = confidence interval; statistically significant values in bold. Logistic regression analysis performed using Generalised Estimating Equations. Adjusted for age, sex, residence, year of death, primary diagnosis and dementia status. Missing values: <sup>1</sup><0.5% <sup>2</sup>8% <sup>3</sup>6%

**Table 4.4** Additional analyses: association between having a coexistent palliative treatment aim throughout the last three months and palliative care outcomes

	No palliative treatment aim N = 320	Coexistent palliative treatment aim N = 393	OR (95% CI)	p-value
Hospitalisation in last month <sup>1</sup>	167 (51)	193 (49)	0.99 (0.73-1.34)	0.932
ED visit in last month <sup>1</sup>	107 (32)	122 (31)	0.95 (0.68-1.31)	0.731
Died at PPOD <sup>2</sup>	270 (91)	320 (90)	0.89 (0.53-1.51)	0.663
Patient died peacefully <sup>1</sup>	240 (73)	291 (74)	1.08 (0.77-1.53)	0.658
Patient had accepted death <sup>3</sup>	241 (80)	285 (77)	0.84 (0.57-1.24)	0.374
Bereavement care for relatives after death of patient <sup>1</sup>	280 (85)	342 (87)	1.19 (0.76-1.86)	0.453

OR = Odds Ratio; CI = confidence interval. Logistic regression analysis performed using Generalised Estimating Equations. Adjusted for age, sex, residence, year of death, primary diagnosis and dementia status. Missing values: <sup>1</sup><0.5% <sup>2</sup>8% <sup>3</sup>6%

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## Discussion

### Main findings

The majority of patients in our study had a palliative treatment aim in the last three months of their life according to their GP, and most did not have a curative or life-prolonging treatment aim. A palliative treatment aim throughout the last three months of life was found to be associated with improved advance care planning and communication on end-of-life topics. Further, having only a palliative treatment aim throughout the last three months, as opposed to having a coexistent palliative treatment aim, was found to be associated with improved palliative care outcomes, and with limited further improved advance care planning and communication on end-of-life topics.

### Strengths and limitations

The sentinel network accounts for approximately 0.8% of the Dutch population and is designed and managed to be representative of the population for age, gender and population density<sup>122</sup>. The retrospective design allows for the identification of all patients receiving palliative care in the primary care setting, although it is unfit to demonstrate causality. While registration of deceased patients occurs on weekly basis, GPs are asked to recall aspects of care that occurred much earlier such as topics of conversations, potentially introducing recall bias. Social desirabil-

ity bias is also a potential limitation, although minimised through the anonymity of both patients and GPs. Finally, the occurrence of discussions of end-of-life topics is reported from the GPs point-of-view only. Patients and relatives may have had a different view on what was discussed.

## What this paper adds

In our study, 78% of patients with a life-threatening illness had a palliative treatment aim in the last three months of life, and this increased to 94% in the last week of life. Still, a considerable proportion (also) aimed for cure or life-prolongation: 49% in the last 2-3 months, and 13% in the last week of life. While consistent with earlier primary care research on treatment aims in the last three months of life<sup>121,128</sup>, these numbers may be different in patients in the secondary care setting.

The incidence of GPs' awareness of their patients' preferred place of death in our study (92%) is remarkably high compared to earlier studies in the Dutch primary care setting.<sup>119,126</sup> The proportion of patients that expressed end-of-life treatment preferences (72%) and the proportion that appointed a surrogate decision-maker (54%) in our study was also higher compared to earlier research.<sup>128</sup> A possible explanation is the increased attention and appreciation for palliative care and advance care planning in the Netherlands in recent years. Regarding the discussion of end-of-life topics, we found that for each of the probed topics, a sizeable part of the GPs reported that they had discussed this with patients and relatives, ranging from 42% for spiritual issues to 84% for course of illness. In general, Dutch general practice can be characterised as an open, discussion-led practice<sup>31</sup>, although not all patients may want to discuss everything about their illness and the end of life in detail.<sup>129,130</sup> Some, particularly those with severe dementia, may not be able to, emphasizing the importance of advance care planning.<sup>131</sup> Regarding the differences between the groups, our results suggest that having a palliative treatment aim is associated with improved advance care planning and communication on end-of-life topics, but also that aiming for palliation only, thus letting go of curative and life-prolonging treatment aims, is even more strongly associated with improvement on these aspects of palliative care.

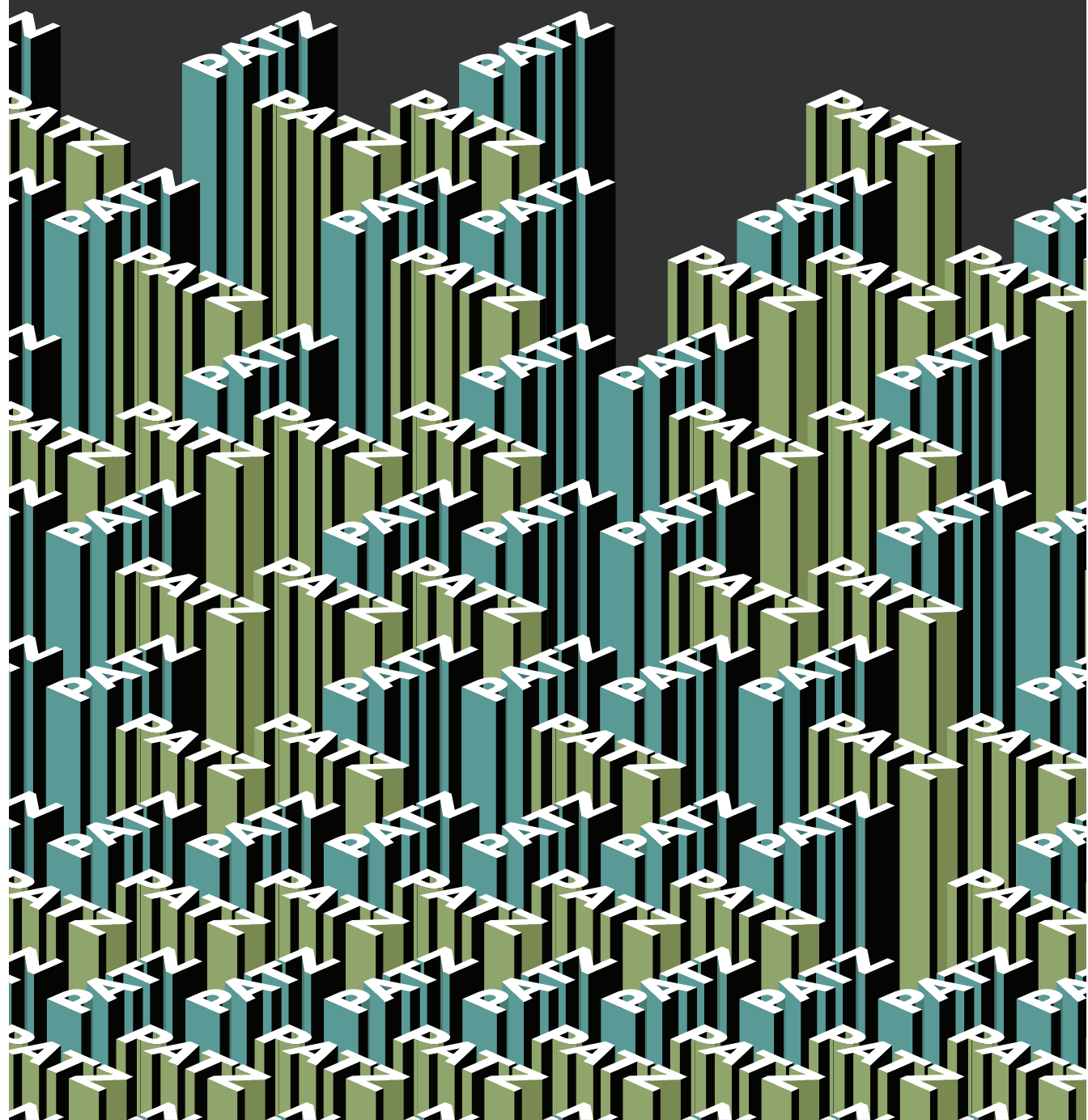
Looking at the differences between the groups regarding palliative care outcomes, we found significant associations between having a palliative treatment aim and hospital admissions, emergency department visits, the patient's acceptance of death and dying peacefully. Interestingly, within the group of patients with a palliative treatment aim, we found that having only a palliative treatment aim is associated with improvement on all but one measured palliative care outcomes. In the additional analyses following these findings, we found that the care outcomes of the group with a coexistent palliative treatment aim did not differ from

the outcomes of the group without a palliative treatment aim, indicating that the improvements in palliative care outcomes are mainly attributable to the group with only a palliative treatment aim. Thus, the improvements we found in care outcomes may not be related to the presence of a palliative treatment aim per se, but to the simultaneous absence of curative and life-prolonging treatments aims. A line of thought that explains these findings is that patients with only a palliative treatment aim may no longer visit the hospital<sup>125</sup>, and shift their focus from hoping for a longer life to accepting that life is finite, making the best of the time that is left and focusing on what matters to them in the end. How these patients and their relatives experience the last months of life and whether their experiences differ from patients without a palliative treatment aim or patients with a coexistent palliative treatment aim, should be investigated in future research.

So, while aiming for palliation alongside cure or life-prolongation could be beneficial with regards to communication on end-of-life topics and advance care planning, our findings also suggest that to improve palliative care outcomes this is not enough. Instead, a timely and complete transition to palliative treatment, and thereby no longer aiming for cure or life-prolongation, may be required to improve palliative care outcomes. In the widely adopted 'trajectory' model of Lynn and Adamson, in which palliative care is a continuum between diagnosis and death in which the focus gradually moves from curative treatment towards palliative treatment<sup>3</sup>, such a transition to palliative care is absent, but in reality, these shifts seem to occur nonetheless. While we investigated treatment aims in the last three months of life in this study, the optimal period of time to focus on palliation only, and whether this period is similar for patients with different types of illnesses, should be subject of future research.

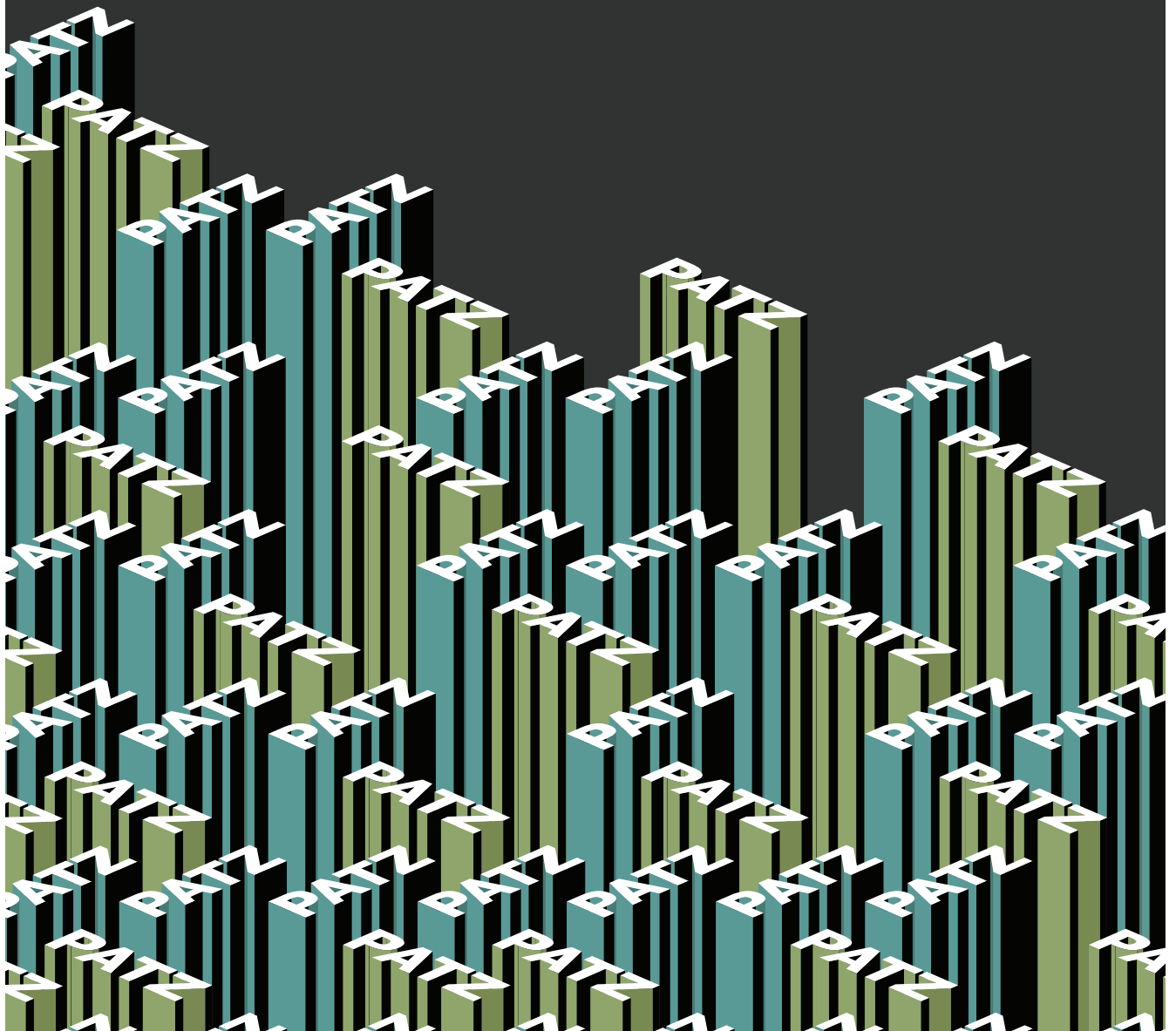
## Conclusion

Most Dutch patients in the primary care setting have a palliative treatment aim in the last three months of life, which is associated with improved advance care planning and communication on end-of-life topics. In addition, having only a palliative treatment aim in the last three months of life, and consequently letting go of curative and life-prolonging treatment aims, is associated with improved palliative care outcomes, such as reduced hospital admissions and emergency department visits and increased acceptance of death. These findings indicate the importance of a timely and complete transition to palliative care.

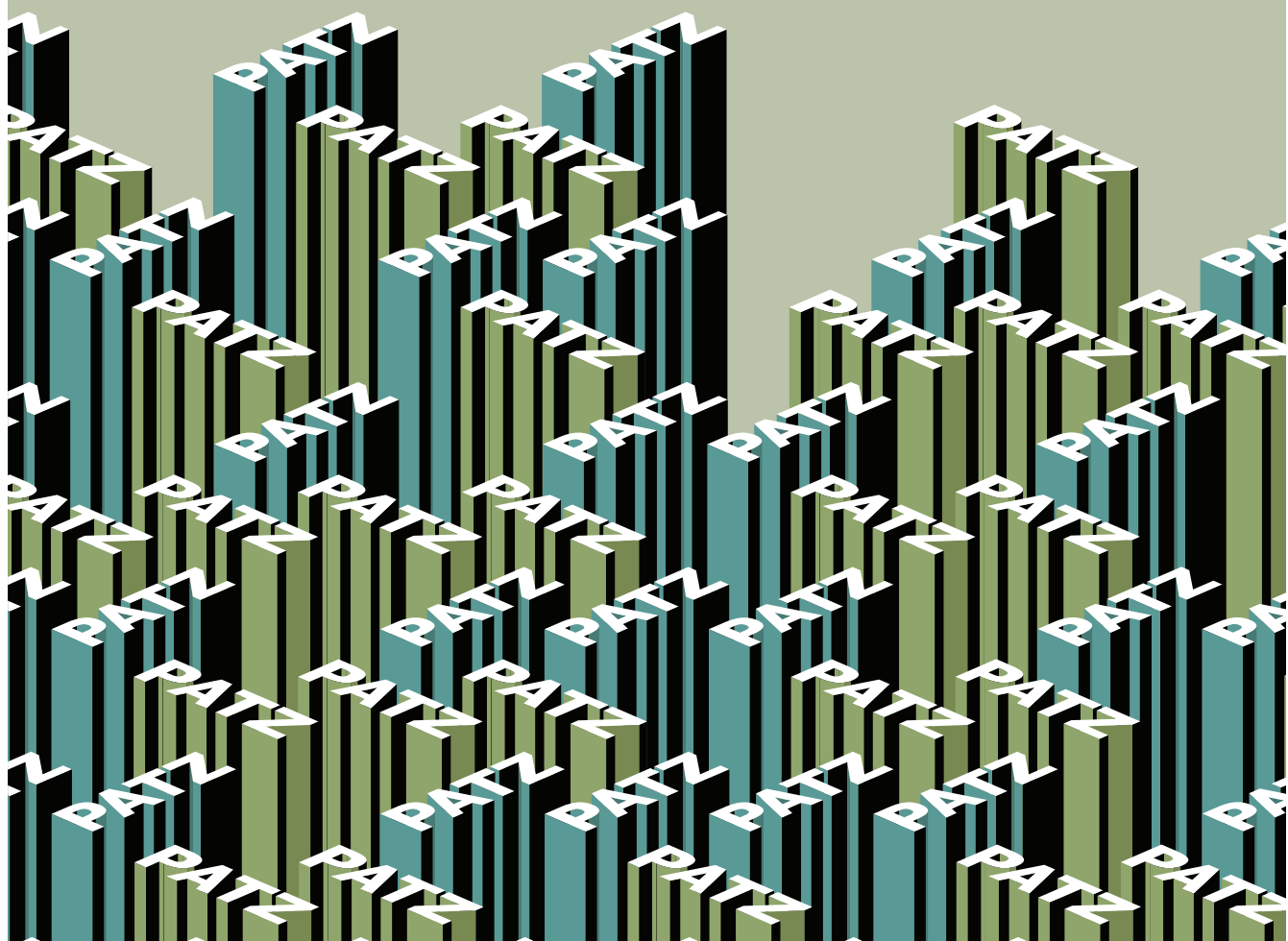


# Part 2

The role of PaTz in improving  
primary palliative care





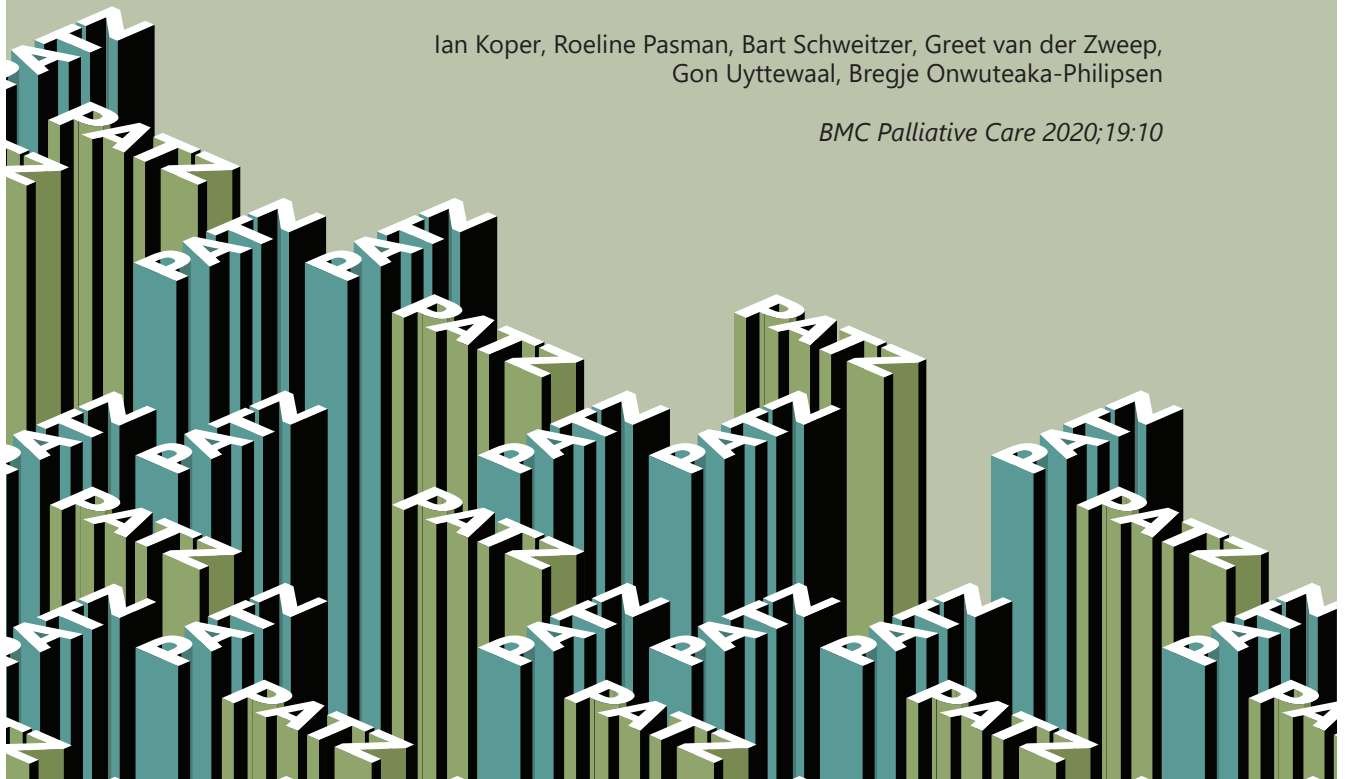


# Chapter 5

## Variation in the implementation of PaTz: a method to improve palliative care in general practice - a prospective observational study

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## Abstract

**Background:** PaTz (palliative care at home) is a method to improve palliative care in the primary care setting in the Netherlands. PaTz has three basic principles: (1) local GPs and DNs meet at least six times per year to a specialist palliative care professional; (3) groups use a palliative care register on which all identified patients are identify and discuss their patients with a life-threatening illness; (2) these meetings are supervised by listed. Since the start in 2010, the number of PaTz-groups in the Netherlands has been growing consistently. Although the theory of all PaTz-groups is the same, the practical functioning of PaTz-groups may vary substantially, which may complicate further implementation of PaTz as well as interpretation of effect studies. This study aims to describe the variation in practice of PaTz-groups in the Netherlands.

**Method:** In this prospective observational study, ten PaTz-groups logged and described the activities in their meetings as well as the registered and discussed patients and topics of discussions in registration forms for a one year follow-up period. In addition, non-participatory observations were performed in all participating groups. Meeting and patient characteristics were analysed using descriptive statistics. Conventional content analysis was performed in the analysis of topic discussions.

**Results:** While the basic principles of PaTz are found in almost every PaTz-group, there is considerable variation in the practice and content of the meetings of different PaTz-groups. Most groups spend little time on other topics than their patients, although the number of patients discussed in a single meeting varies considerably, as well as the time spent on an individual patient. Most registered patients were diagnosed with cancer and patient discussions mainly concerned current affairs and rarely concerned future issues.

**Discussion:** The basic principles are the cornerstone of any PaTz-group. At the same time, the observed variation between PaTz-groups indicates that tailoring a PaTz-group to the needs of its participants is important and may enhance its sustainability. The flexibility of PaTz-groups may also provide opportunity to modify the content and tools used, and improve identification of palliative patients and advance care planning.

## Background

Palliative care is challenging care, primarily focused on multidimensional symptom relief and quality of life rather than on curation and life prolongation<sup>2</sup>. In the Netherlands palliative care is provided according to a coordinated palliative care model<sup>18</sup>, and in the primary care setting, general practitioners (GPs) and district nurses (DNs) are the designated palliative care providers<sup>32,34</sup>. The provision of good palliative care requires proper communication, coordination and collaboration between healthcare providers and with patients<sup>5,6,132,133</sup>. Already facing a high work load<sup>134,135</sup>, the combination of an aging population and the Dutch policy to provide palliative care at home where possible<sup>31</sup>, is likely to put a strain on GPs<sup>136</sup> and DNs<sup>137</sup> alike. At the same time, market mechanisms in the Dutch health care system have led to scattering of home care organisations, impeding communication and collaboration between GPs and DNs<sup>138</sup>. Evidently, the provision of good palliative care in the primary care setting is under threat.

In 2010, an initiative to reinforce communication and collaboration between GPs and DNs, called PaTz (acronym for 'Pallatieve Thuiszorg'; palliative care at home) was introduced in the Netherlands<sup>29</sup>. Derived from the British Gold Standards Framework (GSF)<sup>28</sup>, PaTz aims to improve palliative care in the primary care setting through timely identification of patients eligible for palliative care, improving expertise and reinforcing the collaboration and communication between key healthcare providers in the primary care setting. The basic principles of PaTz are summarized in box 1. Recurrent multidisciplinary meetings between local GPs and DNs, supported by a specialist palliative care professional (physicians and nurses with formal palliative care training) are the foundation of each PaTz-group. Participants identify patients with palliative care needs using the Surprise Question<sup>139</sup> (SQ: would I be surprised if this person died in the coming year?), put them on a register and code the patients with a colour indicating the urgency, intensity and/or the complexity of the care needs of that patient and his or her relatives. As such, the register provides an overview of all identified patients in the PaTz-group and serves as the backbone for the meetings. Currently, two versions of the PaTz-register are in use. The first version is the original version, a simple Excel-file in which basic information regarding all patients, their diagnosis and their stability is registered in a single Excel-sheet. The second version is an extended, web-based register called the PaTz-portal in which, apart from the basic information and the colour code, members of the PaTz-group can click on a patient to open that patient's page, where they are prompted to provide additional information regarding the patient. This includes a description of the patient's current problems in four dimensions as well as future problems and care needs. In the PaTz-portal, other tools and interventions that may be helpful in the care for the patient are suggested, like a joint home visit of GP and DN.

