Transmural Collaboration in Palliative Care: Perspectives of Nurses and Physicians

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Cover illustration: Claude Monet, part of a landscape painting/Shutterstock.com
Cover design: Erwin Timmerman.

Lay-out and printing by Optima Grafische Communicatie (www.ogc.nl)
ISBN 978-94-6361-596-9

This thesis was printed with the financial support of the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, and the Erasmus University Rotterdam.

Transmural Collaboration in Palliative Care: Perspectives of Nurses and Physicians

Transmurale samenwerking in de palliatieve zorg:
perspectieven van verpleegkundigen, verzorgenden en artsen

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de
rector magnificus

Prof.dr. A.L. Bredenoord

en volgens besluit van het College voor Promoties.
De openbare verdediging zal plaatsvinden op
dinsdag 23 november 2021 om 13:00 uur

door

Marijanne Engel
geboren te Utrecht

Erasmus University Rotterdam

PROMOTIECOMMISSIE

Promotoren:	Prof.dr. A. van der Heide Prof.dr. C. van Zuylen
Overige leden:	Prof.dr. C.C.D. van der Rijt Prof.dr. P.J.E. Bindels Prof.dr. B.M. Buurman – van Es

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Chapter 1

General introduction

PALLIATIVE CARE

Worldwide, the life expectancy of people has increased enormously in the last century.[1] Important factors that contributed to that increase are improved hygiene, availability of good food, improved living conditions, peace, and a highly developed healthcare system.[2] More treatment options have emerged for all kinds of diseases, which means that many people live longer despite their illness or disability. However, improved possibilities to cure diseases and extend lives also have a downside. Some treatments are burdensome without having a beneficial impact and both healthcare professionals and patients are more often confronted with choices about which care is most appropriate for patients with a limited life expectancy.

Besides more treatment options, many other aspects have changed in recent decades in care for people with a chronic or acute illness, people with disabilities, the elderly and the dying. From the 1950s onwards, more attention was paid to care of seriously ill and dying patients, and in 1974 the term 'palliative care' was introduced by Balfour Mount, a Canadian physician and academic.[3] This term referred to a new approach to care for patients with a limited life expectancy, in which healthcare providers (gradually) switch to a different type of care for patients for whom cure is no longer possible. In 2002 the World Health Organization (WHO)formulated the following definition of palliative care[4]: *'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*

In 2018 this WHO definition of palliative care was reformulated into[5]: *'Palliative care is the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members.'*

CARE SETTINGS WHERE PALLIATIVE CARE IS PROVIDED AND TRANSFERS OF PATIENTS

From 1990 onwards more attention has been paid in the Netherlands to palliative care, with the establishment of the Network Palliative Care for Terminal Patients Netherlands (NPTN) and active government policy aimed at the further development of palliative care. In nursing homes and hospitals, 'palliative care units' were created in which specialized palliative care was provided to patients having complex problems (hospitals) or to patients having a limited life-expectancy of only a few weeks or days (nursing homes).[6] There was a growth in the number of hospices, both ‘high-care’ hospices and ‘almost –home’ hospices, where patients are admitted to spend their last phase of life until they die. A nationwide system of palliative care networks was established.[7] These networks are formal partnerships of independent care organizations involved in palliative care, such as hospitals, care and nursing homes, home care, general practitioners, hospices and volunteers, in a specific region.

In addition to this increasing interest in palliative care, since 2014 the Netherlands has been undergoing a transformation ‘from welfare state to participation society’. The idea is that the citizen/patient determines what care and treatment is needed in order to achieve the highest possible quality of life, in consultation with healthcare professionals.[7] In line with this, the government has stimulated that people continue to live at home for as long as possible, even if they need (palliative) care.[8]

Research has shown that, regardless of the place where they live, patients in the palliative phase usually receive care from several healthcare professionals often from various care organizations.[9] For several reasons, often related to an acute episode of their illness, the majority of patients is at least once transferred between different care settings in the last months of life.[10] Most transfers in the last 3 months of life involve an admission to a hospital, where sometimes death follows, or, in case of improvement, discharge to home or to another care setting.[10] In all care settings, high-quality palliative care is important, with patients and relatives indicating that they attach great importance to continuity of care between the healthcare professionals and care organizations involved.[9,11]

In the Netherlands, a total of 140.813 persons died in 2012. Most people (30%) died at home, 25% died in a nursing home, 27% in hospital (including psychiatric care facility), 10% in a care home and 8% in a hospice or other type of care organization.[12] In more recent years there has been a slight change in the place of death. In 2018, a total of 153.363 persons died: 32% died at home, 27% in a nursing home, 24% in a hospital (including psychiatric care facility), 7% in a care home and 10% in a hospice or other type of care organization.[13]