### Box 5.1 The three basic principles of PaTz

- (1) In a PaTz-group, local GPs and DNs meet at least six times per year to identify and discuss their patients with a life-threatening illness;
- (2) PaTz-meetings are supervised by a specialist palliative care professional;
- (3) PaTz-groups use a palliative care register on which all patients with a limited life expectancy are listed.

While clear benefits in terms of patient outcomes have yet to be determined, evaluation studies of PaTz have shown positive results. PaTz-participants feel that PaTz improves collaboration, while strengthening participants' expertise and providing emotional support <sup>29</sup>, and PaTz is associated with improved communication, both between healthcare providers and with patients <sup>140</sup>. The PaTz-register seems a crucial element in PaTz-groups, as compared to patients who are not on the register, the preferred place of death is more often known for patients who are on the register, who also are less often admitted to the hospital in the final month <sup>30</sup>. In addition, their death is anticipated earlier by their GP, treatment is aimed at palliation earlier and they more often have conversations on end of life topics, like life expectancy and palliative care treatment options <sup>30</sup>.

Since the first PaTz-groups in 2010, over 180 PaTz-groups have been established throughout the Netherlands <sup>141</sup>. Before the start of a new PaTz-group, the PaTz-foundation provides training for the chair and, if needed, the Comprehensive Cancer Centre Netherlands (IKNL) provides a specialist palliative care professional <sup>142</sup>. But from that moment on the group is left without regulation from outside, and although the three principles are the basis for any PaTz-group, there are some practical examples of variation between PaTz-groups in composition and use of additional elements. For example, there are groups in which a coordinator of volunteers in palliative care joins the meetings, while in other groups a spiritual caregiver is present. Also, some groups use the original PaTz-register, while others have switched to the web-based version, or have been using this version from the start. Thus, while the theory of PaTz is known, the functioning of PaTz-groups in practice remains unclear. A clear perspective on the extent of this variation is primarily important for further implementation and development strategies. Secondly, uncertainty regarding the variation in practice of PaTz-groups complicates interpretation of studies on the effect of PaTz-groups. Therefore, this study aims to describe the practice of PaTz-groups by investigating how the basic principles of PaTz are applied in practice, and what the content of PaTz-meetings is.

## Methods

### Design

To investigate the practice of running PaTz-groups in the Netherlands we used a prospective observational design. For a follow-up period of one year, chairs of participating PaTz-groups were asked to log and describe the activities in their meetings. In addition, non-participatory observations were performed in all participating groups. A mortality follow-back design was used to register the date of death of patients in included PaTz-groups.

### Recruitment of participants

Recruitment of PaTz-groups took place between January 2017 and September 2017. PaTz-groups were eligible for inclusion if they had been running for a year or longer, and were not participating in another study, influencing their performance. At that time, approximately 100 PaTz-groups were eligible for inclusion. At first, PaTz-groups were recruited through contacts at the PaTz-foundation, who provided a list of nineteen PaTz-groups who might be interested in participation. The chairs of these nineteen groups were sent an information letter regarding the content of study and asked whether the group was interested in participating. Non-responding groups were sent a reminder once. Three groups responded to neither the initial invitation nor the reminder, six groups refused to participate and one group was already participating in a conflicting study. The nine remaining groups agreed to participate. In an attempt to add more groups to the sample, we issued a call to participate through the umbrella organisation of palliative care networks in the Netherlands (Fibula), which provided a list of four other groups that were interested in participation. A member of the research team visited these groups to explain the study and three groups agreed to participate, adding up to a total sample of twelve PaTz-groups. Although the observations were performed in all twelve groups, one group stopped participating after the observations, and one group did not start registration at all. In the end, 10 PaTz-groups completed registration in the follow-up period and were reimbursed for their efforts. Figure 5.1 summarizes the inclusion in a flowchart.



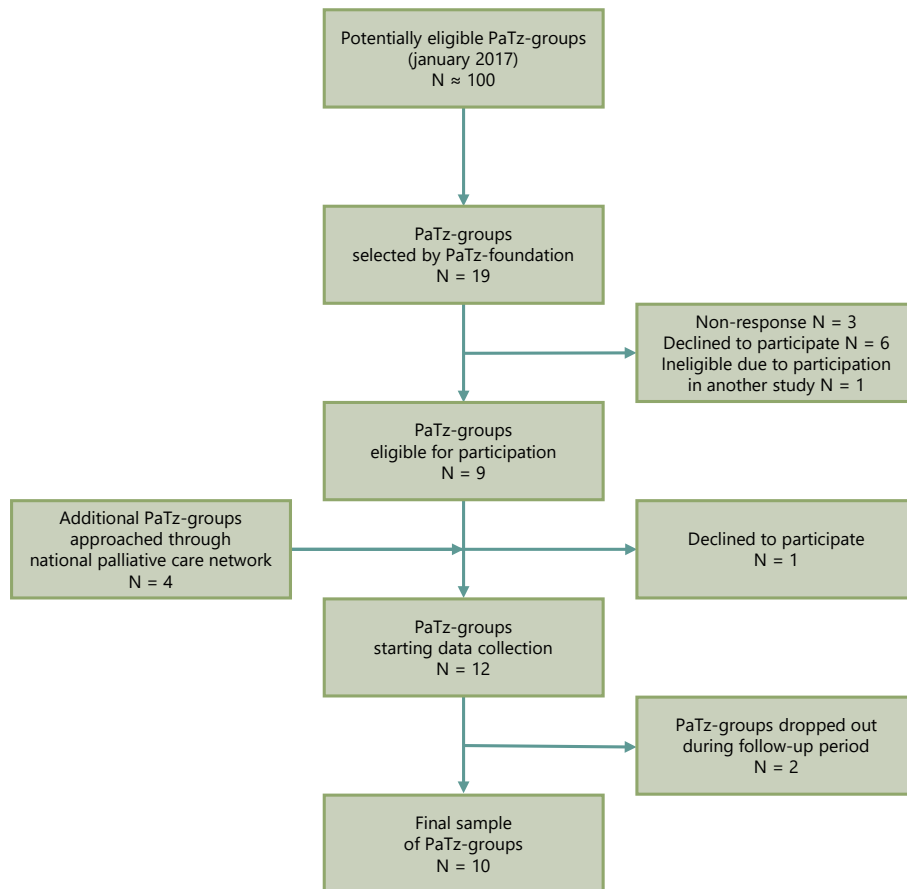


Figure 5.1 Flowchart of inclusion of PaTz-groups

## Data collection

Data collection took place between January 2017 and November 2018. Chairs were asked to register who were present at the meetings, which patients were put on the PaTz-register, and which patients were discussed. They were also asked to describe what topics were covered in the discussions, both regarding the patients as well as general topics and how much time was spent on each subject. A form was created to guide the chairs through the registration of activities and reminders were sent to chairs who did not return the forms. The first two meetings, a researcher performed non-participatory observations using a topic list (see Appendix 1), paying extra attention to the basic principles of PaTz in each PaTz-group and the interaction between members of the group. After the follow-up period, a researcher (IK) visited the GPs of the participating PaTz-groups to assess which patients on the PaTz-register had died in that period, and registered their date of death.

## Data analysis

Analysis of meeting characteristics derived from the non-participatory observations and registration forms and patient characteristics derived from the registration forms were performed using descriptive statistics. Selection of specific groups of patients was performed where appropriate. The descriptions of topics in patient discussions were analysed by IK and discussed with RP and BOP using conventional content analysis, in which codes and categories are derived from data during the analysis rather than established beforehand<sup>143</sup>. Two thirds (248/384) of the topic descriptions contained information eligible for analysis. During the first analysis, the codes and categories that were generated from the data underwent content and definition changes, resulting in a final coding tree consisting of three categories: current or future situation, the content of the discussion and the domain of discussed situation. This coding tree was discussed with RP and BO before using in a second analysis of the data. In the second analysis new codes were added for data that did not fit into an existing code.

Meeting and patient characteristics were compared between the groups to establish practice variation, while the topics of patient discussion were analysed collectively to describe their general content.

## Results

Of the ten PaTz-groups that completed follow-up and mortality follow-back, four groups were situated in a major city, five in a town or suburb and one group was situated in a rural area. At the time of inclusion, seven groups had been active for more than five years, two for more than three years, and one group had been active for just over a year.

## Completeness of data

In all ten groups, observations of two meetings were performed. Regarding the registration data, there was one PaTz-group that did not return a registration form for all meetings, due to absence of the chair on one occasion. In total, 78 out of a possible 79 registration forms were included in the analysis. Unfortunately, data on the (changes in) colour coding of registered patients was insufficiently reported and could not be analysed for analysis.



## Application of basic principles of PaTz

From the observations and registration we found that in all groups but one, the basic principles of PaTz were met. The core of all but one groups consisted of GPs, DNs and a specialist palliative care professional, all groups used a PaTz-register, whether it be the original Excel-sheet or the more advanced PaTz-portal, and all groups met at least six times per year.

One particular group stood out as GPs were not the driving force of this group. The backbone of this unique group consisted of palliative care specialists from an academic hospice and local DNs, while GPs only joined the meeting when deemed necessary, by the chair's invitation. This hospice-centred group also had a different meeting frequency, as this group met once every two weeks, while we found that the other groups met once every 6-8 weeks. The specialist palliative care professionals in the different groups fulfilled their role diversely. Some experts kept a low profile, only giving advice or information when asked directly. Others were more involved, and one specialist palliative care professional, albeit unofficially, even took over chairmanship of a meeting, deciding which patients to discuss and elaborating on palliative care subjects without being asked. Some groups planned their meetings after working hours, other groups met during lunch time, whichever was preferred by the group members. In most groups, healthcare providers from other disciplines, like spiritual caregivers, a coordinator of palliative care volunteers and nurse specialists, joined the meetings, and observations showed that they incidentally contributed to patient discussions by asking questions, expressing their view on a subject or proposing involvement in a patient.

We found that in all groups a palliative care register was used to list patients with a limited life expectancy. In the groups using the PaTz-portal, we observed that the PaTz-portal provided guidance and structure when discussing a patient. The hospice-centred group used a custom online register, and for each patient a separate online care plan, featuring a four-dimensional description of the patient, his or her problems and wishes and care, was filled out. An overview is presented in table 5.1.

## Content of PaTz-meetings

### Meeting characteristics

An overview of the characteristics of the meetings of the participating PaTz-groups during the follow-up period can be found in table 2. It shows that all groups but the hospice-centred group met 5-7 times in the follow-up period. Generally, the groups were made up of 4-6 GPs, 3 or 4 DNs, 1 consultant in palliative care and 1 additional discipline, varying from a coordinator of volunteers in palliative care

**Table 5.1** Application of the basic principles of PaTz in 10 PaTz-groups during a one-year follow-up period

PaTz-group	1. Group composition			2. Use of PaTz-register	3. Meeting frequency	Basic principles met?
	Specialist palliative care professional	GP	DN			
1	Yes, a GP	Yes	Yes	Excel-sheet	Once per two months	Yes
2	Yes, a GP	Yes	Yes	Excel/PaTz-Portal	Once per two months	Yes
3	Yes, a GP and a nurse specialist	Yes	Yes	Excel/PaTz-Portal	Once per two months	Yes
4	Yes, a hospital nurse	Yes	Yes	Excel-sheet	Once per two months	Yes
5	Yes, a GP and a nurse specialist	Only on request	Yes	Custom version of register	Twice per month	No
6	Yes, a GP and a nurse specialist	Yes	Yes	PaTz-Portal	Once per two months	Yes
7	Yes, an elderly care specialist and a nurse specialist	Yes	Yes	PaTz-Portal	Once per two months	Yes
8	Yes, an elderly care specialist and a nurse specialist	Yes	Yes	PaTz-Portal	Once per two months	Yes
9	Yes, a GP	Yes	Yes	Excel/PaTz-Portal*	Once per two months	Yes
10	Yes, a GP	Yes	Yes	Excel-sheet	Once per two months	Yes

\* During the follow-up period this group switched to the PaTz-portal

to a spiritual caregiver or a nurse elderly care specialist. From the observations we found that while all PaTz-groups were on a first-name basis, the interaction between participants varied across groups, likely depending on their personalities and familiarity with each other. Consistent throughout all groups, however, was the seeming reluctance of DNs to introduce a patient for discussion or engage in patient discussions started by others.

Table 5.2 shows that the mean number of individual patients that was discussed per group during the follow-up period was 24 (42% of all patients on the register), ranging from 13 (or 12%) to 39 (or 98%). The majority of discussed patients were discussed once, and one quarter was only discussed after death. Regarding group composition, the proportion of patients discussed and frequency they were discussed, the hospice-centred group is a clear outlier here.



Table 5.2 Characteristics of meetings of 10 PaTz-groups in a one-year follow-up period, derived from registration data

	Total	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6	Group 7	Group 8	Group 9	Group 10
<b>Group composition (number present on average)</b>											
GPs	5	6	5	6	6	0*	3	6	4	6	5
DNs	3	3	3	3	2	4	2	4	4	3	4
Consultant in palliative care	1	1	1	1	1	2	2	2	2	1	1
Other disciplines	1	1	0*	1	0*	2	2	0*	1	1	1
Number of meetings	79	6	5	6	6	25	7	6	6	7	5
Number of patients on the PaTz-register	583	75	107	122	48	40	45	29	39	36	42
<b>Patient discussions</b>											
Individual patients discussed	243 (42%)	39 (52%)	13 (12%)	21 (17%)	23 (48%)	39 (98%)	22 (49%)	21 (72%)	27 (69%)	26 (72%)	12 (29%)
Number of times individual patients were discussed											
Once	163/243 (67%)	33 (85%)	10 (77%)	19 (91%)	16 (70%)	10 (26%)	12 (55%)	18 (86%)	18 (67%)	20 (77%)	7 (58%)
Twice	54/243 (22%)	5 (13%)	3 (23%)	2 (9%)	7 (30%)	10 (26%)	8 (36%)	2 (10%)	6 (22%)	6 (23%)	5 (42%)
Three or more times	26/243 (11%)	1 (3%)	0	0	0	19 (49%)	2 (9%)	1 (5%)	3 (11%)	0	0
Discussed only after death	58/243 (24%)	4 (10%)	6 (46%)	12 (57%)	3 (13%)	1 (3%)	11 (50%)	8 (38%)	12 (44%)	0	1 (8%)
Number of patient discussions per meeting (mean, range)	4.8 (0-20)	7.7 (0-20)	3.2 (1-5)	3.8 (2-7)	5.0 (3-7)	4.8 (0-10)	5.0 (1-11)	4.2 (1-6)	6.7 (4-14)	4.6 (3-6)	3.4 (1-6)
Duration per patient											
Mean (range), minutes	8.8 (1-45)	3.5 (1-8)	13 (3-40)	15 (3-45)	11 (5-20)	11 (1-20)	9 (3-20)	8 (1-20)	5 (3-16)	12 (1-20)	8 (5-15)
25%-75%, minutes	5-10	3-4	3-18	5-23	5-13	8-12	5-12	3-10	5-5	9-15	5-10
<b>Discussion of other topics</b>											
Number of other topics discussed	94	4	13	3	17	5	24	6	12	6	4
Minutes spent discussing other topics per meeting (mean, range)	5.7 (0-90)	2.5 (0-5)	18.1 (0-90)	3.3 (0-10)	3.6 (5-20)	3.4 (0-10)	2.5 (5-15)	5.8 (0-15)	3.6 (1-20)	7.5 (0-10)	3.8 (0-10)

\* Less than 0.5 present on average

Table 5.3 Characteristics of patients who were registered on the PaTz-register and who were also discussed in 10 PaTz-groups in a one-year follow-up period

Patients who were registered											
	1	2	3	4	5	6	7	8	9	10	
Total	N=583	N=107	N=122	N=48	N=40	N=45	N=29	N=39	N=36	N=42	
Age, years (mean, range)	74 (34-101)	78 (47-99)	78 (34-101)	66 (36-89)	74 (55-97)	71 (41-97)	70 (43-88)	71 (37-95)	72 (58-90)	67 (40-95)	
Sex (% male)	50	49	50	55	43	51	66	40	59	51	
Diagnosis											
Cancer %	65	36	63	81	78	89	100	72	58	71	
Organ failure %	17	19	19	13	23	7	0	10	6	12	
Frailty / dementia %	10	28	13	2	0	4	0	3	0	5	
Other %	10	28	7	0	3	4	0	5	28	7	
Patients who were also discussed											
	1	2	3	4	5	6	7	8	9	10	
Total	N=243	N=39	N=13	N=23	N=39	N=22	N=21	N=27	N=26	N=12	
Age, years (mean, range)	73 (37-98)	78 (39-98)	79 (63-94)	67 (46-81)	75 (55-97)	71 (41-92)	73 (58-88)	70 (37-90)	75 (58-90)	62 (49-92)	
Sex (% male)	54	49	54	73	41	50	71	54	52	55	
Diagnosis											
Cancer %	70	39	69	87	77	86	100	59	58	83	
Organ failure %	13	18	23	13	21	5	0	15	8	0	
Frailty / dementia %	6	26	8	0	0	0	0	4	0	8	
Other %	12	28	15	0	3	9	0	7	35	0	

The number of patients discussed and associated amount of time spent per patient varies both between and within all groups. Some groups averaged less than 4 patients per meeting, while others averaged more than 6, and while some groups never spent more than 15 minutes discussing an individual patient, other groups spent 40 minutes or more. The number of patients discussed and time spent on individual patients also varied per meeting within the same group, as can be seen by the ranges displayed in table 2. Interestingly, two groups had one meeting where no patients were discussed: group 1 and group 5. Further enquiry revealed that group 1 had dedicated that meeting to cooperation with local pharmacists and had spent the entire meeting on this topic, while group 5 simply had no patients to discuss at that time.

Finally, table 5.2 shows that the time spent on the discussion of other topics differed greatly between groups, and between meetings. While some groups spent 2.5 minutes on average on other topics beside patients, there is one group that spent 18.1 minutes on other topics on average. At the same time, in this group, the time spent on other topics ranges from 0 to 90 minutes.

### Patient characteristics

In table 5.3 the characteristics of patients that were registered and patients that were also discussed in the follow-up period are displayed. On average, patients on the register were 74 years old, ranging from 34 to 101 years and 50% was male. The majority was diagnosed with cancer, and a minority was diagnosed with either organ failure or frailty/dementia. Ten percent had a different diagnosis. From the observations, it was not always clear how individual patients had been identified, but in general all PaTz-groups seemed to use the Surprise Question to identify patients with palliative care needs. Communication from the treating clinical specialist that curative treatment options had been exhausted also seemed an important identifying trigger.

A few striking differences can be seen between PaTz-groups. The mean age of registered patients ranged from 66 years to 78 years, and while most groups also registered patients with organ failure or frailty/dementia as primary diagnosis, one group only registered patients with cancer. Further, the proportion of male patients on the register also varied per group, ranging from 40% to 66%. For the patients that were also discussed (243/583), we found similar figures and variation: their mean age was 73 years, 70% was diagnosed with cancer, varying from 39% to 100% between groups. Interestingly, most groups discussed more men than women during the follow-up period (49% - 73%).

## Topics of patient discussions.

The analysis of the topics of the patients discussions was based on 248 descriptions. An overview can be found in table 5.4. More than half (139/248) of the discussions of patients occurred less than three months before death, while one fifth (53/248) of the discussions occurred more than three months before death, and another fifth (56/248) occurred after death. While we found no major differences in the topics of discussion pre or post three months before death, the topics of discussion after death logically mainly concerned evaluation of care. We found that the majority of discussions pre-mortem concerned current problems, treatment or wishes, mainly in the physical domain although none of the other domains are completely ignored. A relatively small proportion of the discussions concerned future situations. An overview can be found in table 5.4 and some exemplary descriptions of patient discussions with their assigned codes is provided in Appendix 2.

**Table 5.4** Content of patient discussions derived from informative descriptions

	Total N = 248	More than three months before death or end of follow-up N = 53	Less than three months before death or end of follow-up N = 139	After death N = 56
<b>Discussion concerned:</b>				
Past situation	51 (21%)	-	-	51 (91%)
Current situation	181 (73%)	48 (91%)	127 (91%)	6 (11%)
Future situation	28 (11%)	8 (15%)	18 (13%)	2 (4%)
<b>Content of discussed situation:</b>				
Problems	134 (54%)	37 (70%)	91 (66%)	6 (11%)
Treatment (options)	70 (28%)	19 (36%)	39 (28%)	12 (21%)
Wishes of patient/family	61 (25%)	16 (30%)	35 (25%)	10 (18%)
Evaluation of care	51 (21%)	-	-	51 (91%)
<b>Domain of discussed situation:</b>				
Physical	103 (42%)	29 (55%)	62 (45%)	12 (21%)
Psychological	45 (18%)	10 (19%)	30 (22%)	5 (9%)
Social	59 (24%)	12 (23%)	34 (25%)	13 (23%)
Existential	31 (13%)	7 (13%)	21 (15%)	3 (5%)
Practical	44 (18%)	14 (26%)	21 (15%)	9 (16%)
Healthcare provider – patient relationship	10 (4%)	3 (6%)	7 (5%)	-

## Other topics

Table 5.2 showed that, although the number of other topics discussed differed greatly per group and per meeting, all groups spent time on other topics, beside discussing patients. From the descriptions of the discussion of these topics we derived a number of categories of topics that were addressed. A large part of the discussions concerned (1) collaboration with other healthcare providers, like pharmacists and spiritual caregivers, or healthcare institutions, like local hospitals or hospices; (2) specific illnesses, treatment or medication, following from but unrelated to a specific patient, like the suitability of certain medication in palliative sedation. Other discussions concerned (3) the functioning of the PaTz-group; (4) difficult (situations regarding) patients, such as patients or families with demanding attitudes; (5) options in palliative care, such as the option to involve volunteers in palliative care; and (6) tools and knowledge centres that can be of help in palliative care.

## Discussion

### Summary of the results

While the basic principles are found in every PaTz-group but the hospice-centred group, there is considerable variation in the practice and content of the meetings of different PaTz-groups. Most groups spend little time on other topics than their patients, although the number of patients discussed in a single meeting varies considerably as does the time spent on an individual patient. Most registered patients were diagnosed with cancer and patient discussions mainly concerned current affairs and rarely concerned future issues.

### Strengths and limitations

A strength of this study is that through the combination of registration and observations, we experienced the functioning of PaTz-groups first-hand in addition to the complete picture we received from the registration. A limitation of this study lies in the fact that we included only 10 of approximately 180 PaTz-groups in the Netherlands. Considering that they were willing to participate in research, it is possible that they perform better than the average PaTz-group, regarding attendance and registration. Another weakness of the study is that one third of the topic descriptions was not informative, and the number of informative descriptions differed per group, with a large part of the informative descriptions coming from the

hospice-centred group (110/248). But, as we found no major differences in topics between this group and the other groups, and the purpose of the analysis of these descriptions was to create an overview of topics in the patient discussion in general and not to compare topics between groups, we feel that the impact is limited.

## Reflections on the application of the basic principles of PaTz

All groups consist of GPs, DNs and a specialist palliative care professional, use a palliative care register and meet at least six times per year. The hospice centred-group is the exception, as GPs are not the driving force of this group and join only incidentally when invited by the hospice team, and the group meets fortnightly. This group runs by a different model, hospice care at home (HaHo), which incorporated the element of recurrent meetings from the PaTz-model as the second of four components<sup>144</sup>. The first component is a GP requested home visit to a patient from a hospice nurse consultant (HNC), who performs a multidimensional assessment, develops a care plan and provides specialist support to patients and relatives. The third and fourth component are telephone backup provided by the hospice and the assignment of one coordinator of care respectively<sup>144</sup>. As a lack of time is considered the most important barrier to participate in a regular PaTz-group<sup>140</sup>, the higher meeting frequency may explain the practical absence of GPs in this group. The deviant group composition and the application of the HaHo-model suggest that this group cannot be seen as a regular PaTz-group. Whether it is both desirable and feasible to diffuse this model throughout the country deserves further empirical study.

How specialist palliative care professionals fulfilled their role varied across the PaTz-groups. While the added value of their knowledge and expertise is clear<sup>29</sup>, incongruence between the specialist palliative care professional's style and the PaTz-group's needs and preference may cause friction and dissatisfaction. Finally, it is also worth noting that some PaTz-groups include other disciplines, like a spiritual caregiver, a volunteer in palliative care or a nurse specialist in mental health, but we could not determine whether this influenced the topics discussed.

## Reflections on the content of the meetings of the PaTz-groups

The number of patients on the register during follow-up varied greatly between PaTz-groups, ranging from 29 to 122. Although this variation may be due to differences in patient population, a more likely explanation is that different groups have different registration practice. Considering that in the three groups with highest number of patients, the patients also have the highest mean age, it could be that





some groups use the SQ to include all patients who they think might die in the coming year, including all elderly patients, while other groups only register patients who are certain to die due to advanced illness in the coming year. In general, GPs find the timely identification of palliative non-cancer patients particularly challenging <sup>145,146</sup>, and PaTz-groups appear to be no exception. As cancer was the cause of death in 30% of all deaths in the Netherlands in 2017 and 2018 <sup>147</sup>, the proportion of cancer patients among the registered and discussed patients is remarkably high, ranging from 36% up to a notable 100%. At the same time, it is worth noting that these patients were also more often identified closer to death. While this may be explained by the typical illness trajectories <sup>4</sup> of these patients, late identification leaves little room for anticipatory action <sup>148</sup>. In addition, as these results reflect the poor performance of the SQ in the identification of non-cancer patients reported in previous literature <sup>139</sup>, it might be worthwhile to investigate the performance of other identification tools like SPICT <sup>149</sup> or RADPAC <sup>150</sup> in this context.

Regarding the proportion of registered patients that are also discussed, we found that the hospice-centred group discussed 98% of their registered patients, which is inherent to the HaHo-method described earlier. In PaTz-groups this proportion ranges from 12 to 72%, influenced by both the groups' registration practice, as well as their differences in discussion practice, as is shown in table 2. While some groups seem to briefly touch upon all patients of interest and discuss on average nearly 8 patients in a single meeting, other groups seem to select a few patients per meeting to discuss more in-depth. It is also worth noting that one in four discussed patients was only discussed after death. While undoubtedly valuable and informative, this does not seem to match with one of the prime goals of PaTz, looking ahead and planning care in advance. The same applies to the topics of patient discussions which mostly concerned current affairs and rarely future situations. While the abundance of discussions of current situations probably benefits participants and possibly also future patients, it also shows that there is room for improvement regarding advance care planning.

Further, we saw that although problems and treatment options in the physical domain are the predominant subject, problems in the psychosocial and spiritual domain are also discussed. As previous research shows that patients' and carers' psychosocial and spiritual needs are frequently unmet in home-based palliative care <sup>37</sup>, this is an encouraging finding. At the same time, this does not necessarily imply additional and sufficient attention for these domains in every patient that needs it. We recommend examining the added value of discussing a patient in a PaTz-group on the psychological, existential and the social domain in future studies.



## Reflections on the variation between PaTz-groups

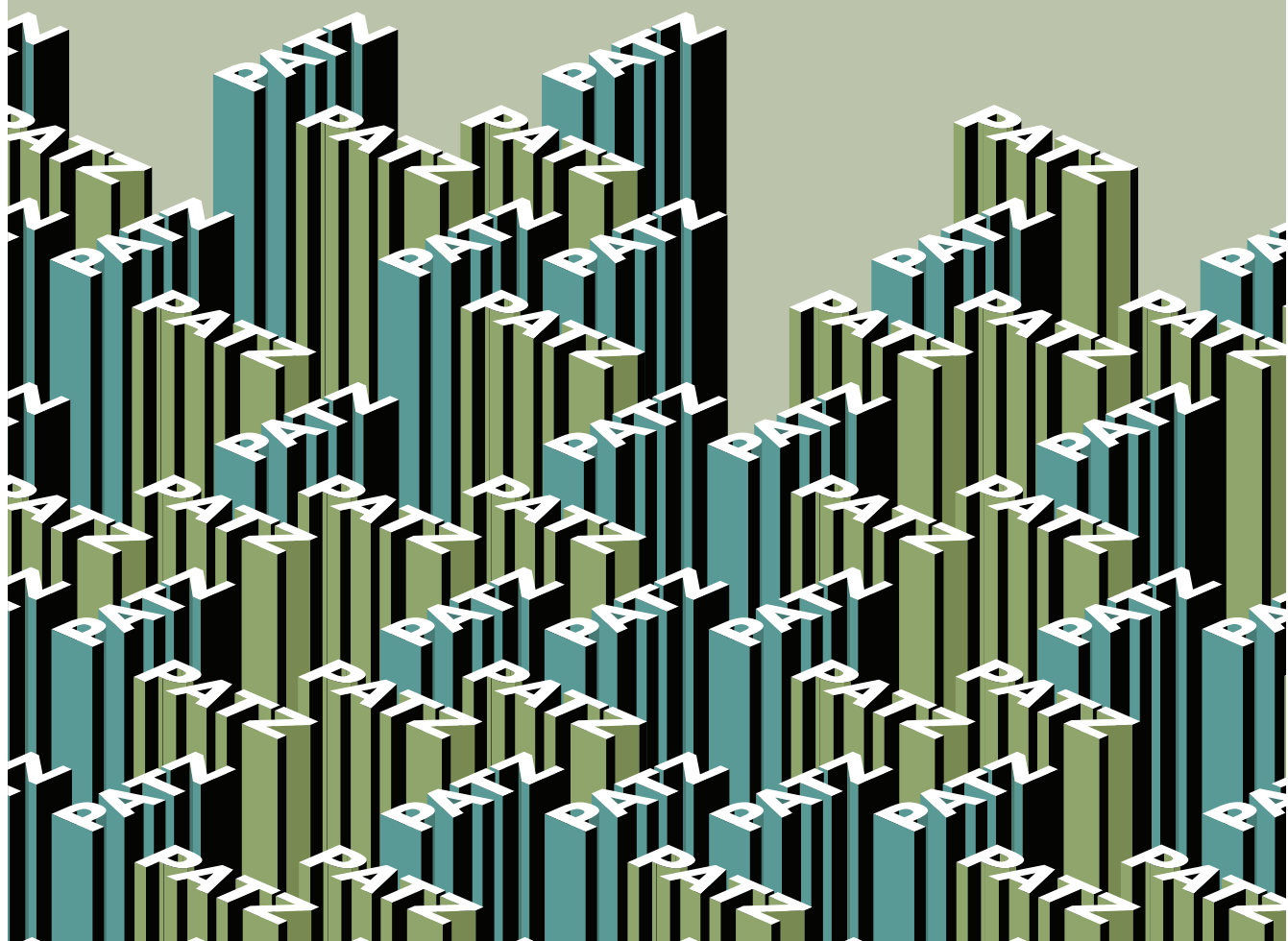
Overall, this study shows that, even though the basics are the same, the structure and content of PaTz-groups can be adapted to the preferences of the group members. As healthcare providers in all settings, including primary care, generally have a high workload and are pressed for time, multidisciplinary meetings like PaTz need to provide value. Tailoring the structure and content of the meetings to their needs and wishes is likely to increase the perceived added value, thus increasing its sustainability <sup>151</sup>. In addition, the apparent flexibility of PaTz-groups introduces opportunities to improve the performance of the PaTz-groups regarding palliative patient identification and advance care planning.

As mentioned earlier, the GSF was the basis for the PaTz-method in the Netherlands. The original GSF programme required general practices to identify and register patients with a life-threatening illness and discuss these patients in quarterly team meetings <sup>152</sup>. Reported shortcomings of this programme included a tendency 'to focus on mainly patients with cancer and most only in the final weeks or days of life' <sup>152</sup>. Although the latter does not seem to apply to PaTz-groups, we saw that similarly, in PaTz-groups the focus lies on patients with cancer, leaving patients with other diseases overlooked. Since the start, the GSF developed 'silver' and 'gold' levels of the programme, which involve considerably more training and tools, and require more time and commitment from its participants. These 'upgrades' are reported to result in an increase of registered patients both with and without cancer, more patient-focused care including advance care planning and improved active support for informal caregivers <sup>152</sup>. It may be worthwhile to investigate whether upgrading PaTz-groups in such a fashion is both feasible and beneficial for participants and patients.



## Conclusion

Although the foundation of all PaTz-groups is the same, there is considerable variation in practical implementation of PaTz-groups, regarding organization, number and types of patients on the register and discussed during meetings between PaTz-groups. While the basic principles are essential in the functioning of PaTz-groups, the variation between PaTz-groups is also important, as tailoring a PaTz-group to the needs of its participants is likely to enhance its sustainability. The flexibility of PaTz-groups also provides ample opportunity to modify the content and tools used, and improve identification of palliative patients and advance care planning.

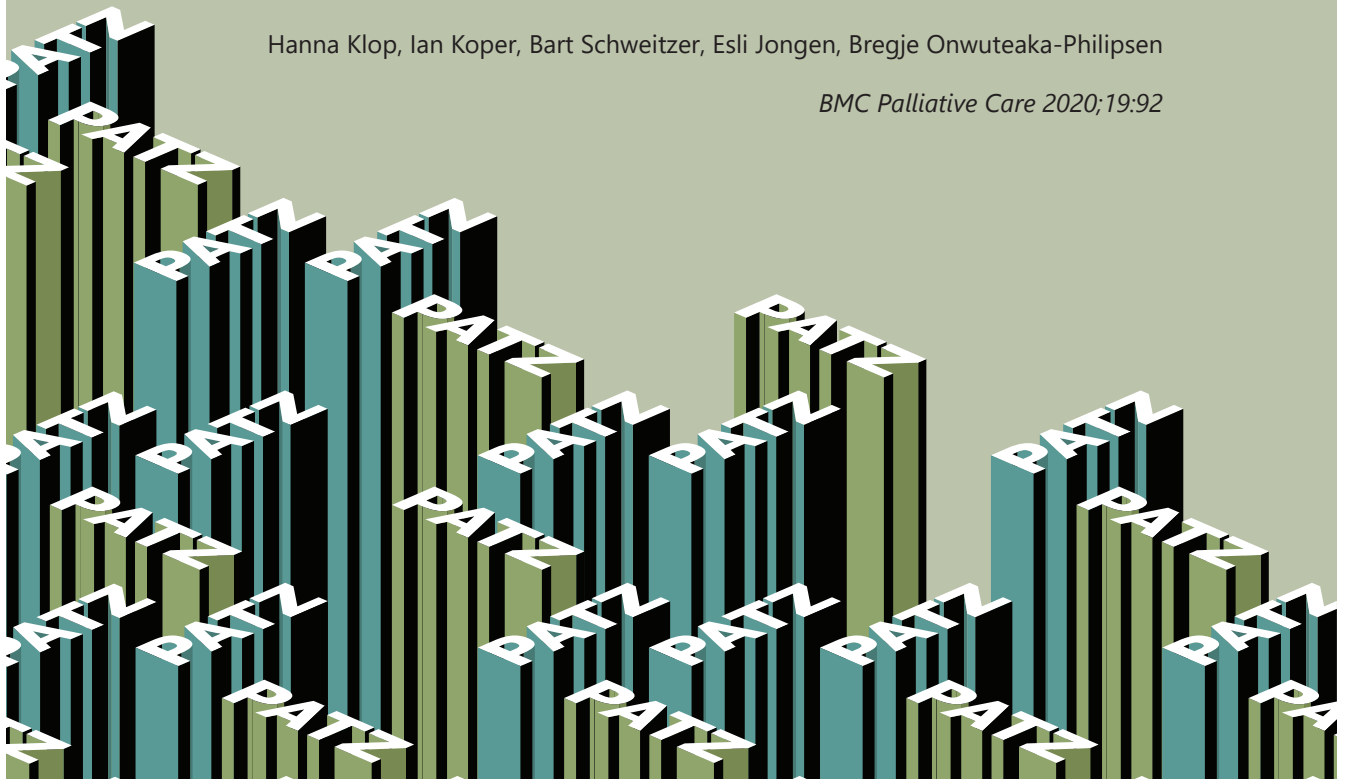


# Chapter 6

## **Strengthening the spiritual domain in primary palliative care through a listening consultation service: a pilot study**

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## Abstract

**Background:** Palliative care should be holistic, but spiritual issues are often overlooked. General practitioners and nurses working together in PaTz-groups (palliative home care groups) consider spiritual issues in palliative care to be relevant, but experience barriers in addressing spiritual issues and finding spiritual caregivers. This study evaluates the feasibility and added value of a listening consultation service by spiritual caregivers in primary palliative care.

**Methods:** From December 2018 until September 2019, we piloted a listening consultation service in which spiritual caregivers joined 3 PaTz-groups and members of these groups referred patients or their relatives with spiritual care needs to them. Evaluation occurred through several methods: (i) monitoring of the implementation, (ii) in-depth interviews were held with patients (n=5) and involved spiritual caregivers (n=5), (iii) short group interviews were held in 3 PaTz-groups (17 GPs, 10 nurses and 3 palliative consultants), and (iv) questionnaires were filled out after each referral by the GP and after each consultation by spiritual caregivers. Data was analysed thematically and descriptively.

**Results:** Consultations mostly took place on appointment at the patients home instead of originally intended walk-in consultation hours. Consultations were most often with relatives (72%), followed by patients and relatives together (17%) and patients (11%). Relatives also had more consecutive consultations (mean 4.1 compared to 2.2 for patients). Consultations were mainly on loss, grief and identity. Start-up of the referrals took more time and effort than expected. In time, several GPs of each PaTz-group referred patients to the spiritual caregiver. In general, consultations and joint PaTz-meetings were experienced as of added value. All patients and relatives as well as several GPs and nurses experienced more attention for and awareness of the spiritual domain. Patients and relatives particularly valued professional support of spiritual caregivers, as well as recognition of grief as an normal aspect of life.

**Conclusions:** If sufficient effort is given to implementation, listening consultation services can be a good method for PaTz-groups to find and cooperate with spiritual caregivers, as well as for integrating spiritual care in primary palliative care. This may strengthen care in the spiritual domain, especially for relatives who are mourning.

## Background

Spiritual care is an important part of holistic palliative care<sup>2</sup>. In the Dutch guideline on 'Spirituality and meaning in the last phase of life', spirituality is defined as "the dynamic dimension of human life that relates to the way persons experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred"<sup>153</sup>.

Insufficient attention for spiritual issues has been identified as one of the barriers in providing holistic palliative care in the Netherlands<sup>138,154</sup>. Palliative care is not a medical specialty in the Netherlands and it is preferably provided in the primary care setting, where it primarily falls under the responsibility of general practitioners (GPs) in close collaboration with district nurses. In respect of palliative care, Dutch GPs are encouraged to work together with district nurses and other health-care providers in local PaTz-groups (palliative home care groups)<sup>20</sup>. PaTz-groups meet at least six times per year under supervision of a palliative care consultant<sup>29</sup>. The goal of these meetings is to identify patients facing a life-threatening illness, e.g. by using the surprise question, and to discuss current and future care needs of these patients, and to arrange and plan care accordingly.

Although spiritual issues are considered relevant by Dutch GPs<sup>155</sup>, they often struggle to provide adequate spiritual care, due to lack of time or attention for spiritual issues, or insufficient expertise and training<sup>156</sup>. When a GP finds him- or herself unable to provide adequate spiritual care, for example in a case with complex spiritual needs or when crisis intervention is needed, they can theoretically refer their patient to a professional spiritual caregiver, a healthcare provider with specific expertise in the assessment of spiritual needs and the delivery of spiritual care<sup>105,153</sup>. In reality, only half of the Dutch GPs occasionally involve a spiritual caregiver. When asked what reasons they have to not refer patients to spiritual caregivers, GPs mention that it is 'not needed', 'not my job', or that they 'do not know where to find them'<sup>157</sup>. In addition, they experience barriers in finding and engaging spiritual caregivers<sup>155</sup>, and cooperation between spiritual caregivers and other healthcare providers has been reported to be poor<sup>156,158</sup>. Thus, in practice, although providing spiritual care as part of holistic palliative care in cooperation with spiritual caregivers is considered to be very relevant and essential, it is often neglected and problematic, a phenomenon which has also been reported in international literature<sup>16,80,159,160</sup>.

There is anecdotal evidence with regard to involving spiritual caregivers in palliative care in order to strengthen the spiritual domain of palliative care. In Scotland, a Chaplain Community service aimed at seriously ill patients, known as listening consultations, was perceived by patients, GPs and spiritual caregivers to be very beneficial. Activities of spiritual caregivers included therapeutic listening; being present; recognition of fear, loss and sadness; building trustful relationships in which difficult topics could be discussed; and helping patients to find hope, re-



silience or inner strength in times of illness, loss and death <sup>161</sup>. Knowing each other and each other's activities well proved to be pivotal for the cooperation between spiritual caregivers and other healthcare providers <sup>161</sup>.

In the Netherlands, the above-mentioned PaTz-groups may provide an opportunity for fruitful cooperation between healthcare providers and spiritual caregivers, potentially resulting in improved spiritual care in the primary care setting. With the Chaplain Community project serving as an example, the PaTz-foundation launched a pilot in which a listening consultation service by spiritual caregivers was connected to PaTz-groups in an effort to strengthen the spiritual domain in Dutch primary palliative care.

In this study, we aimed to evaluate the listening consultation service with regard to its feasibility and perceived added value for healthcare providers and patients. Our research questions were:

1. How did the process of implementation of a listening consultation service within PaTz-groups go, and what are barriers and facilitators for implementation?
2. What is the added value of a listening consultation service for healthcare providers and for patients?

## Methods

### Design

For a period of ten months, the listening consultation services ran in three PaTz-groups. Qualitative data for the evaluation of the listening consultation service was collected through questionnaires as well as individual and group interviews, supplemented with quantitative data on personal and consultation characteristics. A description of the intervention is shown in Figure 6.1. The consolidated criteria guidelines for reporting qualitative studies (COREQ) were followed for reporting on qualitative data (17).

### Recruitment for the intervention

PaTz-groups were recruited via the PaTz-foundation and via the Palliative Care Consortium in Noord-Holland and Flevoland. Chairmen of four interested PaTz-groups were provided with information during a meeting with the researcher and after consenting to participate in the pilot, the researcher visited a meeting of each PaTz-group in which the spiritual caregiver was introduced. In this meeting, the researcher provided all PaTz-group members with flyers which could be handed out to patients. As a result, three interested PaTz-groups participated in the pilot.

The listening consultation service consists of the following elements:

**1) Spiritual caregivers join PaTz-meetings**

In these meetings, spiritual caregivers provide general information on spirituality and spiritual care, and join patient discussions to raise awareness for the spiritual domain and identify potential spiritual care needs.

**2) Training of healthcare providers in recognizing spiritual issues.<sup>1</sup>**

During the PaTz-meetings, a spiritual caregiver trains healthcare providers of the PaTz-group to recognize spiritual issues, and clarify when to refer to a spiritual caregiver. In this training, several aspects are involved, such as discussing recent cases, provision of background information about theory, practice and relevance of spiritual care, and training skills in recognizing and discussing spiritual issues with patients. Training was developed by the participating spiritual caregivers and tailored to needs and availability of time of PaTz-groups.

**3) Spiritual caregivers provide consultations to patients with spiritual needs<sup>2</sup>**

The listening consultation service is aimed at patients and their relatives of GPs and district nurses who participate in PaTz-groups. After referral by another healthcare provider, spiritual caregivers can meet with patients for a listening consultation, providing spiritual care as needed. Activities of the spiritual caregiver in these consultations include therapeutic listening, being present, recognizing fear, loss and sadness, developing relationships based on trust, and helping people to regain hope, resilience and inner strength in times of illness, loss and death. Patients can make unlimited use of consultations with a spiritual caregiver. Consultations are free of charge for patients, as well as for referrers. Spiritual caregivers have approximately 50 minutes available for a consultation.

<sup>1</sup> This element proved necessary during the first three months of the pilot.

<sup>2</sup> The service was originally planned to be a walk-in consultation hour, but this was changed to home visits for practical reasons and according to the patients' preferences.

**Figure 6.1** Overview of the intervention: Listening consultation services

Spiritual caregivers were included through a collaboration with the 'Centre for Life Questions' (in Dutch: Centrum voor Levensvragen), who selected interested spiritual caregivers based on their availability and their fit to the patient population of involved general practices. In total, seven spiritual caregivers were recruited (two per PaTz-group, with one backup and one who was recruited after drop-out of another spiritual caregiver). Four of them had a humanistic denomination, one an Islamic denomination, one Christian and one Buddhist. All spiritual caregivers



were affiliated with the Dutch Association of Spiritual Caregivers (VGVZ) and were registered in the Quality Register of Spiritual Caregivers (SKVG). All spiritual caregivers had to be available during planned PaTz-meetings.

During the study, patients and relatives with spiritual care needs were asked by the participating GPs whether they were interested in receiving the listening consultation service, or informed by a flyer in the waiting room. If so, they were provided with information, and were asked for permission to be approached by the spiritual caregiver attached to the GP's practice. The spiritual caregiver then contacted the patient for a first introduction and schedule a meeting. Patients and relatives who received the listening consultation services could also involve their relatives. Consultation with patients or relatives were free of charge. For time spend on consultations and attendance at PaTz-groups, spiritual caregivers were reimbursed from the project budget.

## Data collection

Data was collected from December 2018 until September 2019. Several qualitative and quantitative data collection methods were used to collect data on the implementation process, the intervention and the perceived added value. Questionnaires with structured and open questions on characteristics and content of the consultation were filled out by spiritual caregivers after each consultation, which resulted in an overview of characteristics of users of consultations, and content of consultations. Additionally, at the end of the pilot study, questionnaires with structured and open questions on experiences with and added value of spiritual care were filled out by referrers for all patients and relatives who used the listening consultation service. For the qualitative part, all participants were recruited by opportunity sampling and informed by an information letter. Semi-structured in-depth interviews were held with spiritual caregivers (n=5) at the end of the pilot study or when they were not longer involved in the pilot study. In addition, semi-structured in-depth interviews were held with patients and relatives (n=5). They were recruited by the spiritual caregiver, who provided an information letter and asked if the patient was willing to participate in an interview on experiences with the consultation service. If the patient or relative was interested, the spiritual caregiver provided contact details to the researcher, who contacted and informed the patient by phone. With their consent, an appointment for the interview was made. Finally, short group interviews were held with PaTz-groups at the end of the pilot study (n=3, with 17 GPs and 10 nurses). All interviews were performed by one female researcher in palliative care (HK) who was trained in qualitative research, and were conducted at the participants' location of choice. Duration of interviews was between 20 and 60 minutes for patients, between 40 and 70 minutes for

**Table 6.1** *Characteristics of participants involved in data-collection*

Type of participant(s)	Type of data-collection method	Sex	Age range (years)	Conviction*/denomination**
Relative of deceased family member, patient of GP	Individual interview	F	50-55	None
Relative of deceased family member, patient of GP	Individual interview	F	55-60	None
Relative of deceased family member, patient of GP	Individual interview	F	20-25	None
Relative of (deceased)*** family member, patient of GP	Individual interview	M	75-80	Christian, other
Relative of deceased family member, patient of GP	Individual interview	F	60-65	Buddhist
Spiritual caregiver	Individual interview	F	60-65	Humanistic
Spiritual caregiver	Individual interview	M	35-40	Islamic
Spiritual caregiver	Individual interview	F	60-65	Humanistic
Spiritual caregiver	Individual interview	F	55-60	Buddhist
Spiritual caregiver	Individual interview	F	30-35	Humanistic
7 GPs, 5 district nurses, 1 palliative care consultant	Group interview	4M 9F	N/A	N/A
5 GPs, 5 district nurses, 1 nurse specialized in palliative care, palliative care consultant	Group interview	2M 10F	N/A	N/A
3 GPs, 4 district nurses, palliative care consultant	Group interview	8F	N/A	N/A

\* In case of patients / relatives who had one or more consultations with the spiritual caregivers

\*\* In case of spiritual caregivers

\*\*\* Family member deceased during the pilot period

spiritual caregivers and between 20 and 45 minutes for PaTz-groups. No participants refused to participate. All interviews were guided by semi-structured topic lists (Additional file 1), and audio recorded and transcribed verbatim. A weekly diary was used to monitor the implementation process in this pilot. The characteristics of all participants in the interviews are presented in Table 6.1.

## Data analysis

After answers to open questions were categorized by one researcher (IK) and checked by a second (HK), descriptive analyses took place for quantitative data using SPSS 26.0. Qualitative data of the semi-structured interviews with spiritual caregivers, patients and relatives, and health care professionals in PaTz-groups, were analysed following the principles of thematic analysis <sup>162</sup>. After rereading

transcripts, one researcher (HK) derived codes inductively from the data using Atlas.ti 8, which was checked by a second researcher (IK). Then, codes were grouped into themes and all themes were discussed in the research team, until no new themes occurred (HK, IK, BO).

## Ethics

Patients, spiritual caregivers and healthcare providers who participated in the interviews gave written informed consent prior to the interview. Patients who participated in the interviews received a gift voucher for their participation. To ensure anonymity of participants, any personal identifying information was removed from the transcripts. Access to the data was limited to three researchers (HK, IK, BO).

## Results

First, characteristics of the implementation process of listening consultation services including involvement of a spiritual caregiver to PaTz-groups and experienced facilitators and barriers are described. Second, the perceived added value and experiences regarding the listening consultation services and involvement of spiritual caregivers to PaTz-groups, are provided.



### Implementation of the intervention

Spiritual caregivers attended eleven of fourteen possible PaTz-meetings during the pilot period. They were involved in patient discussions, asked questions concerning spiritual issues to the present GPs and nurses, and answered their questions. The time investment and effort required from spiritual caregivers turned out to be more than expected, due to the time-intensive start-up of referrals. The combination of collaboration between GPs, nurses and spiritual caregivers in PaTz-groups, and possibilities of referring to a spiritual caregivers proved to lead hardly to referrals. For GPs and nurses, recognition of spiritual issues appeared to be a barrier in this. Therefore, all spiritual caregivers provided PaTz-groups with at least one training in recognizing and discussing spiritual issues in patients, as well as referring to spiritual caregivers. Besides, activities such as (preparation for) training and meetings with other spiritual caregivers and the researcher needed time and effort in the beginning phase of the pilot.

## Process of referrals

From the start of the pilot, the number of consultations started slowly and became more frequent during the pilot period. Consultations had been offered to both patients and relatives, however, it was found that relatives in particular made use of the possibility of consultations. Referral was not only made by GPs, but also by relatives who used or had used consultations. Training proved to increase the number of referrals over time.

## Characteristics of consultations

A total of 46 consultations were held with 19 individuals (patients with a life-threatening illness and their relatives) with an mean age of 73. The majority was female (15/19), had no specific religious beliefs (8/19) or a Christian belief (4/19), were of Dutch descent (18/19) and were referred by their GP (13/19) or a family member (6/19). Nurses did not refer at all. They did not indicate a clear reason for this, except that they thought the patient had sufficient resources for spiritual care. The listening consultation service was used in particular by relatives (13/19) of terminal or deceased patients. Although the initial idea was to organize walk-in consultation hours in general practice, this turned out not to be feasible; home visits proved to be the preferred alternative. Mainly one-to-one consultations were held (33/46), but group consultations with several relatives (7/46) or relatives and patients (6/46) were also held in varying compositions. Relatives used more consecutive consultations ( $M=3.6$ ) than patients ( $M=1.8$ ). Most care requests contained existential (32/46) or relational (24/46) components. The most often discussed topics were loss, grief and identity. Table 6.2 provides an overview of characteristics of participants who had consultations with the spiritual caregivers. A practical example of a consultation of spiritual caregivers by a patient is provided in Figure 6.2.

**Table 6.2** Characteristics of participants who had consultations with spiritual caregivers

	n/N	Mean (range)
<b>Total unique users</b>		
Patients	6/19	
Relatives	13/19	
<b>Sex</b>		
Female	15/19	
Male	4/19	
<b>Conviction</b>		
None	8/19	
Christian	4/19	
Other	3/19	
Unknown	4/19	
<b>Nationality</b>		
Dutch	18/19	
Surinamese	1/19	
<b>Referred by</b>		
GP	13/19	
Relative (already involved)	6/19	
<b>Total unique consultations</b>		
First consultation	14/46	
Follow-up consultation	32/46	
<b>One-to-one consultations</b>		
Patients at the end of life	5/33	
Relatives	28/33	
<b>Group consultations</b>		
Patient and relative	6/13	
Multiple relatives	7/13	
<b>Consultations per user</b>		<b>3.1 (1-10)</b>
Per patient		1.8 (1-3)
Per relative		3.6 (1-10)
<b>Lengths of consultations (minutes)</b>		<b>69 (15-150)</b>
One-to-one consultations (minutes)		62 (15-100)
Group consults (minutes)		89 (45-150)
<b>Care request*</b>		
Existential	32/46	
Relational	24/46	
Psychological	12/46	
Religious	3/46	

Table 6.2 Continued

	n/N	Mean (range)
<b>Discussed topics**</b>		
Grief	33/46	
Loss	30/46	
Identity	24/46	
Death / passing away	22/46	
Support	21/46	
Meaning	19/46	
Fear	18/46	
Finding strength	18/46	
Hope	11/46	
Other / diverse	33/46	

\* Participants could have more than one care request

\*\* Spiritual caregivers could report more than one discussed topic

A 68-year-old man visited his GP after his wife died. His parents died five years before. He had been an informal caregiver for his wife for several years, and he had also been an informal caregiver for his parents for 15 years. Since the death of his wife, the man had strong social fears and he struggled with the loss of his loved ones and the meaning of life. The GP noticed that the patients' fears, worries and questions persisted and became stronger, and he discussed these with the patient during regular 10-minute consultations. The patient mentioned that he did not want to see a psychologist, but that he would like to delve deeper into topics such as memories, meaning, grief and sadness. The GP mentioned the free and non-binding listening consultation service, handing him a flyer with information and the patient agreed to try a consultation with the spiritual caregiver. The GP informed the spiritual caregiver that she could call this patient for an introduction and a first appointment, in which the patient indicated that he was not familiar with 'spiritual care' or 'meaning issues'. The spiritual caregiver explained that the conversation was about meaning, about what is valuable and the conversation quickly deepened. After four conversations, the spiritual caregiver and the patient together performed a farewell ritual for the loved ones of the patient. Afterwards, the patient indicated that he felt heard and seen by someone who gave him space to grief and who did not feel the need to label him with a diagnose. He felt that he progressed in his mourning, and experienced recognition for his loss and grief.

Figure 6.2 Practical example of a consultation of a spiritual caregiver by a patient.

## Facilitators for implementing spiritual care into palliative care in primary care

First, frequent contact between spiritual caregivers and healthcare providers, in terms of spiritual caregivers attending PaTz-groups regularly and providing feedback about consultations to the referrer, proved to be a facilitator for implementation. This resulted in health care providers more often thinking of spiritual issues and also referring patients more easily. Second, customization and flexibility in setting up listening consultation services and involvement of spiritual caregivers proved to be encouraging, e.g. consultations by home visits or a focus on relatives as a target group. This resulted in a service that was feasible and useful for those involved. Third, a project manager proved to be valuable when integration of spiritual care into already existing PaTz-groups took more time and effort than expected. Fourth, freedom of spiritual caregivers, e.g. consultations on appointment instead of a walk-in consultation hour or an unlimited number of consultations, was found to be a facilitator, as were the enthusiastic PaTz chairmen. Lastly, training given by spiritual caregivers on recognizing spiritual issues and discussing them with patients, proved to be facilitating for integrating spiritual issues in primary palliative care.

## Barriers for implementing listening consultation services

There were a few factors impeding the implementation and functioning of the listening consultation service. Spiritual caregivers mentioned that they struggled to get into contact with PaTz-groups and that the PaTz-groups did not meet as regularly as expected. The other healthcare providers mentioned the limited availability and occasional last-minute cancellations of spiritual caregivers as barriers for cooperation. Also, the terms 'spirituality' and 'spiritual care' turned out to be barriers, as this often proved to be associated with religion or to be difficult to concretize. Furthermore, GPs had some privacy concerns when referring a patient to a spiritual caregiver. Finally, the relatively short pilot period turned out to be a barrier, as spiritual caregivers and healthcare professionals needed more time to get to know and find each other. In addition, addressing and recognizing spiritual issues by GPs proved to increase over time.

## Added value of the listening consultation services

Experiences of healthcare professionals, patients and patients' relatives and spiritual caregivers, are illustrated by quotes in Table 6.3.

Table 6.3 Quotes illustrating the added value of the listening consultation service

Theme	Quote
Added value for healthcare providers	<i>"R1: The fact that she [spiritual caregiver] is involved in PaTz-groups, means that you think of it as well, you see someone, and then you think of consultations, and of a different perspective, or of some extra possibilities. R2: R2: Because here [PaTz-group meeting] you sometimes can get stuck in the medical issues. Or when you have issues with providing care to a patient or whatever, and then you can say: maybe it's an idea that..." (GPs in PaTz-group)</i>
Added value for patients or relatives	<i>"Well, it just seems a bit like a soft way to talk about loss, without having a label or something, I experienced that as very pleasant. Because sometimes I have discussed these issues with my friends or sometimes family when I felt sad at certain moments. Then they say that you should just take a pill. Sometimes I have received that advice. Or that I had to engage a psychologists. But I don't think I want that at all. That's not the point at all. Then you feel somewhat misunderstood. And then I'd rather talk to an expert about it." (Patients' relative, 50y)</i>
Added value for spiritual caregivers	<i>"Maintaining the part of communication with each other, that has had quite a lot of attention in such a start-up phase. (...) And then, I just think, that is worth the investment you know, if you can find each other well at the moments that matter. And if patients sometimes appreciate it if you give something back to the GP, yes, then you just work together on good, holistic patient care. So sometimes the investment is that it costs you extra time, but I think it is definitely worth it over time.." (Spiritual caregiver involved in pilot)</i>

## Experiences of healthcare professionals participating in PaTz-groups

Enthusiasm for and perceived value of the listening consultation services varied per healthcare professional. Most GPs and district nurses who participated in the PaTz-groups felt the listening consultation services' added value. Firstly, the additional expertise of spiritual caregiver provided them with a broader perspective on the patient or relative(s) which was often focused on (psycho)social and spiritual wellbeing of the patient. Secondly, healthcare professionals felt that the listening consultation services facilitated identification and discussion of spiritual issues with the patient, although addressing spiritual issues in daily practice remained difficult. Also, healthcare professionals mentioned that spiritual caregivers sometimes spoke a "different language". A small amount of GPs and district nurses did not experience added value of the listening consultation services, most often due to available alternatives, such as a centre for relief and support for people with cancer, a nurse specialist in mental health (POH-GGZ), or because of their own capacities on the field of spiritual care.



## Experiences of patients and relatives using the listening consultation services

Interviewed relatives who had one or more consultations with spiritual caregivers, experienced much added value from the conversations especially in the recognition of normal feelings in times of loss and the recognition of grief as a normal aspect of life. Also, they experienced added value when they were mourning, and they appreciated this low-threshold and free initiative of listening consultation services. In particular, the role of the spiritual caregiver as a “humane person” who provides professional support, was well-appreciated. In addition, interviewed PaTz-group members mentioned that their patients perceived the consultations as of added value in a similar way as relatives did.

## Experiences of spiritual caregivers who were involved in consultations and PaTz-groups

Spiritual caregivers experienced added value of the listening consultation service in the contribution to holistic palliative care and the possibility to integrate spiritual care as a professional discipline into palliative care. At the same time, spiritual caregivers experienced that they needed time to become familiar with the PaTz-group members and their professions, and that integrating spiritual care into palliative care took them more time and effort than expected. As a positive side effect of this intervention, some spiritual caregivers mentioned increased knowledge of possibilities for spiritual care among healthcare professionals, as well as increased reach of patients in palliative care.

## Discussion

### Summary of results

This study evaluated a pilot of a listening consultation service by spiritual caregivers in PaTz-groups. It showed that, although time-intensive and difficult at start, the intervention is feasible and has added value. After a period of gaining momentum, the listening consultation services resulted in more attention for spiritual issues of patients and relatives in particular, who both highly appreciated this. Healthcare providers in PaTz-groups, particularly GPs, were more aware of (addressing) spiritual issues that could be relevant for their patients. They also experienced added value in the complementary expertise of spiritual caregivers. Still,

the enthusiasm among GPs varied and nurses did not refer patients to spiritual caregivers at all. Involving spiritual caregivers in PaTz-groups seemed to be a good method to improve spiritual care in the primary care setting and cooperation between healthcare professionals and spiritual caregivers.

## Scarce evidence on integrating spiritual care in palliative care

Previous research has shown that healthcare professionals consider spiritual issues in palliative care to be relevant<sup>163,164</sup>, and that attention for spiritual issues positively affects the patients' relationship with their care provider, reduces discomfort, and increases quality of life<sup>163,165</sup>. This is, to our knowledge, the first intervention in which spiritual caregiver consultations of patients with a life-threatening illness and relatives, are combined with training of healthcare professionals in spiritual issues as well as enhanced collaboration between primary healthcare providers and spiritual caregivers. This study provides useful insights into the integration of spiritual care in primary palliative care, and into the added value of listening consultation services from the perspectives of patients and relatives, and all healthcare professionals that are involved.

Training as core element of integrating spiritual care into palliative care  
Several European studies have shown that spiritual caregivers can play an important role in the training of other healthcare providers to discuss spiritual issues in palliative care<sup>163</sup>. Training turned out to be an essential part of this intervention, especially in the ability of healthcare providers to recognize and address spiritual issues in patients. Despite the relatively small set-up of this pilot study, our results indicate that training combined with close collaboration and regular meetings between GPs, nurses and spiritual caregivers gradually resulted in more awareness of and skills in spiritual care. Our results with regard to training and education are in line with other studies, that showed some positive effects of training hospice staff and hospice volunteers<sup>106,166,167</sup>.

## Comparison to the Scottish Chaplain Community Listening services

Similar to the Scottish Chaplain Community Listening service<sup>161</sup>, our pilot study showed unfamiliarity of healthcare professionals with spiritual issues. Healthcare providers found it difficult to recognize and address spiritual issues of patients, and often associated spiritual issues with religious care, like in the Scottish example. Also similar to the Scottish example was that this intervention seemed a good alternative for psychotherapy or counselling when patients experienced mourning

and feelings of sadness due to (nearing) loss of a loved one. Both patients in the Scottish and Dutch situation appreciated this type of spiritual care particularly because of the non-judgmental and non-stigmatizing approach. This could be helpful for patients who do not want to be referred to other specialists or care providers. Lastly, similar to the Scottish situation, Dutch patients valued “safe space” by visits and availability of time of spiritual caregivers, as well as an unlimited number of consultations and no expectations, as positive. In addition, our study showed the benefits of a combined approach that consists of a spiritual caregiver using existing infrastructure in palliative care such as PaTz, and consultations with patients by the same spiritual caregiver. This combined approach enhanced close collaboration between healthcare providers and spiritual caregivers as well as competency and skills of especially GPs in providing holistic palliative care.

## Financial considerations

In this pilot, the time spiritual caregivers spent attending PaTz-meetings, training healthcare providers and in consultations with patients and relatives was funded from the projects budget, removing a potential hurdle for healthcare providers and patients to make use of the listening consultation service. Without funding, the accessibility of these services may be limited as people may not be willing or able to pay for these consultations. In 2018, a governmental budget for consultations with spiritual caregivers, training and activities to increase awareness of the (possibilities of) spiritual caregivers has been introduced for a period of two years<sup>105</sup>. Since 2019, this budget is managed by local networks of palliative care<sup>168</sup>. As a result, financing this care does not have to be a barrier to the deployment of spiritual care in the Netherlands. In other countries, if there is no financial arrangement for spiritual care, this could be a barrier.

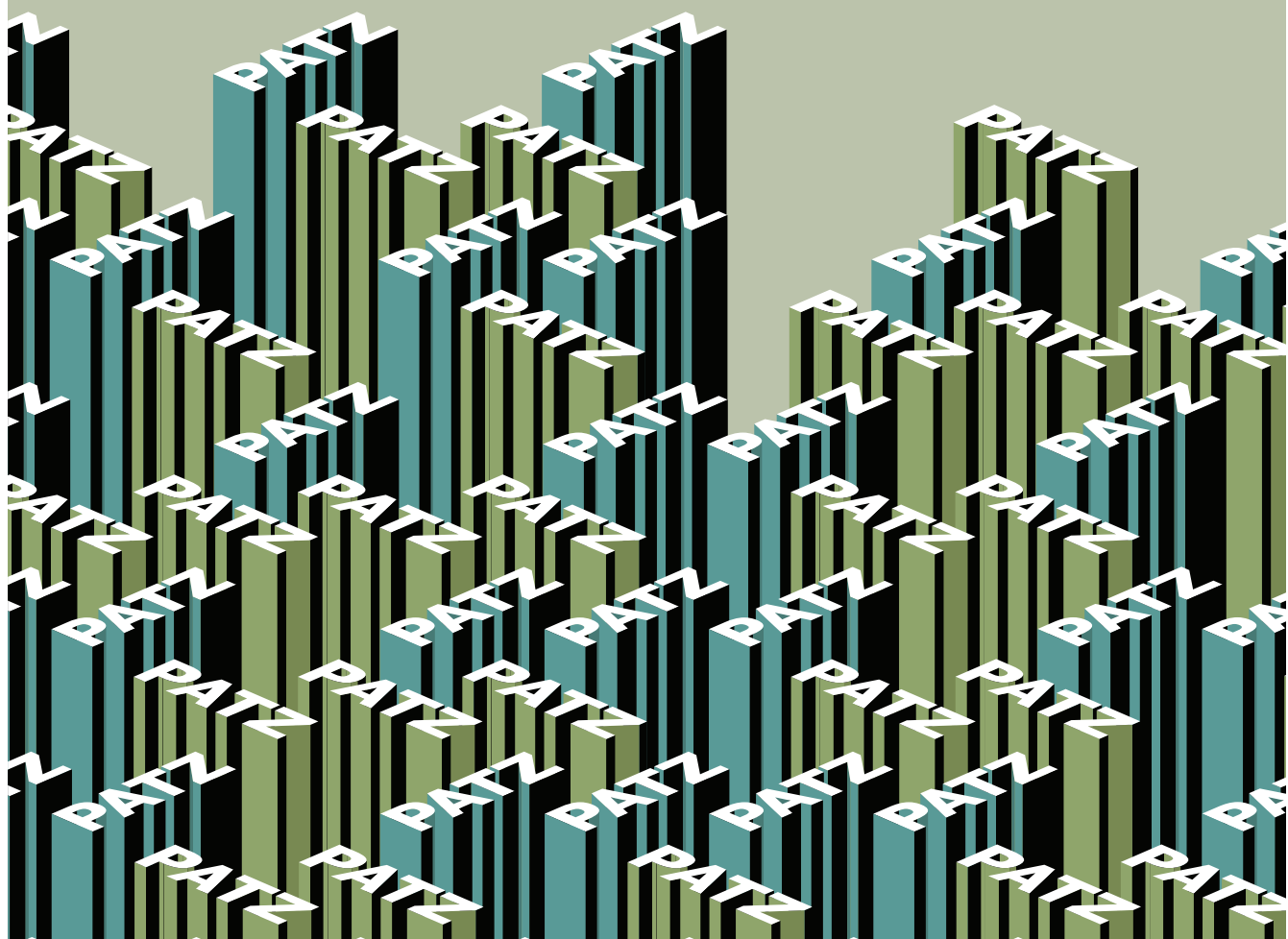
## Strengths and limitations

A strength of our study is that we were able to adapt the intervention to the needs of the participants, adding training for healthcare providers as well as home visits instead of a walk-in consultation hour. By these changes, this study offers insight into facilitators and barriers to the provision of holistic palliative care, which resulted in a list of practical recommendations before starting an intervention focused on the integration of spiritual care in palliative care (Additional file 2). The small scale of the pilot impacts the generalizability of the results. Although the listening consultation services seemed beneficial in the three participating PaTz-groups, this may be different in other PaTz-groups that may be less receptive

to spiritual care. More research is needed to understand large-scale provision of spiritual care in primary palliative care, also in a wider context such as other countries. Further, the district nurses in this study did not refer to spiritual caregivers, but we found no clear explanation for this. Also, this study used mainly qualitative or descriptive quantitative methods in order to monitor implementation and to evaluate added value. A more rigid, large scale method such as an RCT would be recommendable for the effect of this intervention over time. Further, while we know that patients and relatives who participated valued the consultations, we do not know why patients and patients' relatives with spiritual issues who did not use the consultations, did not participate. Finally, this study does not provide any insights into the relatively high use of consultations by relatives instead of patients. We recommend these issues for future research.

## Conclusion

If sufficient effort and time is given to implementation, the listening consultation service can be a good method for PaTz-groups to cooperate with spiritual caregivers, to receive training in spiritual care skills and to refer patients and relatives with spiritual needs to spiritual caregivers. Listening consultation services could also serve as a good method for integrating spiritual care in primary palliative care other contexts, such as multidisciplinary meetings between healthcare professionals in other countries or contexts.

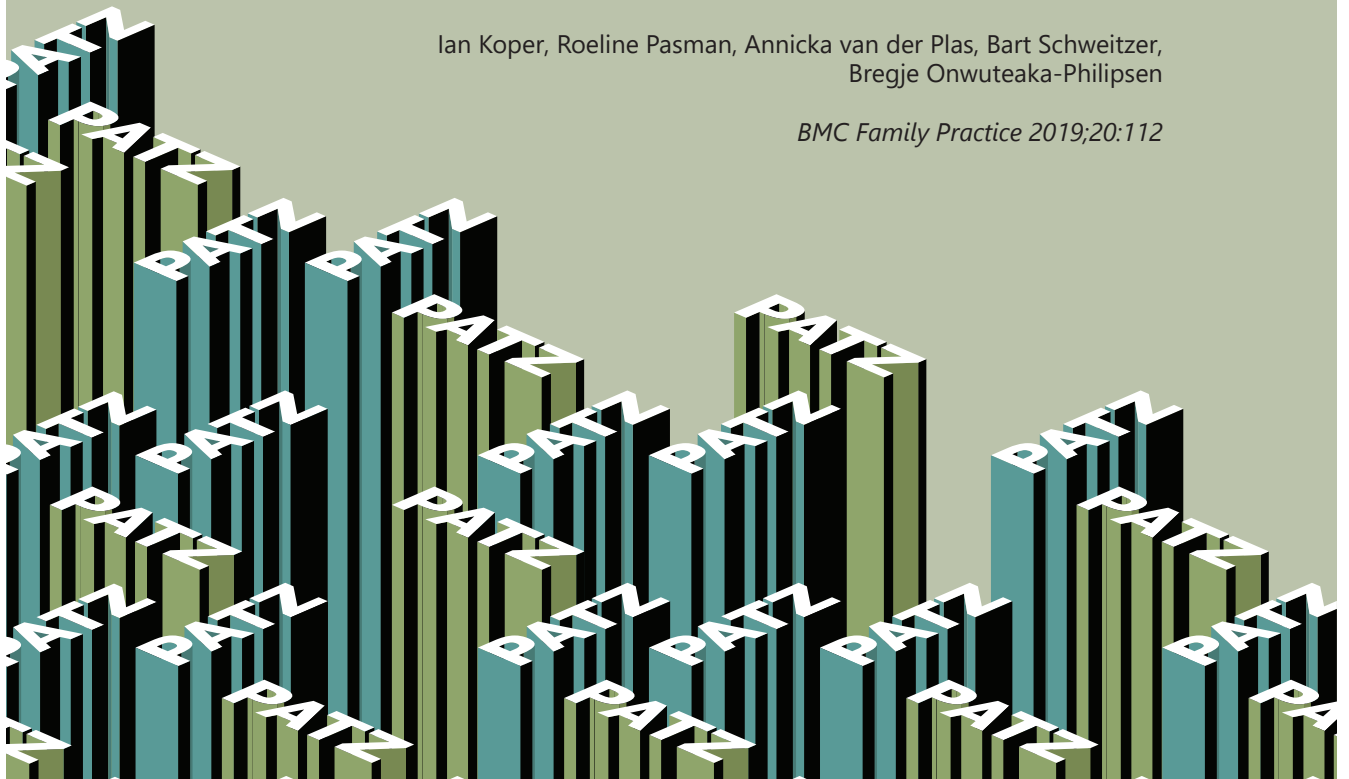


# Chapter 7

**The association between PaTz and improved palliative care in the primary care setting: a cross-sectional survey.**

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## Abstract

**Background:** The PaTz-method (acronym for Palliatieve Thuiszorg, palliative care at home) is perceived to improve coordination, continuity and communication in palliative care in the Netherlands. Although important for further implementation, research showing a clear effect of PaTz on patient-related outcomes is scarce. This study aimed to examine perceived barriers and added value of PaTz and its association with improved care outcomes.

**Methods:** 98 Dutch general practitioners and 229 Dutch district nurses filled out an online questionnaire with structured questions on added value and barrier perception of PaTz-participation, and palliative care provided to their most recently deceased patient, distributed online by Dutch medical and nurses' associations. Data from PaTz-participants and non-participants was compared using Chi-square tests, independent t-tests and logistic regression analyses.

**Results:** While both PaTz-participants and non-participants perceived PaTz to be beneficial for knowledge collaboration, coordination and continuity of care, time (or lack thereof) is considered the most important barrier for participation. PaTz-participation is associated with discussing five or more end-of-life topics with patients (OR = 3.16) and with another healthcare provider (OR = 2.55). PaTz-participation is also associated with discussing palliative sedation (OR = 3.85) and euthanasia (OR = 2.97) with another healthcare provider. Significant associations with other care outcomes were not found.

**Conclusions:** General practitioners and district nurses feel that participating in a PaTz-group has benefits, but perceive various barriers for participation. While participating in a PaTz-group is associated with improved communication between healthcare providers and with patients, the effect on patient outcomes remains unclear. To stimulate further implementation, future research should focus on the effect of PaTz on tangible care characteristics and how to facilitate participation and remove barriers.

## Introduction

Palliative care, an approach aimed to improve quality of life of patients with a life-threatening illness and their relatives, is complex, focusing on the prevention and relief of suffering from physical, psychosocial, and spiritual issues at the end of life.<sup>2</sup> Contrary to many other western countries like the US, Canada, the UK and Australia, palliative care is not a medical specialty in the Netherlands.<sup>69</sup> It is one of few countries where palliative care is provided in a coordinated care model<sup>18</sup> and national policy states that palliative care should principally be provided by generalists close to patients.<sup>31</sup> In practice, it is often provided by Dutch general practitioners (GPs, in some countries better known as family physicians), who can rely on national guidelines on palliative care provision,<sup>169</sup> and on supportive services and facilities such as palliative care consultation teams.<sup>100</sup> However, the ageing population and the increasing numbers of non-acute deaths are likely to lead to a higher demand of palliative care,<sup>136</sup> and as GPs are already facing a heavy case-load,<sup>134,135</sup> the provision of good palliative care may be under threat. Furthermore, while multidisciplinary collaboration has shown to be crucial in the delivery of palliative care,<sup>132</sup> this is hampered by financial constraints, poor communication and a lack of time.<sup>73</sup> In addition, while communication with patients with a life-threatening disease and relatives on end-of-life topics has consistently been shown to improve quality of care,<sup>5,6,133</sup> GPs struggle to have these conversations with their patients.<sup>170</sup>

In recent years, PaTz, a method aimed to improve palliative care through early identification of palliative patients, early assessment of their needs, symptoms and preferences, and planning care accordingly, has been implemented in the Netherlands. PaTz is an adaption of the British Gold Standards Framework (GSF), a programme aimed at optimising end of life care provision by generalists in all settings including primary care, which has been shown to improve multidisciplinary collaboration, and the consistency and reliability of palliative care in primary care.<sup>28</sup> In local PaTz-groups, GPs and district nurses (DNs, in some countries better known as community nurses) meet bimonthly to identify and discuss their patients with support from a palliative care consultant (a physician or nurse with formal training in palliative care).<sup>29</sup> A qualitative evaluation study showed that, like the GSF, PaTz is beneficial to healthcare providers: participants felt that it improved cooperation between GPs and DNs, and that it led to better continuity of care, more knowledge on palliative care, and emotional support.<sup>29</sup> A more recent pre-post evaluation study showed again that GPs felt that continuity and coordination of care as well as their own competence to provide palliative care improved after implementation of PaTz.<sup>30</sup>

Implementation of PaTz has progressed from four groups at the start in 2012 to more than 160 groups at present. But, as these groups cover only a small part of primary care, further implementation is necessary to improve palliative care in the home setting nationwide. Successful implementation requires understanding



of possible barriers for participation, the perceived added value of PaTz, and evidence of the effect on patient related outcomes.<sup>171</sup> However, again like the GSF,<sup>172</sup> research showing a clear effect on patient-related outcomes is scarce. The above-mentioned pre-post evaluation study also examined the effect of PaTz on aspects of care that are considered important in quality of palliative care: GPs' awareness of preferred place of death, hospital admission in the final month, treatment goals and GP-patient communication,<sup>31,173-177</sup> but failed to show differences between GPs who did or did not participate in a PaTz group.<sup>30</sup> As some differences were found between patients who were or were not on the PaTz-register or discussed in a PaTz meeting, the authors suggested this might be related to underuse of these important elements of PaTz. Further, they indicated the high level of palliative care before implementation among GPs interested in participating in PaTz might have been influential: a so-called 'ceiling effect'. The authors recommended therefore including a control group in future studies to be able to account for the latter.

Thus, in order to facilitate further implementation of PaTz, this study first aims to compare PaTz-participants' perceptions of the added value of PaTz and barriers for participating in PaTz with non-participants' perceptions. As the roles of GPs and DNs in PaTz-groups differ, and the added value and barriers for participation may be different for GPs and DNs,<sup>28,29</sup> this study aims to compare the perceptions of participants and non-participants separately for each professional group. Second, this study aims to examine the association between PaTz-participation and care outcomes, by comparing the care provided to patients of GPs and DNs participating in a PaTz-group with the care provided to patients of GPs and DNs who are not.

## Methods

### Design

This study is part of a larger project aiming to improve palliative care in the primary care setting. In this project an assessment of the needs and experiences of GPs and DNs with palliative care was performed through an online questionnaire, available online from 5 April 2016 until 5 August 2016. The results of this study were derived from this questionnaire.

### Study population

Potential respondents were invited by professional associations, the national organization of palliative care networks (Fibula) and regional care support networks (ROS) through a call in newsletters and on their websites. Participating profession-

al associations were the Dutch College of General Practitioners (NHG), the Advisory Board of General Practitioners on palliative care (PalHag) and the Dutch Nurses' Association (V&VN). Respondents were eligible for inclusion if they: 1) were working as a GP or DN in patient care in the Netherlands, 2) had experience with palliative care. In order to assess the representativeness of the sample respondents they were compared to national figures for GPs and DNs on sex, age and working full or part time. The first question participants were asked was whether or not they had cared for a patient with a life-threatening illness or age-related decline in the final phase of their life. If so, they were presented with the rest of the questionnaire. If not, they had no access to the questionnaire.

## Measures

For this study, a questionnaire on perceptions of PaTz, and patient and care characteristics was created in which questions from previous primary palliative care research<sup>30</sup> were used where possible.

*Respondent characteristics.* Respondent demographic information included profession, age, gender, employment, years of practice and training in palliative care. After a description of the PaTz-method, respondents were asked whether they participated in PaTz and if not, whether they had heard of the method before.

*Perceptions of added value of PaTz and barriers to participation.* Respondents were asked to indicate to what extent they thought PaTz contributes to four aspects of palliative care provision: (1) knowledge, (2) coordination, (3) continuity and (4) collaboration. Respondents were also asked to indicate to what extent they thought five particular aspects are barriers to participation in PaTz. These aspects were: (1) time, (2) financial aspects, (3) administration, (4) the desire to work alone, and (5) gathering a group of participants. For the purpose of analysis (ensuring sufficient observations in all categories), response options for both questions were: 'not at all', 'hardly', 'partly', 'greatly' and 'don't know'. The answers were dichotomized by transforming the first two response options into 'no', and 'partly' and 'greatly' into 'yes'. Missing data was treated as 'don't know'. The data from these questions was analysed separately for GPs and DNs.

*Patient and care characteristics.* Next, respondents were to report on patient characteristics of their most recently deceased patient, such as age, gender and primary diagnosis and care characteristics, such as hospitalisations in the final two weeks, involved healthcare providers and whether or not the patient died in their preferred place of death. In addition, respondents were asked to report on interdisciplinary communication and communication with the patient, by presenting eight end-of-life topics, for which the respondents were asked to indicate whether they had discussed them with the patient and/or with another healthcare provider. These eight topics

were: life expectancy, expected complications, (wishes regarding) hospital admissions, preferred place of death, (wishes regarding) palliative sedation, spiritual issues, treatment options, and (wishes regarding) euthanasia. GPs were asked if they had discussed the topics with a DNs, and vice versa. Again, missing data was treated as unknown.

## Statistical analyses

Chi-square tests and independent sample t-tests were used to compare demographic information between GPs and DNs who participated in PaTz, and GPs and DNs who did not. Chi-square tests were also used to compare perceptions on the added value of and barriers for participation in PaTz between these two groups. Logistic regression analyses were used to compare the characteristics of patients described by either group, as well as the topics discussed and other care characteristics. First, crude logistic regression analysis were performed with being a PaTz participant or not as independent variable and the difference care characteristics as dependent variable. In order to adjust for healthcare provider characteristics that differed between health care providers who did and did not participate in PaTz, we performed multivariable analyses in which these characteristics were added as independent variables. We present the results of these analyses as Odds Ratios with respective 95%-confidence intervals. All statistical analyses were performed using SPSS, IBM Statistics for Windows version 22.

## Results

### Sample characteristics.

The characteristics of the 327 respondents are shown in Table 7.1. The majority was female (86%), and their mean age was 47 years. Most worked part-time (77%), averaging 26 hours per week. The mean years in practice was 14 (13 for DNs and 17 for GPs), and 58% of the respondents had received training in palliative care. GPs participated in a PaTz-group more often than DNs (70% vs 28%), while 23% and 35% of the non-participating GPs and DNs had not heard of PaTz before. When comparing the characteristics between PaTz-participants and non-participants, the only significant difference was found in DNs' employment: DNs not participating in PaTz more often worked part-time. Nationwide, the mean age of GPs is 48 years, and 51% are women,<sup>50</sup> while the mean age of DNs is 45 years, and 92% are women.<sup>51</sup> Thus, compared with these national figures, our sample was of similar age while consisting of a high proportion of female GPs. While all respondents reported on the barriers and added value of PaTz, 98 were unwilling to report on their most recently deceased patient.

**Table 7.1** Characteristics of 327 Dutch respondents in the online questionnaire on PaTz-participation and palliative care

Characteristics*	Total N = 327	General practitioners (n=98)		District nurses (n=229)	
		PaTz N = 69 (70%)	No PaTz N = 29 (30%)	PaTz N = 64 (28%)	No PaTz N = 165 (72%)
Female gender, N (%)	280 (86%)	50 (73%)	17 (59%)	57 (91%)	156 (95%)
Age, (mean (SD))	47 (10.6)	50 (8.5)	47 (8.9)	46 (11.3)	46 (11.1)
Working part-time, N (%)	252 (77%)	51 (74%)	18 (62%)	37 (58%) <sup>1</sup>	146 (89%) <sup>1</sup>
Part-time hours per week, mean (SD)	26 (8.6)	31 (8.7)	30 (5.6)	24 (8.3)	24 (8.2)
Working experience, mean years (SD)	14 (10.4)	18 (8.9)	15 (10.0)	13 (8.9)	13 (11.1)
Training in palliative care, N (%)	190 (58%)	37 (54%)	14 (48%)	39 (61%)	100 (61%)

\* Missing data &lt; 5% for each variable.

<sup>1</sup> Statistically significant difference found for 'working part-time' in DNs between PaTz and No PaTz ( $p < 0.001$ )

## Perceptions of added value of PaTz and barriers to participation.

Table 7.2 provides GP and DN perceptions of added value of PaTz and barriers to participation in PaTz. The percentage of GPs and DNs perceiving added value of PaTz was relatively high for all four aspects of palliative care, ranging from an average of 85% for 'continuity' to 96% for 'knowledge' and 'collaboration'. Except for 'collaboration', no statistically significant differences between perceptions of added value of PaTz were found between GPs and DNs participating in PaTz and those who were not. Overall, 'time' was most often considered a barrier for participation (84%), whereas 'desire to work alone' was least often perceived to hinder participation (16%). When comparing perceptions of barriers between GPs, we found that non-participants more often perceived 'time' (100% vs 88%) and 'administration' (73% vs 50%) as a barrier for participation than their participating colleagues. For 'financial aspects', 'the desire to work alone' and 'finding a group' we found no statistically significant difference. When comparing perceptions of barriers for participation between DNs, we found that non-participating DNs perceived all aspects as barrier for participation more often than DNs who were.

**Table 7.2** Perceived added value of PaTz and perceived barriers for participation of 98 GPs and 229 DNs in the Netherlands

Aspect	Total	General practitioners		District nurses	
	N = 327 (yes (%))	PaTz N=69 (yes (%))	No PaTz N=29 (yes (%))	PaTz N=64 (yes (%))	No PaTz N=165 (yes (%))
<b>PaTz is of added value to*</b>					
Knowledge	310 (96)	63 (93)	28 (97)	62 (98)	157 (96)
Collaboration	303 (96)	66 (99) <sup>1</sup>	26 (90) <sup>1</sup>	63 (98)	148 (95)
Coordination	279 (88)	55 (83)	24 (83)	60 (94)	140 (89)
Continuity	270 (85)	51 (76)	18 (64)	57 (92)	144 (90)
<b>Barrier for participation<sup>#</sup></b>					
Time	258 (84)	59 (89)	29 (100)	38 (62) <sup>2</sup>	133 (87) <sup>2</sup>
Finding a group	179 (66)	31 (53)	19 (70)	28 (50) <sup>2</sup>	101 (78) <sup>2</sup>
Financial aspects	166 (62)	33 (51)	17 (68)	28 (50) <sup>3</sup>	88 (72) <sup>3</sup>
Administration	163 (60)	32 (50)	17 (71)	21 (36) <sup>2</sup>	93 (72) <sup>2</sup>
Desire to work alone	42 (16)	7 (11)	2 (8)	5 (9) <sup>4</sup>	28 (22) <sup>4</sup>

\* Missing data < 5% for all added values variables.

<sup>#</sup> Missing data for 'time' < 1%, for other barrier variables between 13% and 14%.

<sup>1</sup> Statistically significant difference found for 'collaboration' in GPs ( $p=0.046$ )

<sup>2</sup> Statistically significant difference found for 'time', 'finding a group', and 'administration' in DNs ( $p<0.001$ )

<sup>3</sup> Statistically significant difference found for 'financial aspects' in DNs ( $p=0.004$ )

<sup>4</sup> Statistically significant difference found for 'desire to work alone' ( $p=0.044$ )

## Characteristics of patients described by PaTz-participants and non-participants.

The characteristics of the described patients are shown in Table 7.3. The mean age at death was 70-72 years, and 53-55% was female. Most patients were diagnosed with cancer (62-70%), and the majority had been living at home (89-90%). We found no statistically significant differences between the patients described by GPs and DNs participating in PaTz and those who were not in the crude nor in the adjusted analysis.

**Table 7.3** Characteristics of patients described by 93 PaTz-participants and 142 non-PaTz-participants in the Netherlands

Characteristics*	Total (n=235)	PaTz (n=93)	No PaTz (n=142)	Crude OR <sup>‡</sup> (95% CI)	Adjusted OR <sup>‡</sup> (95%CI)
<b>Age at death (years)</b>					
65 or younger (ref)	71 (31%)	28 (31%)	43 (31%)	1	1
66-75	60 (26%)	29 (32%)	31 (22%)	1.44 (0.72 – 2.88)	1.12 (0.51 – 2.43)
76-85	60 (26%)	20 (22%)	40 (29%)	0.77 (0.38 – 1.57)	0.69 (0.31 – 1.53)
86 or older	40 (17%)	14 (15%)	26 (19%)	0.83 (0.37 – 1.85)	0.73 (0.29 – 1.85)
<b>Gender (% female)</b>	55%	53	55	0.92 (0.54 – 1.6)	0.76 (0.42 – 1.4)
<b>Diagnosis</b>					
Cancer (ref)	153 (65%)	65 (70%)	88 (62%)	1	1
Cardiovascular disease	4 (2%)	2 (2%)	2 (1%)	1.4 (0.19 – 9.9)	0.83 (0.07 – 10.3)
COPD	8 (3%)	3 (3%)	5 (4%)	0.81 (0.19 – 3.5)	1.3 (0.26 – 6.0)
Stroke	3 (1%)	0	3 (2%)	0	0
Dementia	2 (1%)	1 (1%)	1 (1%)	1.4 (0.08 – 22.1)	1.3 (0.06 – 30.5)
Frailty/age-related decline	10 (4%)	3 (3%)	7 (5%)	0.58 (0.14 – 2.3)	1.2 (0.27 – 5.3)
Multi-morbidity	53 (23%)	18 (19%)	35 (25%)	0.70 (0.36 – 1.3)	0.81 (0.39 – 1.7)
Other	2 (1%)	1 (1%)	1 (1%)	1.4 (0.08 – 22.1)	3.5 (0.21 – 58.3)
<b>Setting</b>					
Home (ref)	191 (90%)	75 (89%)	116 (90%)	1	1
Residential care home	12 (6%)	3 (4%)	9 (7%)	0.52 (0.14 – 2.0)	0.27 (0.06 – 1.2)
Hospice	10 (5%)	6 (7%)	4 (3%)	2.3 (0.63 – 8.5)	2.0 (0.48 – 8.4)

\* Missing data <2% for each variable

<sup>‡</sup> OR = Odds ratio

<sup>‡</sup> Adjusted for healthcare providers' profession (GP or DN) and employment (part-time or full-time)

## Characteristics of care provided by PaTz-participants and non-participants.

Table 7.4 provides an overview of the topics discussed and care characteristics of the patients as described by the respondents and their relationship to PaTz-participation. Logistic regression analyses were adjusted for healthcare providers' profession (GP or DN) and employment (part-time or full-time). While some GPs and DNs had discussed 0-1 (21-24%) and 2-4 of the topics (19-28%) with another

Table 7.4 Logistic regression analyses estimating the association between PaTz-participation and characteristics of palliative care provided by 235 Dutch healthcare providers

Care characteristics*	Total (n=235)	PaTz (n=93)	No PaTz (n=142)	Crude OR (95% CI)	Adjusted OR <sup>a</sup> (95% CI)
<b>Number of topics discussed with another healthcare provider</b>					
0-1 topics	63 (27%)	26 (28%)	37 (26%)	1	1
2-4 topics	78 (33%)	26 (28%)	52 (37%)	0.71 (0.26-1.42)	1.31 (0.57-2.99)
5-8 topics	94 (40%)	41 (44%)	53 (37%)	1.10 (0.58-2.10)	<b>2.55 (1.11-5.88)</b>
<b>Topics discussed with another healthcare provider</b>					
Life expectancy	150 (64%)	60 (65%)	90 (63%)	1.05 (0.61-1.81)	1.75 (0.91-3.37)
Expected complications	137 (58%)	57(61%)	80 (56%)	1.23 (0.72-2.09)	1.41 (0.75-2.63)
(Wishes regarding) palliative sedation	137 (58%)	57 (61%)	80 (56%)	1.23 (0.72-2.09)	<b>3.85 (1.71-8.66)</b>
(Wishes regarding) hospital admission	113 (48%)	46 (50%)	67 (47%)	1.10 (0.65-1.85)	1.60 (0.86-2.98)
Treatment options	107 (46%)	40 (43%)	67 (47%)	0.85 (0.50-1.43)	1.24 (0.66-2.30)
Preferred place of death	102 (43%)	43 (46%)	59 (42%)	1.21 (0.71-2.05)	1.70 (0.91-3.17)
(Wishes regarding) euthanasia	82 (35%)	37 (40%)	45 (32%)	1.42 (0.83-2.46)	<b>2.97 (1.48-5.97)</b>
Spiritual issues	45 (19%)	17 (18%)	28 (20%)	0.91 (0.47-1.78)	1.41 (0.66-3.01)
<b>Number of topics discussed with patient</b>					
0-1 topics	28 (12%)	5 (5%)	23 (16%)	1	1
2-4 topics	31 (13%)	10 (11%)	21 (15%)	2.19 (0.64-7.46)	2.95 (0.77-11.3)
5-8 topics	176 (75%)	78 (84%)	98 (69%)	<b>3.66 (1.33-10.1)</b>	<b>3.16 (1.04-9.64)</b>

Table 7.4 Continued

Care characteristics*	Total (n=235)	PaTz (n=93)	No PaTz (n=142)	Crude OR (95% CI)	Adjusted OR* (95% CI)
<b>Topics discussed with patient</b>					
Life expectancy	191 (81%)	79 (85%)	112 (79%)	1.51 (0.75-3.03)	1.21 (0.56-2.63)
Expected complications	161 (69%)	71 (76%)	90 (63%)	<b>1.87 (1.04-3.36)</b>	1.60 (0.84-3.07)
(Wishes regarding) hospital admission	185 (79%)	82 (88%)	103 (73%)	<b>2.82 (1.36-5.85)</b>	1.68 (0.75-3.74)
Preferred place of death	185 (79%)	80 (86%)	105 (74%)	<b>2.17 (1.08-4.35)</b>	2.05 (0.95-4.41)
(Wishes regarding) palliative sedation	168 (72%)	75 (81%)	93 (66%)	<b>2.20 (1.18-4.08)</b>	1.70 (0.86-3.36)
Spiritual issues	155 (66%)	62 (67%)	93 (66%)	1.05 (0.61-1.83)	1.17 (0.63-2.18)
Treatment options	164 (70%)	72 (77%)	92 (65%)	<b>1.86 (1.03-3.38)</b>	1.24 (0.64-2.43)
(Wishes regarding) euthanasia	144 (61%)	68 (73%)	76 (54%)	<b>2.36 (1.34-4.16)</b>	1.56 (0.83-2.94)
<b>Healthcare provider expecting the patient's death</b>					
More than 6 months in advance (ref)	52 (22%)	23 (25%)	29 (21%)	1	1
3-6 months in advance	68 (29%)	29 (31%)	39 (28%)	0.94 (0.45-1.94)	1.19 (0.51-2.74)
1-2 months in advance	41 (18%)	14 (15%)	27 (19%)	0.65 (0.28-1.52)	0.83 (0.31-2.17)
In the final month	45 (19%)	17 (18%)	28 (20%)	0.77 (0.34-1.73)	1.63 (0.64-4.13)
In the final week	27 (12%)	10 (11%)	17 (12%)	0.74 (0.29-1.93)	1.53 (0.52-4.51)
<b>Hospital admission in the final two weeks</b>	<b>45 (19%)</b>	20 (22%)	25 (18%)	1.26 (0.65-2.43)	1.60 (0.77-3.35)
<b>Preferred place of death known</b>	<b>226 (96%)</b>	89 (96%)	137 (96%)	1.30 (0.23-7.24)	0.95 (0.15-5.93)
Died at preferred place of death	219 (93%)	85 (91%)	134 (94%)	0.48 (0.10-2.18)	0.76 (0.15-3.95)



Table 7.4 Continued

Care characteristics*	Total (n=235)	Pa Tz (n=93)	No Pa Tz (n=142)	Crude OR (95% CI)	Adjusted OR# (95% CI)
Place of death					
Home (ref)	175 (75%)	72 (78%)	103 (74%)	1	1
Residential care home	18 (8%)	5 (5%)	13 (9%)	0.55 (0.19–1.61)	0.59 (0.18–1.93)
Hospice	27 (12%)	10 (11%)	17 (12%)	0.84 (0.36–1.94)	0.76 (0.30–1.93)
Hospital	8 (3%)	4 (4%)	4 (3%)	1.43 (0.35–5.91)	0.88 (0.18–4.26)
Other/don't know	4 (2%)	1 (1%)	3 (2%)	0.48 (0.05–4.67)	0.33 (0.03–3.95)

\* Missing data <2% for all variables, #Adjusted for healthcare providers' profession (GP or DN) and employment (part-time or full-time)

er healthcare provider, a substantial part (37-44%) had discussed 5 or more of the presented topics with another healthcare provider. Logistic regression analysis showed that PaTz-participation was significantly associated with discussing 5 or more topics (OR = 2.55, 95% CI = 1.11 – 5.88). The same pattern applies to PaTz-participation and the number of topics discussed with the patient. While few GPs and DNs (5-16%) had discussed 0-1 of the topics, and a minority (11-15%) had discussed 2-4 topics, most GPs and DNs (69-84%) had discussed 5 or more topics with the patient. Again, logistic regression analysis showed a significant association between PaTz-participation and discussing 5 or more topics (OR = 3.16, 95% CI = 1.04 – 9.64). Regarding the relationship between PaTz-participation and the discussion of specific topics, logistic regression analysis showed that PaTz-participation was significantly associated with discussing ‘(wishes regarding) palliative sedation’ (OR = 3.85, 95% CI = 1.71 – 8.66) and ‘(wishes regarding) euthanasia’ (OR = 2.97, 95% CI = 1.48 – 5.97) with another healthcare provider. The significant associations between PaTz-participation and topics discussed with patients found in the crude analysis disappeared in the adjusted analysis, indicating that PaTz-participation was not associated with the discussion of particular topics with patients.

Considering the other care characteristics, no significant differences were found between PaTz-participants and non-participants. Around half (49-56%) of the GPs and DNs expected the patients’ death 3 months in advance or earlier while a minority (11-12%) did not expect the patient’s death until the final week. Further, almost all GPs and DNs (97-98%) were aware of their patient’s preferred place of death and the vast majority of patients (93-95%) died at their preferred place. Most patients (74%-78%) died at home, and even though one fifth (18-22%) patients was admitted to a hospital in the final two weeks, only a small minority (3-4%) died there. Logistic regression analysis showed no significant association between PaTz-participation and any of these care characteristics.



## Discussion

### Summary of findings

Respondents considered PaTz to be of value on all four prompted aspects: knowledge, coordination, continuity of care and collaboration. A lack of time was considered the most important barrier for participation in PaTz, but financial aspects, administrative burden and having to find a group to participate in were also perceived as barriers by the majority of respondents. While we found an association between participating in a PaTz-group and discussing more topics with another healthcare provider and with patients, we found no associations between PaTz-participation and other care characteristics.

## Strengths and limitations of this study

A strength of this study is that, contrary to prior evaluation studies, a control group was included. Still, even though the cross-sectional design of this study can demonstrate associations between PaTz and care outcomes, it is not suitable to demonstrate causality. Another limitation of this study lies in the recruitment strategy. While our recruitment strategy enabled GPs and DNs from all over the country to participate, it does not allow for response rates to be calculated. Also, as the care characteristics were self-reported by GPs and DNs, recall bias could play a role and the patient perspective is underexposed. Finally, it is possible GPs and DNs interested in palliative care are overrepresented in the sample. This could lead to an overly positive image of palliative care in the primary care setting, and an underestimation of the effect of PaTz.

## Comparison and reflection

A large majority of both participants and non-participants recognized the benefits of PaTz regarding knowledge, coordination, continuity and collaboration. PaTz-participants, particularly nurses, generally saw fewer barriers for participation, but regardless of participation or profession, it is clear that a lack of time is the most important one. It is possible that participating in a PaTz-group leads to reduced barrier perception, but it could also be the other way around: participation *requires* reduced barrier perception. However it may be, the reduced barrier participation and unchanging added value perception of PaTz-participants can be used in the promotion of PaTz. Still, further in-depth qualitative exploration of the benefits of PaTz, how to increase value and how to remove barriers for participation is recommended.

Further, the results showed that, like participating in the GSF,<sup>178</sup> PaTz-participation seems to be associated with improved communication with other health-care providers as PaTz-participants more often discussed 5 or more topics relevant to palliative care than non-participants. Similarly, as PaTz-participants more often discussed 5 or more topics with their patient, PaTz-participation seems to be associated with improved communication with the patients. As end-of-life communication between GPs and DNs and with patients is crucial to the delivery of adequate palliative care,<sup>5,6,72,179</sup> these are important findings.

Still, beside the number of topics discussed, we found no differences in care characteristics. A ceiling effect, as suggested by Van der Plas,<sup>30</sup> could be the cause, as the level of palliative care provided was generally high. Over two thirds of the respondents expected the patients' death more than a month in advance, providing time to plan and deliver effective end-of-life care.<sup>180</sup> Also, nearly all respondents

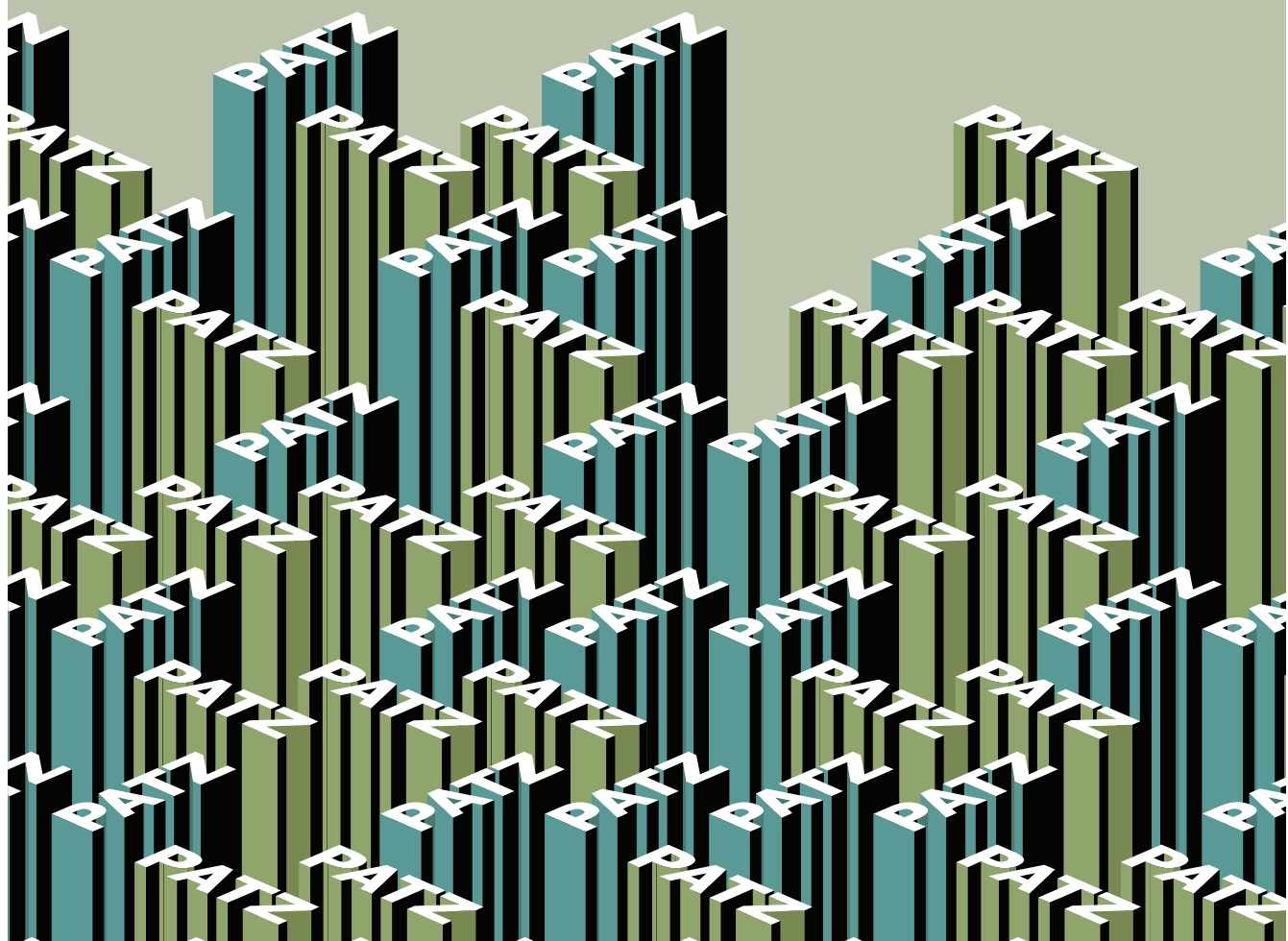
were aware of the preferred place of death of the patient (96%), even though the percentage of GPs and DNs that reported to have discussed the topic with the patient was somewhat lower at 74-86%. Finally, most patients died at their preferred place (93%). Despite being self-reported and the possibility of recall bias, these numbers are impressive compared to earlier studies, where the patients preferred place of death was known in 54-60% of the cases and approximately 80% died at their preferred place.<sup>119,126</sup> This high level of palliative care may not be representative for the general level of palliative care in primary care, and healthcare providers with less affinity for palliative care may benefit more from PaTz. It should also be mentioned that, for reasons unknown to us, 30% of the respondents did not report on their most recent case. Next to merely not wanting to spend more time on the questionnaire it is also possible that for some their most recent case concerned patients where the care was managed less than ideal. Further, it is possible that respondents who did provide patient and care details, reported on a recent patient whose care was managed well, rather than their actual most recent case.

Overall, while this study has shown a few promising associations, we recommend future research to focus on the effect of PaTz on tangible care outcomes in a design suitable to show causality, and on the perspective of patients and relatives on the care provided and how to facilitate participation and remove barriers in a qualitative manner.

## Conclusions and practical implications

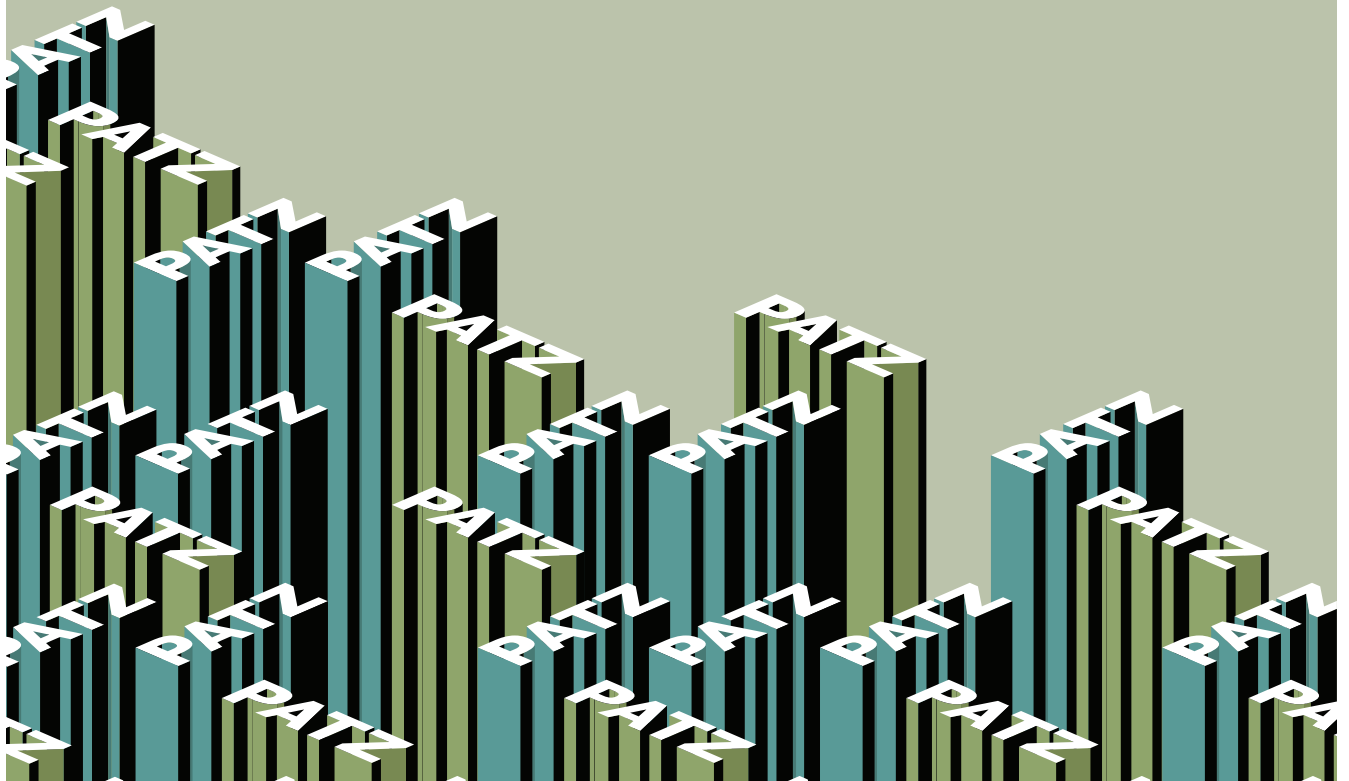
Confirming the previously reported perception of participants that PaTz improves communication in palliative care,<sup>29,30</sup> this article adds to the body of evidence of the value of PaTz in the primary care setting. As communication with other healthcare providers and with patients is key in palliative care,<sup>5,181</sup> participating in PaTz can aid healthcare providers in their task. Tailored to country-specific health care systems, this may also be the case in other countries where generalists are the primary palliative care providers, like Canada, Australia, Belgium, Italy and Spain.<sup>19,70,71</sup>

Our study also shows that further implementation of PaTz is barred by GPs' and DNs' perceived lack of time, and financial compensation and involves additional administrative red tape. Targeted promotion of PaTz by colleagues sharing success stories and positive experiences and firm evidence of its effects, could facilitate adoption of the method. In addition, as PaTz is more likely to benefit healthcare providers with less affinity with palliative care, implementation of PaTz in that particular group deserves extra attention.



# Chapter 8

## General discussion



This thesis about palliative care in the primary care setting had two main aims:

1. To explore potential areas for improvement in primary palliative care (Chapters 2, 3 and 4); and
2. To explore the role PaTz can play in these improvements (Chapters 5, 6 and 7).

After a brief summary of the findings from the previous chapters, this final chapter will discuss some methodological considerations. Next, it looks at some themes generated from the findings in the previous chapters and finally, it provides recommendations for practice, policy and future research.

## Summary of findings

### Potential areas for improvement in primary palliative care

The first part of this thesis examined room for improvement in primary palliative care from the perspective of professional caregivers. Cooperation between general practitioners and district nurses, who have a coordinating role in primary palliative care, and other healthcare providers is suboptimal. Chapter 2 showed that less use is made of psychological, social and spiritual services, suggesting that care is still overly focused on somatic issues. More familiarity regarding the availability and added value of services that can provide care in the other dimensions of palliative care could improve the quality of life for patients and relatives at the end of life. An example of such a service is a spiritual caregiver, a specialist healthcare provider who can be brought in when regular healthcare providers are out of their depth on spiritual issues. Chapter 3 showed that spiritual caregivers provide broad spiritual care at the end of life and discuss many different topics besides spiritual issues with patients in the palliative phase, supporting them when making medical end-of-life decisions. Spiritual care in the primary care setting may be improved by arranging better cooperation between spiritual caregivers and other healthcare providers, through improved education and better promotion of spiritual caregivers' services. A PaTz group may be a good place for familiarizing general practitioners and district nurses with additional healthcare providers (Chapter 3). Furthermore, another potential area of improvement was found in Chapter 4, which showed that early identification of patients who may benefit from palliative care is positively associated with communication and palliative care outcomes in primary palliative care. This chapter also showed that patients with a palliative treatment aim throughout the final three months of life had improved advance care planning and communication about end-of-life topics compared to patients without a palliative treatment aim. But to improve care outcomes in these patients, merely having a palliative treatment aim seems insufficient: the simultaneous absence of curative or life-prolonging treatment aims seems equally important.

## The role of PaTz in improving primary palliative care

The second part of the thesis examined the role of the PaTz method in improving palliative care in the primary care setting. Chapter 5 showed that the basic principles of PaTz (meeting at least six times a year, using the PaTz register and including a palliative care consultant) are the cornerstone of any PaTz group. Furthermore, it showed that PaTz groups are flexible and can be adjusted to fit the needs and preferences of its members. This flexibility offers opportunities to improve the performance of PaTz groups regarding patient identification and advance care planning, and it is also likely to help keep the groups going. In addition, the PaTz groups seem very well suited to facilitating multidisciplinary cooperation, as long as the members of the PaTz group have a positive attitude towards the other disciplines. Still, there are areas for improvement in the practice of PaTz groups. The results in Chapter 5 suggest that PaTz groups are primarily identifying cancer patients as patients in need of palliative care and they seem to struggle to identify patients with a different primary diagnosis. At the same time, when patients with a non-cancer diagnosis *were* identified as potentially in need of palliative care, this often occurred earlier in the process. Furthermore, Chapter 5 showed that when patients were discussed in a PaTz group, these discussions mostly concerned current matters and problems, and rarely concerned future situations. Additionally, one in four patients was discussed only after their death. These findings suggest room for improvement in advance care planning. Chapter 7 showed the results of a pilot in which spiritual caregivers joined PaTz groups to improve attention for the spiritual domain in palliative care. Although this listening consultation service required considerable effort and fine-tuning at the start, it turned out to be valuable for both the healthcare providers and the recipients of the spiritual care. Still, although Chapter 6 showed that PaTz participation is associated with improved communication with other healthcare providers and with patients, we have no direct quantitative evidence that PaTz participation improves palliative care. For instance, we found no associations between PaTz participation and reduced hospital admissions in the final two weeks, or an increased likelihood of dying in the preferred place of death. This may be due to a ceiling effect, but also due to methodological limitations of the design of the study, which be discussed below.



## Methodological considerations

The data for this thesis were derived from four studies: a mixed methods study on the needs and experiences of healthcare providers working in primary palliative care (Chapters 2, 3 and 6); the Sentinel study (Chapter 4); a prospective observational study on the practice of PaTz groups (Chapter 5); and the listening consulta-



tion study (Chapter 7). The strengths and limitations of these studies are discussed in the individual chapters, including a discussion of the suitability and generalizability of the different study designs. The discussions established that although the methods used were appropriate for the explorative aims of Chapters 2, 3, 5 and 7, they were less appropriate for Chapters 4 and 6, which aimed to estimate relationships between specific determinants and outcomes. Furthermore, the perspective of patients and relatives on primary palliative care is missing in this thesis. Here I will elaborate on these two limitations.

### **Cross-sectional studies are not suitable for demonstrating causal relationships**

All studies described in this dissertation have a cross-sectional design. Some of the general strengths of cross-sectional studies are that they are suitable for measuring many variables of interest, they can estimate associations between variables of interest, and there is no loss to follow-up. Additionally, specific strengths of the cross-sectional studies in this thesis include the fact that the mixed methods used in Chapters 2, 3, 5 and 7 provide a broad and in-depth perspective on the outcomes of interest. Another strength is the accessibility of the survey used in the mixed methods study (Chapters 2, 3 and 5). A major limitation of cross-sectional studies is that, although they can show associations, they are not suitable for establishing causal relationships. Both Chapter 4 and Chapter 6 estimate the relationship between a specific determinant and palliative care outcomes, including communication about end-of-life topics and advance care planning. For instance, the results in Chapter 4 show that having a palliative treatment aim in the final three months of life was associated with improved communication about end-of-life topics. But because of the limitations of cross-sectional studies, the direction of this association cannot be established: did these patients discuss end-of-life topics with their general practitioner because they had a palliative treatment aim, or did they have a palliative treatment aim because they discussed these end-of-life topics with their general practitioner? The associations found in these studies should thus be interpreted with caution.

### **Perspective of patients and relatives**

Palliative care focuses on quality of life at the end of life, which can be different for different people. Therefore, the perspective of patients and relatives is particularly relevant in palliative care. Still, conducting research with patients in the final phase of life can be controversial due to the perceived vulnerability of these patients and

their relatives, and the potential burden it can put on the participants.<sup>182</sup> This is known to lead to gatekeeping: healthcare providers restricting access to patients and relatives whom they perceive to be vulnerable.<sup>183</sup> Still, denying patients the opportunity to participate in research based on perceived vulnerability can be seen as paternalistic. Furthermore, while including patients and relatives in research may increase the validity of study results, it may also be of direct benefit to the participants.<sup>184</sup>

In this thesis, the perspective of patients and relatives is mostly absent, apart from in Chapter 7, where the added value of the listening consultation services was also examined from their perspective. This absence has several reasons. First, the relevance of the perspective of patients and relatives is not self-evident in all chapters. For instance, Chapter 2 covers the experiences of healthcare providers with palliative care services and facilities and how to improve cooperation with these services and facilities. Involving patients and relatives in this study would be unlikely to contribute to this particular research question. Second, in the studies where we did attempt to include the perspective of patients and relatives on palliative care, the response rates were underwhelming. In the mixed methods study (Chapters 2, 3 and 6), the inclusion of patients and relatives did not lead to a substantial amount of data. Only 11 patients and 16 relatives completed the online questionnaire, too few for a representative overview of the needs of Dutch patients and relatives in primary palliative care. Similarly, in the mortality follow-back part of the prospective observational study (Chapter 5) we tried to include the relatives' view on the care that was provided in the final three months of life, contacting the relatives through the general practitioner. Unfortunately, due to gatekeeping and possibly due the use of written questionnaires, only 13 questionnaires were returned, offering insufficient data for analysis. Third, in the context of research on the PaTz method, the recruitment of these patients comes with a major problem. An obvious way to examine the patients' perspective is to ask general practitioners who are involved in a PaTz group and GPs who do not participate in PaTz to recruit patients nearing the end of life and compare the views of these patients on the care provided in the final phase of their life. So in order to include patients in the research, healthcare providers must first identify these patients as potentially in the last year of their life. This identification process is an important element of the PaTz method: realizing that someone may need palliative care is the first step towards them actually receiving appropriate palliative care. Asking healthcare providers who do not participate in PaTz to identify and recruit their patients with palliative care needs for research would therefore potentially negate a major part of the PaTz method. Retrospectively asking relatives of deceased patients about the palliative care that was provided would prevent this contamination, but this is also problematic. Approaching relatives who have lost one of their loved ones is accompanied by the same ethical and gatekeeping problems as described above,



as we experienced in the prospective observational study. Furthermore, their views may not be a valid representation of the views of the deceased patient.<sup>185</sup>

Although the reasons for the absence of the patient's perspective are abundant, it is of course still regrettable. Quality of care and quality of life are very personal, and without the patient's perspective or relative's perspective, we can only measure these aspects using general standards and quality indicators, leaving the personal preferences of patients and relatives and the adaption of care to these preferences unclear. Continuing burdensome curative treatment until the very end may not be considered good palliative care according to general standards, but if it was precisely what the patient wanted, it may have been the right care in that specific case. In addition, in the chapters that examined quality of care, we were now completely reliant on the healthcare provider's perspective, which may be different from the patient's perspective. For example, in Chapter 4 and Chapter 6, healthcare providers reported whether or not certain end-of-life topics were discussed with the patient. Without the patient's perspective, it remains unclear whether or not the patient was open to discuss these topics in the first place and if they were, whether these topics were discussed sufficiently in their opinion.

## Reflections on the findings

### 1. Cooperation between healthcare providers in primary palliative care

Palliative care is pre-eminently multidisciplinary care, often intensive and multidimensional.<sup>2</sup> General practitioners and district nurses often work together in providing palliative care in the primary care setting. Because of the proliferation of home care organizations and high workload of general practitioners, good cooperation and communication between general practitioners and district nurses is not self-evident. In 2014, an evaluation study of the PaTz method showed that the method is successful in bringing together primary care teams. General practitioners and district nurses participating in PaTz groups experienced renewed cooperation, leading to informational and emotional support and improved continuity of care for patients with palliative care needs.<sup>29</sup> Annual reports on the functioning of PaTz groups show that the vast majority of general practitioners feel that the cooperation with district nurses has improved, and vice versa.<sup>58,186</sup> Even general practitioners and district nurses who are not currently in a PaTz group see the added value of PaTz regarding cooperation between healthcare providers (Chapter 6).

Regarding cooperation with specialized palliative care services, there are many services and facilities available that can aid general practitioners and district nurses in the provision of palliative care in the primary care setting. In their coordinat-

ing role, general practitioners seem perfectly able to find a palliative home care team, consult with palliative care consultation services or refer patients to a hospice when needed (Chapter 2). But services and facilities that deal with non-traditional aspects of palliative care, such as psychologists, spiritual caregivers and social welfare, are involved less often (Chapter 2). Other literature on the use of supportive care professionals showed similar results.<sup>19,25</sup> Spiritual caregivers report insufficient cooperation with general practitioners and other coordinating healthcare providers in the primary care setting, due to the lack of visibility of their profession and a lack of attention for spiritual issues in patients with a life-threatening illness (Chapter 3). Spiritual care in the primary care setting may be improved by arranging better cooperation between spiritual caregivers and other healthcare providers, through improved education in spiritual care and better promotion of spiritual caregivers' services (Chapter 3). Chapter 7 shows that with sufficient time and effort, adding healthcare providers from another discipline to a PaTz group, such as spiritual caregivers but possibly also psychologists or volunteers in palliative care, may be beneficial for healthcare providers and patients alike. Members of the PaTz group benefit from the expertise a different discipline brings to the table, while additionally gaining a broader perspective on the possibilities in primary palliative care.<sup>186</sup> Patients and relatives may benefit as they are more likely to receive multidisciplinary palliative care, tailored to their needs and wishes. In just over half of the existing PaTz groups (58%) healthcare professionals from another discipline attend the meetings, either as an integral part of the PaTz group (38%), or on invitation depending on the patients who are discussed (20%).<sup>186</sup> The professionals most commonly present at these meetings are coordinators of volunteers in palliative care, practice nurses and spiritual caregivers.<sup>186</sup> PaTz groups seem to be conducive to communication and continuity in primary palliative care. However, many patients with palliative care needs are still being treated in the secondary care setting while simultaneously seeing the general practitioner. It is widely acknowledged that communication between secondary care physicians and general practitioners needs improvement. Unless secondary care specialists are invited to PaTz groups on a regular basis, the PaTz method does not resolve these communication problems.

## 2. The timely identification of patients with palliative care needs can be improved

Early identification of patients who could benefit from palliative care is considered essential, as it provides time to assess the current and future needs and wishes of patients and their relatives, document these, and arrange care accordingly. International literature has shown that early palliative care provided by specialist pallia-

tive care teams in conjunction with regular treatment improves the quality of life in patients with a life-threatening illness and reduces unnecessary aggressive treatment, both in hospital<sup>110,112</sup> and in primary care settings.<sup>116,117</sup> Similarly, Chapter 4 of this thesis showed that in the Dutch primary care setting where palliative care is primarily provided by generalists rather than palliative care specialists, focusing on palliation in the final three months of life is positively associated with communication about end-of-life topics and palliative care outcomes. The Surprise Question<sup>10</sup> ('Would I be surprised if this patient died in the coming 12 months?') is a well-known tool to help healthcare providers identify patients with potential palliative care needs. PaTz groups are encouraged to apply the Surprise Question with their patient population, and to subsequently include the patients identified in this way in the palliative care register, which helps them to monitor the progression of their patients' illness and palliative care needs. In addition, the discussion of patients with palliative care needs in the PaTz groups may increase awareness among general practitioners, triggering them to identify similar patients in their practice as potentially in need of palliative care. However, this thesis showed that, in PaTz groups, identification of patients with palliative care needs is currently suboptimal (Chapter 5). Patients with palliative care needs are identified at rather a late stage, and patients with non-cancer diagnoses are overlooked. It seems that in some cases, patients are only identified when the need for palliative care becomes apparent. It could be that PaTz participants are not consistently using the Surprise Question to identify patients in need of palliative care, but its reported shortcomings regarding accuracy, particularly in the identification of non-cancer patients, could also play a role. Either way, PaTz groups apparently need help in the consistent and thorough identification of patients with palliative care needs. Recently, a study has been published introducing the Double Surprise Question, a tool in which a second question ('Would I be surprised if this patient is *still alive* after 12 months?') is added to the original SQ. Although the authors acknowledge that further research is needed, the study showed promising results regarding accuracy in the identification of patients with palliative care needs. In addition, alternative identification tools are available, like the Supportive and Palliative Care Indicators Tool (SPICT) and the RADboud indicators for Palliative Care needs (RADPAC)<sup>150</sup>, but their added value remains unclear. In a recent study comparing the performance of the SQ and the SPICT, the SPICT seemed to be better in identifying patients with palliative care needs.<sup>187</sup> But as only two GP practices participated in this study, the generalizability of the results is limited. A larger-scale study regarding the merits of the SPICT compared with the SQ could provide clarity.

### 3. The future of PaTz: quantity or quality?

Since the introduction of the PaTz method in 2010, the number of PaTz groups has grown remarkably, from four in 2010 and 80 in early 2016 to 232 at the start of 2020. A total of 1,876 general practitioners (approximately 15% of all Dutch general practitioners) and 1,084 district nurses participate in these 232 PaTz groups. Chapter 5 showed that there is considerable variation in the functioning of PaTz groups in practice, and that PaTz groups are easily adjusted to the needs and wishes of the participants. But not all is rosy, as Chapter 5 also showed that patients are identified at rather a late stage, the identification of non-cancer patients is poor and a considerable number of patients are discussed only after their death. While it is undoubtedly valuable to look back at the care trajectory of a patient after death, this is not in line with the goal of PaTz, which is to identify patients early, discuss potential scenarios and plan ahead. These issues raise questions about how further dissemination can be achieved, all the while ensuring consistent quality in the implementation of the PaTz method.

The added value of PaTz for healthcare providers is pretty clear: it improves communication and cooperation between healthcare providers, and improves expertise in palliative care. This alone could be enough to promote and endorse the PaTz method. But in order to engage its full potential, there should be an eye on quality as well. Through the application of its basic principles, PaTz has the potential to rise above conventional multidisciplinary meetings. As in such conventional meetings, the current and future issues of patients are discussed in PaTz meetings. But the PaTz-group offers more: the added value of PaTz lies in the early identification of patients, the multidisciplinary education through the presence of a palliative care consultant and the emotional support for the sometimes intensive and gruelling care. Losing track of these basic principles means losing added value. Without sufficient added value, the interest in PaTz groups could diminish and the momentum or goodwill that PaTz has at the moment might be lost. Of course, tailoring structural or process details to the needs and wishes of the participants should be stimulated, as long as it increases the durability and added value of the PaTz groups. If adaptations reduce the added value, the commitment of the participants will dwindle. In this respect, the focus of the PaTz foundation should be on quality rather than quantity, providing sufficient assistance and support to ensure that the basic principles are upheld in both new and current groups. The PaTz foundation should primarily focus on two aspects of the PaTz method: (i) improving the timely and thorough identification of patients in need of palliative care, because this is the cornerstone of the PaTz-method, essential for good palliative care and a clear area for improvement in PaTz groups (Chapters 3 and 4); and (ii) improving collaboration with other disciplines, because PaTz groups are a good place to start multidisciplinary collaboration, and participants see this as one of



the major strengths of the PaTz group (Chapters 6 and 7). Successful maintenance of the quality of PaTz groups is likely to induce further dissemination of the PaTz method through other channels. In the Quality Framework for Palliative Care<sup>20</sup>, PaTz groups are mentioned as the preferred method of cooperation in palliative care in the primary care setting, and healthcare providers with experience of the added value of PaTz may encourage other healthcare providers to start their own group. Such dissemination is however only desirable if quality maintenance is assured.

#### 4. Dutch policy on palliative care and the role of PaTz

In 2011, the Dutch Ministry of Public Health, Welfare and Sports released a policy brief that stated that palliative care should be available to all those who need it, and that it should principally be provided by primary care professionals. These professionals are supposed to have sufficient expertise to provide basic palliative care and can refer to specialist palliative care services and professionals if the care that is needed exceeds the expertise of primary care professionals. Furthermore, Dutch policy stimulates patients, including the frail and elderly, to live independently for as long as possible. Correspondingly, general practitioners consider the provision of palliative care to be one of their core tasks.<sup>188</sup> The Netherlands Quality Framework for Palliative Care mentions a number of core principles of palliative care. It states that effective communication, shared decision making and advance care planning are at the core of palliative care. The patient's multidimensional palliative care needs are assessed and potentially necessary care is planned proactively. The framework states that palliative care is interdisciplinary care, and the care provided must be either evidence-based or experience-based. Furthermore, it states that healthcare providers must be aware of the potential emotional impact of providing palliative care, reflect on their own actions and attitudes, and be mindful of their own emotional needs and those of other healthcare providers.

Looking at the direction of the Dutch policy and the core principles of palliative care mentioned in the Quality Framework, it seems that the PaTz method fits right in. PaTz is not a specialist palliative care service, it is a method to equip generalists with sufficient skills and expertise to provide good basic palliative care to patients who need it and provide them with a steady link with specialists in palliative care. The PaTz method, which involves primary care professionals and a palliative care consultant, improves communication among healthcare providers and between healthcare providers and patients (Chapter 6), and supports the assessment of multidimensional care needs (Chapter 5), while participants in PaTz groups feel they get both informational and emotional support from other group members.<sup>29</sup> Additionally, the group can be a place where palliative care generalists and spe-

cialists connect (Chapter 7). As stated above, PaTz groups are mentioned in the Quality Framework for Palliative Care as the preferred method of cooperation in palliative care in the primary care setting.<sup>20</sup> So given that Dutch policy is leading to an increase in numbers of home-dwelling patients requiring palliative care, and palliative care is mostly provided by generalists rather than specialists, PaTz has the potential to become the cornerstone of primary palliative care in the Netherlands.

## 5. Improving palliative care: evidence for the value of PaTz

Healthcare providers working with the PaTz method feel that it improved their interdisciplinary cooperation and knowledge of palliative care as well as communication with patients and continuity of care for their patients (Chapter 6). Participating in a PaTz group also seems to improve identification of patients with palliative care needs. Still, this thesis has not produced evidence of concrete causal effects of the PaTz method on palliative care outcomes. The gold standard for effect studies is, naturally, the randomized controlled trial (RCT): subjects are randomly allocated to either an intervention group or a control group and followed up over time, and clearly defined outcome measures are compared between the groups. The randomization, prospective nature and controlled environment of an RCT reduce bias to a minimum, and allow for effects to be interpreted as a causal relationship between determinant and outcomes. While RCTs in 'regular' healthcare research are challenging enough, RCTs in palliative care present additional issues, such as randomization issues, blinding, problems with determining the eligibility of patients, the heterogeneity of the patient group, or the mere complexity of palliative care and the intervention at hand. These issues may explain why reviews that examined the amount and content of palliative care research in several European countries show that RCTs in palliative care are very rare. Thus, RCTs testing complex interventions in palliative care are complicated, requiring meticulous design and tremendous effort, and in some cases an RCT is just not feasible. Regarding PaTz, an additional difficulty would be that the intervention, the PaTz method, does not intervene directly in the outcome measure, palliative care. In fact, there are several steps in between: PaTz aims to improve palliative care *through* improved communication, *through* early identification, *through* improved expertise, and *through* the discussion of current and future care needs. There are many factors at play that create noise in the relationship between PaTz and the outcome, complicating any study on the effect of PaTz even further.

There are studies, including those in this thesis, suggesting considerable benefits of PaTz for healthcare providers, and for the identification of and communication with patients. For healthcare providers already working with the PaTz method,





the benefits apparently weigh up against the investment in terms of time. Additionally, there are no conceivable disadvantages for patients and relatives. However, robust studies of the direct effect of PaTz on palliative care are problematic, if not unfeasible, and require a significant amount of time and resources. This time and these resources would be better spent on research on the further development, further implementation and quality maintenance of the PaTz method, so it can continue to aid generalists in the provision of adequate and appropriate palliative care.

## Recommendations for practice, policy and research

### Practice recommendations

Chapters 2 and 3 in the first part of this thesis showed that in Dutch primary palliative care, services and facilities that can aid primary care professionals in the provision of palliative care are currently rarely involved due to unfamiliarity and a lack of communication. Despite the increased attention for the spiritual dimension of palliative care, spiritual caregivers are rarely called upon in the primary care setting. Chapters 5 and 7 in the second part of this thesis showed that the PaTz method has the potential to improve this aspect of palliative care in the primary care setting. Primary care professionals should strive to work with the PaTz method, and include other disciplines in the PaTz group to improve familiarity and communication with those additional disciplines so they can be involved in the patients' care whenever necessary.

Furthermore, Chapter 4 suggested that patients with palliative treatment aims in the final three months of their lives had better care outcomes than patients who continued to aim for cure or life prolongation. To improve quality of care for all patients in the final phase of life, it is important to identify patients with palliative care needs as early as possible. As it has been suggested that the Surprise Question does not suffice as an identification tool for all patients with palliative care needs, it is recommended that a systematic method should be used to identify these patients. The combined use of International Classification of Primary Care (ICPC) codes and the SPICT tool may provide a solution. Most general practices in the Netherlands store their patient records electronically using special software, general practice information systems (GPIS). Parts of the SPICT can be translated into symptoms and diseases coded by the ICPC. With these codes, the GPIS can quickly and systematically be searched for patients who are potentially in need of palliative care.

Finally, palliative care starts with the diagnosis of a life-threatening illness<sup>3</sup>. So when a patient is diagnosed with a potentially life-threatening illness, speak early

and honestly about the treatment options, treatment outcomes, wishes, needs and expectations. Discuss the end of life, and set the course for palliative care as early as is appropriate (Chapter 4). A PaTz group can help to improve communication on end-of-life topics with patients and colleagues alike (Chapter 6).

## Policy recommendations

As mentioned above, PaTz is already mentioned as the preferred method for interdisciplinary cooperation and communication in the Quality Framework for Palliative Care<sup>20</sup>, and it has the potential to become the cornerstone for primary palliative care in the Netherlands. It should be considered more explicitly as such in Dutch policy, and all generalists who provide palliative care should be advised to join or start up a PaTz group. To facilitate this, healthcare providers should be compensated for the time they spend in the PaTz meetings. For PaTz groups in certain areas in the Netherlands, financial compensation has been arranged with individual health insurers (but only for general practitioners). This should be extended to all current and future PaTz groups in the country. To warrant these recommendations and the financial compensation, PaTz should function as the quality label for palliative care provision in the primary care setting. Although further dissemination of the PaTz method is also important in order for it to become the cornerstone of primary palliative care, the priority of the PaTz foundation should consequently be on quality rather than quantity.

Another point that can be made is that although generalists are expected to be able to provide basic palliative care, as of yet, palliative care is hardly covered in the curricula of Dutch medical education.<sup>189</sup> While providing education and training, and improving expertise are important aspects of PaTz, it is not meant to replace basic palliative care education. Adding palliative care to the curricula of the medical education of our future doctors and nurses is essential to equipping them with the proper skills and knowledge to provide quality palliative care.

## Research recommendations

Future research on the PaTz method should not focus on demonstrating its effect on palliative care at the patient level. As mentioned above in the methodological considerations, performing an RCT to demonstrate this is beset with too many difficulties. Rather, further research should focus on the effect of PaTz on the factors that facilitate good palliative care and on how to establish and maintain the quality of PaTz groups. Since 2017, all PaTz groups have been asked to participate in a yearly questionnaire, monitoring the composition and content of the PaTz

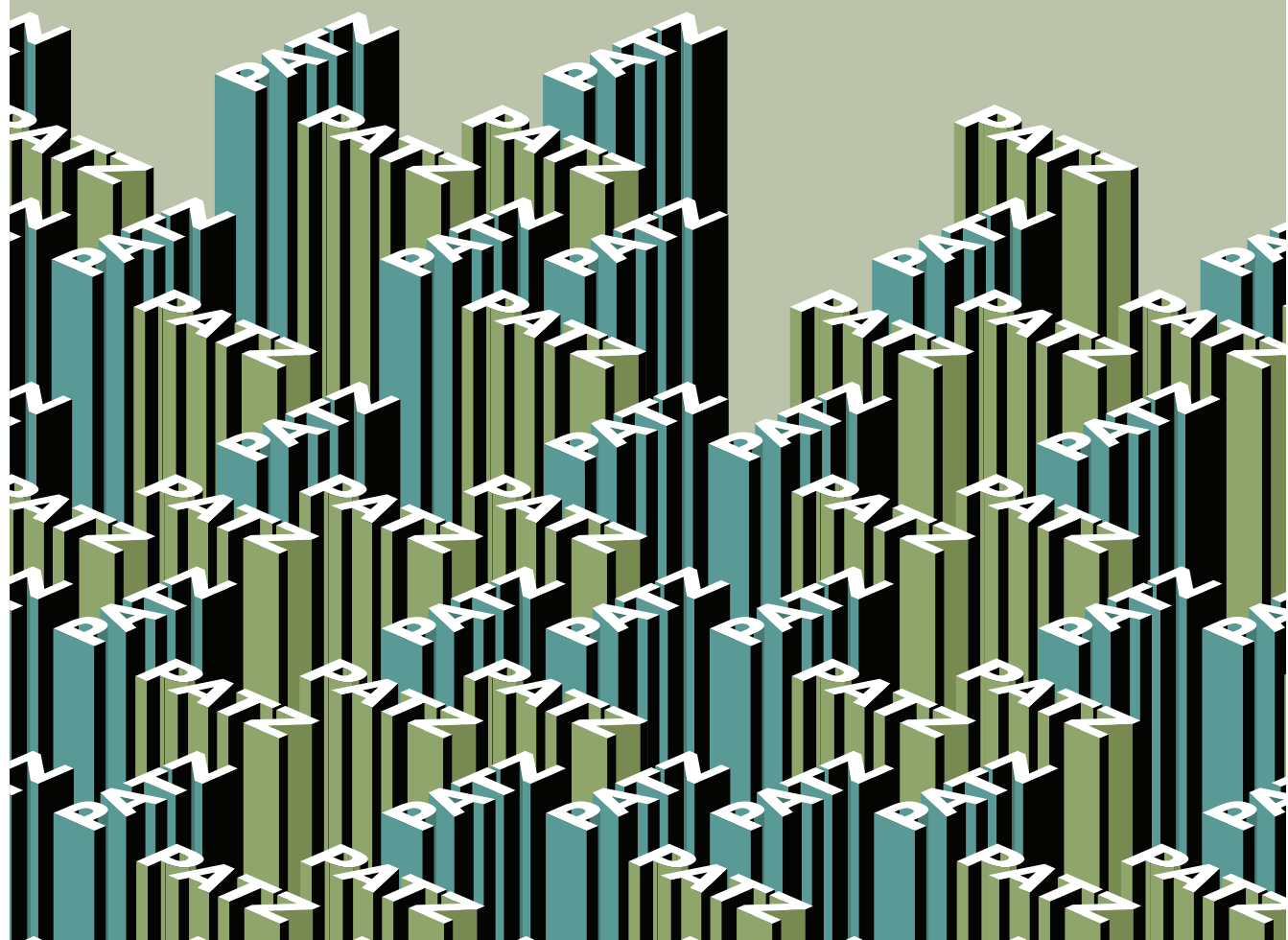
groups as well as the perceived added value and improvements that can be made. This monitor can be used in this respect, but also to investigate ways in which to include the views of patients and relatives in research on the added value of PaTz, as their views have been elusive so far.

Another aspect of PaTz groups that deserves attention is the process in meetings and the inherent group dynamics. When a PaTz group starts, the new chair is trained in how to organize and lead the PaTz group, but as time passes and PaTz meetings occur more routinely, this training may fade. In addition, some groups may develop counterproductive dynamics over time and the added value of the meetings may dwindle for some group members. For instance, some group members may like to have different content, focus more on different dimensions of palliative care, discuss patients more quickly, or discuss fewer patients, but more thoroughly. Long-term (non-participatory) observations could be performed for the purpose of developing specific additional training or guidelines for the chairmen and -women of PaTz groups. This can help them understand and continuously manage the process of the meetings and the group dynamics to ensure smooth and satisfactory meetings for everyone involved.

Chapter 6 suggested that the PaTz method improves communication with patients about several end-of-life topics. But as this was reported from the healthcare providers' point of view only, it remains unclear whether patients have the same experience and whether they feel that their needs, fears, wishes and expectations are discussed sufficiently with their healthcare providers.

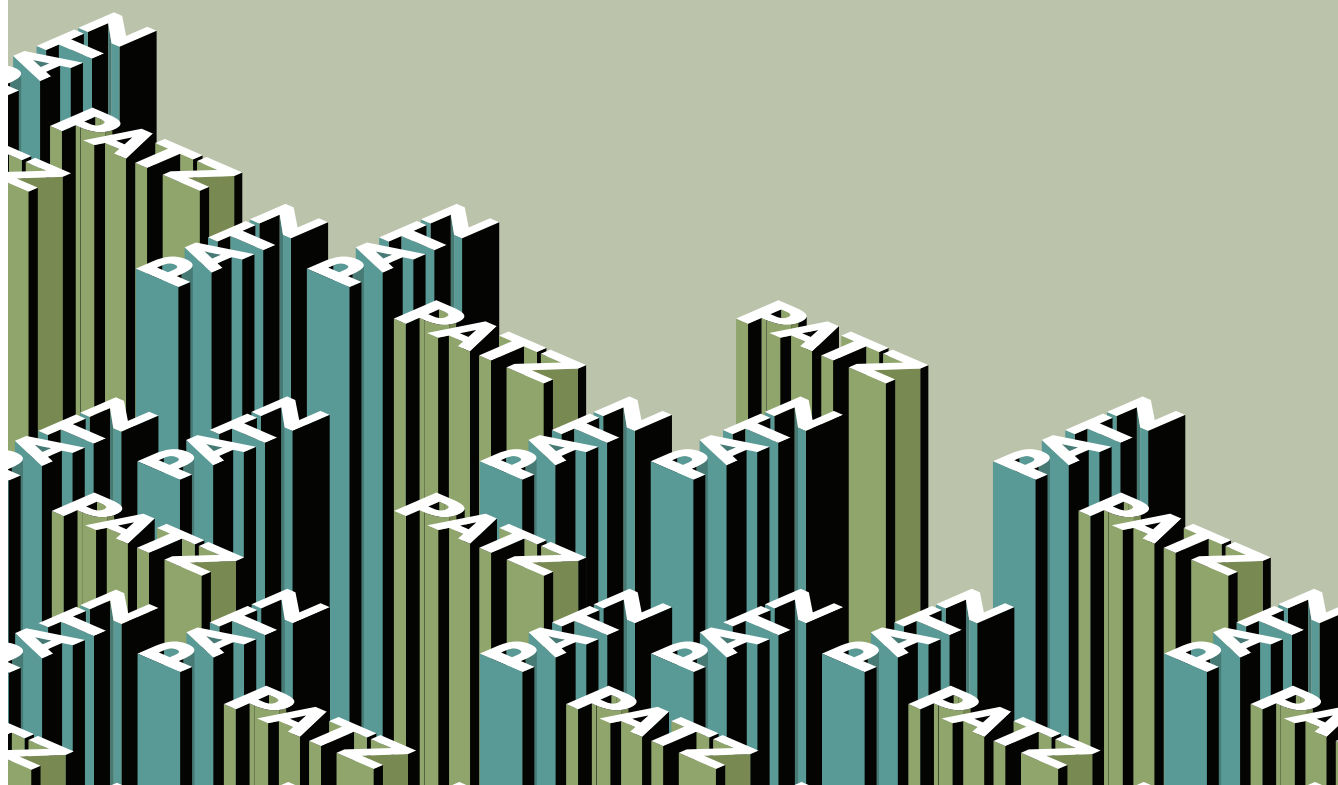
Furthermore, Chapter 5 showed that across PaTz groups, there is no consistent method for identifying patients with palliative care needs, and the identification of non-cancer patients lags behind. How patients with palliative care needs are identified, whether they are identified early enough, which patients are missed, and whether a systematic identification method facilitates early identification of patients in all illness trajectories, should be the subject of future research. As mentioned above, the performance of other identification tools like the SPICT and the RADPAC in PaTz groups should also be investigated in this respect.





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## Appendices



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## Appendices

### Appendix 1 - Observation form

Main question: to what extent are the basic principles and procedures as described in theory visible in practice?

Organisation and procedures	
How many participants, what distribution?	
Is there a recognizable method of working?	
How is the meeting built up?	
Is the order of business available beforehand?	
How much time is invested in the different parts?	
Is a register being used?	
Which other tools are used?	
Who is the chair?	
Who organised the meeting?	
Is there training? How much time is spent on training? What subject? Is the training structural?	
Points of interest regarding process or procedures.	
Time allocation and role division	
How much time is spent on the different points of order? Only patients or are other topics also discussed?	
How much time is spent on the different patients?	
How are patients identified? Surprise Question?	
Which type of patients are discussed?	
What role do the participants have? Who is active, who is not?	
What is the contribution of the different participants?	
Points of interest regarding communication, division of roles.	

## Appendix 2 - Exemplary descriptions of patient discussions with assigned codes

Group number and patient characteristics	Description of discussion	Coded as discussion of:
Group 2 discussing pt. 13, a man with urothelial carcinoma.	<i>"Radiotherapy for bone metastases. What to do when the patient already received radiotherapy and the pain or loss of strength returns? The guideline is clear: impending spinal injury. In consultation with the radiotherapist, second radiotherapy is an option."</i>	Future problems and treatment options in the physical domain.
Group 9 discussing pt. 24, a man with a brain tumour.	<i>"Home care presents scores from symptom diary, seems flat. Patient will undergo further diagnostics for experimental therapy. He is going to meet a buddy, but does not want to burden his friends with his illness. Still has problems structuring his days."</i>	Current problems in the social domain.
Group 1 discussing pt. 118, a woman with dementia.	<i>"An aggressive woman with Alzheimer's disease. Husband is depressed. [...] Mental health care services are not accepted. Haloperidol is no longer given, as people want her to be lucid. Home care expects escalation."</i>	Current and future problems in the psychological and social domain.
Group 7 discussing pt. 12, a man with urothelial carcinoma.	<i>"Comfortable and calm deathbed after a troubled sickbed. Transferred from hospital to hospice to home. Is this the way it should have gone?"</i>	Evaluation of care in the practical domain.
Group 2 discussing pt. 8, a woman with breast carcinoma.	<i>"Stable but poor situation. Mrs wants palliation or euthanasia and no further diagnostics in the hospital. The tumour marker has risen and progression is likely. Strongly desires autonomy. Trembling lower leg is a manageable problem at the moment. Clonazepam or diazepam are options."</i>	Current problems, treatment options and wishes in the physical and existential domain.
Group 10 discussing pt. 67, a man with lung carcinoma.	<i>"Patient with lung carcinoma, in denial. Nurse specialist in mental care was involved, she is theologian and expert in existential problems. No continued conversation as of yet, patient is not up for it. There is a lot of anxiety in the patient. Discussed again, GP stays in touch and this is acceptable for the patient. Discussing the end of life is still not possible. Sometimes talking about death is not possible, and we just keep on caring as well as we can."</i>	Current problems, treatment options and wishes in the existential domain.
Group 6 discussing pt. 4, a man with prostate and colon carcinoma.	<i>"Family was unsatisfied with the home care organization, chose another organization. Patient developed a delirium in the final days, did not want midazolam. In the final hours this was provided by the out-of-hours GP services."</i>	Evaluation of care in the psychological domain.

Group number and patient characteristics	Description of discussion	Coded as discussion of:
Group 2 discussing pt. 28, a man with heart failure.	<i>"Terminal heart failure. What if a statement of terminal illness is given, and the patient does not die? 24 hours care is provided for a maximum of six months. One option is to anonymously inquire at health care insurer. Besides, a statement of terminal illness is required for hospice care."</i>	Future problems in the practical domain.

## Appendix 3 - Topic lists used in group and individual interviews

Group interviews: GPs, district nurses and consultant palliative care

- Short introduction of the subject
- Providing listening consultation services
  - Attitude towards utility
  - Care request of patient
- Referral
  - Reasons for referral and non-referral
  - Practical considerations
- Experiences with consultations
  - Patients' experiences
  - PaTz-group members' experiences
  - Experienced added value
- Experiences with participation of spiritual caregivers in PaTz-groups
  - Contribution to group discussions
  - Experiences regarding collaboration with spiritual caregivers
  - Experiences with (own) attention for spiritual domain
  - Effect on knowledge on / experiences with spiritual care for patients or relatives at the end of life
  - Experienced added value

Individual interviews: Spiritual caregivers

- Short introduction of the subject
- Providing listening consultation services
  - Attitude towards utility
  - Referrals in practice
  - Discussed topics
- Experiences with consultations
  - Patients' experiences
  - Spiritual caregivers' experiences
  - Added value
- Experiences with participation in PaTz-groups
  - Contribution to patient discussions
  - Collaboration with other healthcare providers
  - Attention for spiritual domain
  - Added value

Individual interviews: Patients and relatives who used consultation services

- Short introduction of the subject
- Reasons for using listening consultation services
  - Care request
  - Referral
- The consultation(s)
  - Discussed topics
  - Attitude of spiritual caregiver
  - Added value
  - Effects in daily life or feelings
  - Attention for spiritual care in palliative care

## Appendix 5 – practical recommendations for the integration of a spiritual care intervention in primary palliative care

1. Agree who takes initiative for the (listening consultation) services
  - Appoint a 'champion' who knows and understands both fields of healthcare and spiritual care
  - Select a 'champion' who is willing to invest time in the initial phase of the project
  - Discuss an appropriate title for the initiative with all involved stakeholders
2. Find an motivated, enthusiastic group of healthcare professionals (e.g. PaTz-group or multidisciplinary group)
  - Select a group or chairmen who is motivated for integrating spiritual care into palliative care
  - Seek for a group with frequent meetings
3. Ensure a good match between the spiritual caregiver and the group
  - Determine (e.g. with the chairmen) which "color" or denomination spiritual caregiver is needed
4. Prepare the start well
  - Make customized brochures and hand them out to each group member
  - Agree on a clear route of referral of healthcare professionals to the spiritual caregiver
  - Agree on a financial route of reimbursements: who pays the spiritual caregiver?
    - Think of: rate for consultations, rate for training, rate for participation in group meetings
    - Travel time compensation / travel costs reimbursement
    - Reimbursement for time spend to calling patients for scheduling a consultation
  - Agree on a start date for the consultations, group meeting and training
  - Define the target group (of listening consultation services)
  - Think of: seriously ill patients with chronic disorders, patients' relatives, patients with a wish for euthanasia
  - Agree on form of consultations: walk-in hour or home visits and on route of referral: by patients or by professionals?
  - Agree on (not) sharing personal data
  - Agree on which terms you use and use them unambiguously, e.g. "spiritual caregiver", "chaplaincy"

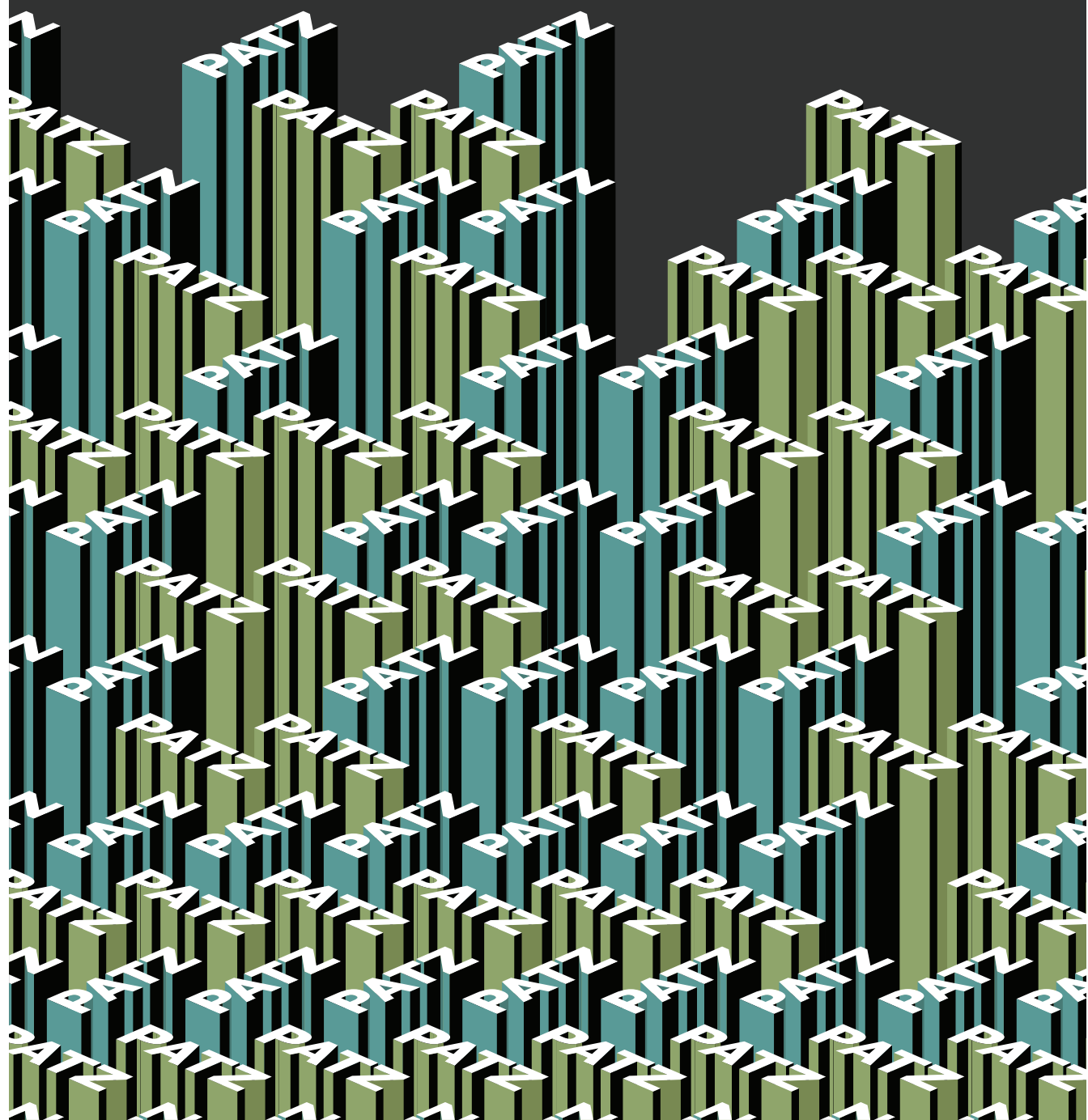
5. Invest in collaboration and get to know each other
  - Arrange an appointment between the chairman / group and spiritual caregiver
  - Make an inventory of whether the spiritual caregiver is available on data of group meetings
  - Provide each group member with contact details of the spiritual caregiver (business card / brochure)
  - Do an inventory of involved healthcare professionals' vision on spiritual care
  - Define role of spiritual caregiver and manage expectations: consultations, group attendance, intervention?
  - Inform group members on spiritual care
  - Ask for specific needs for training
6. Invest in a good start and further collaboration
  - Make clear for all involved professionals when consultations can be used
  - Use flyers to communicate
  - Ensure findability of spiritual caregivers: can he / she be found by everyone?
  - Use posters and flyers to communicate about the services
  - Print and distribute flyers regularly
  - Let group members actively offer listening consultation services (by a co-ordinator)
  - Send a newsletter regularly or put a news message on a website (by a co-ordinator)
7. Continue to invest: training and customization
  - Offer training and adjust duration of training to the needs of group members
  - Repeat training if desired
  - Plan group meetings in close collaboration with the spiritual caregiver as a group member
  - Send the agenda of the group meeting to the spiritual caregiver beforehand
  - Make sure the spiritual caregiver attends meetings regularly
8. Provide feedback on a regular basis
  - Agree whether the referrer(s) wants feedback and how you eventually arrange giving feedback (e.g. phone, e-mail)
  - Agree that spiritual caregivers ask the patients' permission for providing feedback to referrer



9. Sustainability and finance

- Embed the listening consultation services in a local network, e.g. Palliative Care Network
- Discuss whether there is a maximum number of consultations
- Match how consultations / services are paid, e.g. on a claim basis
- Coordinate how a spiritual caregivers keep being involved (e.g. by the Center for Meaning Questions)





# Addendum

Summary  
Samenvatting  
Dankwoord  
List of publications



## Summary

**Introduction** - This thesis is about improving care for people at the end of their lives who reside in the primary care setting. Palliative care is care for people with a life-threatening illness, focused on symptom alleviation and quality of life rather than on cure or life prolongation. The aim of this thesis is to investigate areas of improvement in primary palliative care and the role that the PaTz method can play in these improvements. PaTz is an initiative to improve palliative care in the primary care setting. The first part of this thesis addresses the potential areas of improvement, and the potential role of PaTz in the improvements is described in Part 2.

### Part 1 - potential areas of improvement for primary palliative care

**Chapter 2** describes a mixed methods study regarding the involvement of services and facilities which can support general practitioners and district nurses in the provision of palliative care in the primary care setting. It showed that most general practitioners cooperate sometimes or often with palliative home care teams, hospices or palliative care consultation services. District nurses sometimes or often involve volunteers in palliative care, hospices and spiritual caregivers. Psychologists and psychiatrists and social welfare were involved less often; the main reason for not involving these services was that they were 'not needed' according to general practitioners and district nurses. Regarding the involvement of services and facilities, most general practitioners and district nurses solely reported positive experiences. They suggested that the involvement of services and facilities could be improved through (1) the establishment of local centres giving information on available services and facilities, (2) the presentation of services and facilities in local multidisciplinary meetings, and (3) having support organizations proactively offer their facilities and services.

**Chapter 3** describes the experiences of spiritual caregivers with providing spiritual care at the end of life in the primary care setting, and their thoughts on why they are involved only infrequently in palliative care at home. It showed that spiritual caregivers provide broad spiritual care at the end of life, addressing existential, relational and religious issues, and the emotions of patients and relatives related to these issues. Besides spiritual issues, spiritual caregivers also discuss topics related to medical care with patients and relatives, such as treatment wishes and options. Spiritual caregivers also mentioned barriers and facilitators for the provision of spiritual care, such as communication with other healthcare providers, having a relationship of trust and structural funding (or the absence of such funding). Local multidisciplinary meetings were suggested as ideal opportunities to fa-

miliarize other primary healthcare providers with spirituality and promote spiritual caregivers' services.

**Chapter 4** describes a mortality follow-back study examining the association of treatment aims in the final three months of life with advance care planning and palliative care outcomes in general practices. It showed that more than three-quarters of the 1,464 included patients had a palliative treatment aim throughout the final three months. Half of these patients simultaneously had a curative or life-prolonging treatment aim and half had *only* a palliative treatment aim. The results revealed that having a palliative treatment aim in the final three months is associated with improved advance care planning and end-of-life communication. It seemed however, that in order to improve palliative care outcomes, having a palliative treatment aim alone is not enough. Instead, a timely and complete transition to palliative treatment, and thereby no longer aiming for cure or life prolongation, seemed to be required to improve palliative care outcomes.

## Part 2 – the role of PaTz in improving palliative care

The PaTz method is a method aimed at improving palliative care in the primary care setting. It has three basic principles: (1) in a PaTz group, local general practitioners and district nurses meet at least six times a year to identify and discuss their patients with a life-threatening illness; (2) these PaTz meetings are supervised by a specialist palliative care professional; and (3) PaTz groups use a palliative care register in which all patients with a limited life expectancy are listed.

**Chapter 5** describes the variation in the implementation of PaTz-groups by investigating how the basic principles of PaTz are applied in practice, and what the content of PaTz meetings is. During a follow-up period of one year, ten PaTz-groups logged and described the activities in their meetings, as well as the patients who were registered and discussed. Additionally, non-participatory observations were performed in all groups. The study showed that although the basic principles of the PaTz method are applied in almost every PaTz group, the variation in the practice and content of the meetings of different PaTz groups is considerable. Most groups spend little time on topics other than their patients, although the number of patients discussed in a single meeting varies considerably, as well as the time spent on an individual patient. Most registered patients had been diagnosed with cancer, and patient discussions mainly concerned current matters and rarely concerned future issues. The observed variation between PaTz groups indicates that tailoring a PaTz group to the needs of its participants is important and may enhance its durability. The flexibility of PaTz groups may also provide an opportunity to modify the content and tools used, and improve the identification of palliative patients and advance care planning.

In **Chapter 6**, a pilot study of a listening consultation services is described. In this pilot study, spiritual caregivers joined three PaTz groups, raising awareness for the spiritual domain and identifying potential spiritual care needs in patients who were discussed during the PaTz meetings. Additionally, the spiritual caregivers provided training to the healthcare providers in the PaTz groups to help them recognize spiritual issues and know when and how to refer a patient to a spiritual caregiver. Finally, they provided listening consultations for patients with a life-threatening illness and/or their relatives. The study showed that although implementation of the listening consultation service required considerable effort and time, the addition of spiritual caregivers to PaTz groups improved both the cooperation with the regular healthcare providers and referral of patients and relatives with spiritual issues once the first hurdles and hesitations were overcome. In addition, the patients and relatives who made use of the listening consultation service greatly appreciated these conversations with the spiritual caregivers.

**Chapter 7** explores the perceptions of general practitioners and district nurses regarding the added value of participating in a PaTz group, barriers for participation and the association between participating in a PaTz group and care outcomes. Healthcare providers considered PaTz to be beneficial for collaboration and knowledge, coordination and continuity of palliative care. A lack of time was considered the most important barrier for participation. General practitioners and district nurses were also asked to describe their most recent palliative care case, and we compared the palliative care provided by healthcare providers who were participating in a PaTz group with the care provided by those who were not. We found that participating in a PaTz-group was associated with discussing more end-of-life topics, both with patients and with other healthcare providers. Statistically significant associations with other palliative care outcomes were not found, possibly due to a ceiling effect. The high level of palliative care found in both groups may not be representative for the general level of palliative care in primary care, and healthcare providers with less affinity for palliative care may benefit more from PaTz.

## General discussion

In the general discussion, after summarizing the findings of the previous chapters and discussing some of the strengths and weakness of the studies, some overarching themes are described. These themes are: (i) the cooperation between healthcare providers in primary palliative care; (ii) the importance of timely identification of patients with palliative care needs; (iii) whether the development of PaTz-groups should focus on quality or quantity; (iv) the role

of PaTz in Dutch policy on palliative care; and (v) the evidence for the value of PaTz. Finally, some recommendations for practice, policy and research are discussed.



## Nederlandse samenvatting

**Inleiding** - Dit proefschrift gaat over het verbeteren van palliatieve zorg voor mensen in de thuissituatie. Palliatieve zorg is zorg voor mensen met een levensbedreigende aandoening, gericht op symptoombestrijding en kwaliteit van leven, en niet op genezing en levensverlenging. Het doel van dit proefschrift is te onderzoeken waar ruimte voor verbetering van de palliatieve zorg in de eerste lijn ligt, en welke rol de PaTz(Palliatieve ThuisZorg)-methode kan spelen bij deze verbeterpunten. In het eerste deel van het proefschrift worden mogelijke verbeterpunten onderzocht, en het tweede deel wordt de mogelijke rol van PaTz in deze verbeterpunten besproken.

### Deel 1 – mogelijke verbeterpunten in de palliatieve zorg in de eerste lijn.

**Hoofdstuk 2** betreft een *mixed methods* onderzoek naar de ervaringen van huisartsen en wijkverpleegkundigen met het betrekken van voorzieningen en diensten in de palliatieve zorg in de eerste lijn. De meeste huisartsen gaven aan soms of vaak een palliatieve thuiszorgteam, hospice of een consulent palliatieve zorg te betrekken bij de zorg. Wijkverpleegkundigen gaven aan soms of vaak samen te werken met vrijwilligers in palliatieve zorg, hospices en geestelijk verzorgers. Psychologen, psychiaters en maatschappelijk werk werden minder vaak betrokken. De belangrijkste reden om deze voorzieningen niet te betrekken is dat deze 'niet nodig' werden geacht door huisartsen en wijkverpleegkundigen. De meeste respondenten rapporteerden enkel positieve ervaringen met betrokken voorzieningen. Als mogelijke verbeterpunten suggereerden de respondenten (1) het opzetten van regionale centra of contactpersonen met informatie over de beschikbare voorzieningen en diensten in de omgeving, (2) dat deze voorzieningen en diensten zich presenteren op lokale multidisciplinaire overleggen en (3) dat ondersteunende organisaties hun diensten proactief aanbieden.

**Hoofdstuk 3** beschrijft ervaringen van geestelijk verzorgers met de zorg voor patiënten in de laatste levensfase in de eerste lijn, en hun ideeën over de redenen dat zij weinig worden betrokken bij de palliatieve zorg in de thuissituatie. Dit onderzoek laat zien dat geestelijk verzorgers een breed spectrum aan spirituele zorg leveren bij mensen met zorgen of problemen van existentiële, relationele of religieuze aard. Geestelijk verzorgers bespreken naast deze zingevings- en levensbeschouwelijk vragen ook vragen met betrekking tot de medische zorg, zoals behandelmogelijkheden en –wensen, met patiënten en hun naasten. Geestelijk verzorgers noemden een aantal factoren die het leveren van spirituele zorg bevorderen, zoals communicatie met andere zorgverleners, een vertrouwensband met

de cliënt en structurele financiering van geestelijke verzorging in de eerste lijn. Plaatselijke multidisciplinaire overleggen werden gesuggereerd als ideale mogelijkheid om andere eerstelijns zorgverleners vertrouwd te maken met spiritualiteit en de diensten van geestelijk verzorgers aan te bieden.

In **Hoofdstuk 4** wordt een *mortality follow-back study* beschreven, waarin de associatie tussen behandeldoelen in de laatste drie maanden van het leven met advance care planning en palliatieve-zorguitkomsten zijn onderzocht. Meer dan driekwart van de 1.464 geïnccludeerde patiënten bleek een palliatief behandeldoel te hebben gehad gedurende de laatste drie maanden van het leven. Ongeveer de helft van deze patiënten had gelijktijdig een curatief of levensverlengend behandeldoel, en de andere helft had alléén een palliatief behandeldoel. Uit de resultaten bleek dat het hebben van een palliatief behandeldoel in de laatste drie maanden geassocieerd is met betere advance care planning en communicatie rond het levenseinde. Tegelijkertijd bleek dat voor het verbeteren van de palliatieve zorguitkomsten, het hebben van een palliatief behandeldoel op zich niet voldoende is. Patiënten met alléén een palliatief behandeldoel, en dus geen curatief of levensverlengend behandeldoel, bleken betere palliatieve zorguitkomsten te hebben dan patiënten met een gelijktijdig curatief of levensverlengend doel.

## Deel 2 – de rol van PaTz in het verbeteren van palliatieve zorg in de eerste lijn

Het doel van de PaTz-methode is het verbeteren van de palliatieve zorg in de eerste. De methode heeft drie basisprincipes: (1) in een PaTz-groep komen huisartsen en wijkverpleegkundigen ten minste zes keer per jaar samen om hun patiënten met een levensbedreigende aandoening te identificeren en te bespreken; (2) deze PaTz-bijeenkomsten worden begeleid door een consulent palliatieve zorg; en (3) de PaTz-groepen houden een palliatieve zorgregister bij met alle patiënten met een beperkte levensverwachting.

**Hoofdstuk 5** beschrijft de variatie tussen PaTz-groepen in de praktijk, door de toepassingen van de basisprincipes van PaTz in de praktijk, en de inhoud van PaTz-bijeenkomsten te onderzoeken. Een jaar lang registreerden tien PaTz-groepen hun activiteiten tijdens de bijeenkomsten, en welke patiënten werden geregistreerd en besproken. Ook zijn bij deze tien PaTz-groepen twee bijeenkomsten bijgewoond door de onderzoekers. Uit de resultaten blijkt dat hoewel de basisprincipes in vrijwel alle PaTz-groepen toegepast worden, de praktijk en de inhoud van de bijeenkomsten behoorlijk verschilt tussen de groepen. De meeste groepen besteden weinig tijd aan andere zaken dan de patiënten, al varieert zowel het aantal patiënten dat wordt besproken tijdens bijeenkomsten en de tijd die aan een enkele patiënt wordt besteed aanzienlijk. De meeste geregistreerde patiënten

hadden kanker als belangrijkste diagnose. Patiëntbespreking gingen vooral over actuele problematiek en nauwelijks over toekomstige zaken. De geobserveerde variatie tussen PaTz-groepen suggereert dat het belangrijk is om de vorm en inhoud van de PaTz-groep aan te passen aan de wensen en behoeften van de deelnemers om zo de duurzaamheid te versterken. De gebleken flexibiliteit van PaTz-groepen kan ook de mogelijkheden scheppen om de inhoud en gebruikte instrumenten aan te passen, en de identificatie van patiënten met een palliatieve zorgbehoefte en advance care planning te verbeteren.

In **hoofdstuk 6** wordt een pilot van een luisterspreekuur beschreven. In deze pilot sloot bij drie PaTz-groepen een geestelijk verzorger aan, om meer aandacht voor het spirituele domein te krijgen en mogelijke spirituele kwesties te herkennen bij patiënten die besproken werden tijdens de PaTz-bijeenkomsten. Daarnaast gaven de geestelijk verzorgers training aan de zorgverleners in de PaTz-groep om spirituele kwesties bij patiënten beter te herkennen en te weten wanneer en hoe zij deze patiënten kunnen doorverwijzen naar een geestelijk verzorger. Ten slotte verzorgden zij een luisterspreekuur voor patiënten met een levensbedreigende aandoening en hun naasten. Het onderzoek liet zien dat hoewel het opstarten van het luisterspreekuur veel tijd en moeite kostte, het aansluiten van de geestelijk verzorgers bij de PaTz-groepen leidde tot betere samenwerking met de andere zorgverleners en meer verwijzingen. De patiënten en naasten die gebruikt hadden gemaakt van het luisterspreekuur vonden deze gesprekken zeer waardevol.

In **Hoofdstuk 7** wordt onderzocht wat volgens huisartsen en wijkverpleegkundige de toegevoegde waarde is van deelname aan een PaTz-groep, en wat volgens hun barrières zijn om deel te nemen aan een PaTz-groep. Ook wordt de associatie tussen deelname aan een PaTz-groep en palliatieve zorguitkomsten onderzocht. Volgens zorgverleners is deelname aan een PaTz-groep waardevol voor de samenwerking en communicatie, coördinatie en continuïteit van palliatieve zorg. Tijdsgebrek was volgens hen de belangrijkste barrière voor deelname. Uit de resultaten bleek dat deelname aan een PaTz-groep geassocieerd was met meer communicatie over levenseinde-onderwerpen, zowel tussen zorgverlener en patiënt als tussen zorgverleners. Statistisch significante verschillen in de palliatieve zorguitkomsten werden niet gevonden, mogelijk door een plafond-effect. Het hoge niveau van palliatieve zorg dat is gevonden in deze studie is mogelijk niet representatief voor het algemene niveau van palliatieve zorg in de eerste lijn. Zorgverleners met minder affiniteit met palliatieve zorg profiteren mogelijk meer van deelname aan een PaTz-groep.

## Discussie

In de discussie worden, na een samenvatting van de voorgaande hoofdstukken en het bespreken van de sterke en zwakke punten van de onderzoeken, een aantal overkoepelende thema's besproken: (i) samenwerking tussen zorgverleners in de palliatieve zorg in de eerste lijn; (ii) het belang van tijdige identificatie van patiënten met een palliatieve-zorgbehoefte; (iii) de verdere ontwikkeling van PaTz-groepen: kwantiteit of kwaliteit; (iv) de rol van PaTz in het Nederlandse beleid rond palliatieve zorg; en (v) het bewijs voor de waarde van PaTz. Tot slot worden een aantal aanbevelingen voor de praktijk, beleid en toekomstig onderzoek besproken.

## List of publications

### Publications in English

Klop JT, Koper I, Schweitzer BPM, Jongen E & Onwuteaka-Philipsen BD. *Strengthening the spiritual domain in palliative care through a listening consultation service by spiritual caregivers in Dutch PaTz-groups: An evaluation study*. BMC Palliative Care 2020. 19:1(92).

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### Under review

Koper I, Pasman HRW, Van der Plas AGM, Hendriksen J & Onwuteaka-Philipsen BD. *The association of treatment aims at the end of life with advance care planning and palliative care outcomes: a mortality follow-back study in general practice*.