GOVERNMENT POLICY AND PROFESSIONAL PALLIATIVE CARE

In the Netherlands, the government policy is that palliative care is generalist care that, if appropriate, should be provided by all healthcare professionals.[14,15] In practice, palliative care is mostly offered in non-specialized care settings, both intra- and extramural, by healthcare professionals for whom palliative care is not their main expertise. Palliative care is also typically interdisciplinary care, with many care providers involved.[9] This includes nurses, physicians and other healthcare professionals, such as spiritual carers, social workers, various other paramedical healthcare professionals and volunteers.[16-18] For complex problems, healthcare professionals can consult palliative care specialists from several disciplines.[16] These palliative care specialists are often participating in palliative care teams (PCTs). Since 2017, almost all hospitals in the Netherlands have a hospital PCT for care questions in the field of palliative care, that can be consulted by non-specialist care providers.[19] In addition, there is a nationwide network of regional PCTs for consultation questions from primary care.[20]

Since the 1980s, education for physicians, nurses and other healthcare professionals has gradually focused more on palliative care, but the subject is not yet structurally embedded in education for all professions. Some of the healthcare professionals providing palliative care have not received any training in regular education. An inventory of how palliative care is addressed in nursing and medical schools showed that there are large differences in size, depth, level and degree of fragmentation between educational programs.[21]

PALLIATIVE CARE AND TRANSMURAL COLLABORATION

Whereas high-quality palliative care is supposed to be in line with patients' preferences for treatment and care, it is necessary that healthcare professionals start to communicate with the patient and their loved ones about the patient's preferences at an early stage in patients' illness trajectories.[22] Worldwide, various initiatives are aimed at promoting such communication.[23,24]

Besides communication between healthcare professionals and patients, another important factor in palliative care is collaboration between healthcare professionals. Adequate collaboration between healthcare professionals from different care organizations appears to be an increasingly important factor in providing appropriate care to patients with a limited life expectancy.[9,11,25] Collaboration between healthcare professionals from different care organizations is referred to as transmural collaboration in healthcare. Transmural collaboration has been defined as *'a cooperative, inter-organizational relationship that is negotiated in an ongoing communicative process, and which relies on neither market nor hierarchical mechanisms of control'.*[26] An important aspect of transmural collaboration is information exchange and communication between healthcare professionals from different care organizations. Adequate transmural collaboration is important to ensure continuity, efficiency and safety of care.[27-29]

In the Netherlands and other countries, palliative care networks have been set up to promote transmural collaboration in a region and thus increase the quality of palliative care.[30-32] In the Netherlands, these palliative care networks are part of the public sector. The Ministry of Health, Welfare and Sport sets administrative requirements for the organization of these networks.[33] In these networks, the parties involved appoint an independent network manager or network coordinator.[32,34] The core task of the network coordinators is to stimulate the process of collaboration in a network between healthcare professionals from different care organizations, over whom the network coordinator has no formal authority.[32,35] In Belgium, Hermans et al.[32] did a study on the experiences of network coordinators with transmural collaboration between different care organizations. In this study,[32] the network coordinators indicated that more formalized collaboration between care organizations in the field of palliative care, the establishment of formal communication channels and shared leadership are needed.

NATIONAL QUALITY FRAMEWORK FOR PALLIATIVE CARE AND GUIDELINES

Guidelines on palliative care[36,37] emphasize the importance of adequate collaboration and information transfer. The ‘Netherlands Quality Framework for Palliative Care’ provides an overview of the aspects that are important for arriving at good-quality palliative care. The Netherlands Quality Framework includes ten domains, that each consist of an introduction, one or more standards and a number of criteria.[36] The standards indicate best practice within a domain and the associated criteria are conditions required to achieve the desired standard. One of the standards under the main domain ‘Structure and process of care’ is ‘coordination and continuity of care’, for which adequate transmural collaboration between different care organizations is mentioned as an important condition. Another item in the domain ‘Structure and process of care’ is expertise. Here, “willingness to transmural collaboration” is mentioned as one of the criteria for healthcare professionals with additional expertise in the field of palliative care.[36] However, the Netherlands Quality Framework for palliative care does not include guidance on how transmural collaboration should be organized in practice. It often seems that, because it is considered important it is expected that ‘transmural collaboration will automatically happen’.[38]

In addition to the Netherlands Quality Framework for palliative care, various associations of healthcare professionals have developed general guidelines for collaboration and information transfer. For example, the Royal Dutch Medical Association has written a guideline for the 'Division of responsibility in collaboration in healthcare',[39] in collaboration with associations of various other healthcare professionals and patient representation. Further, the Dutch Association of General Practitioners and the Dutch Association of Medical Specialists have jointly developed a guideline for information exchange between general practitioners and medical specialists (HASP).[40]

Following these general guidelines, some regional partnerships have developed guidelines and toolkits for improving collaboration in palliative care. These guidelines or toolkits often consist of a step-by-step plan and/or tips that are based on theoretical models and experiences with transmural collaboration.[41,42] Goodwin[42] states that to improve knowledge on the implementation of complex interventions, research and clinical practice must be more mutually supportive. According to Goodwin, research showing what is needed for 'integrated care' in a specific context is scarce.[42]

Some studies have shown that transmural collaboration in palliative care is often not optimal.[9,11,43] An example of sub-optimal transmural collaboration is incomplete and/or late information handover, for example by the medical specialist to the general practitioner for a patient with a limited life expectancy who returns home after a hospitalization.[25,44-46] The KNMG report 'Just because we can, doesn't mean we should' from 2015[22] offers healthcare professionals tools to talk to patients about the most appropriate end-of-life care and emphasizes the importance of transmural collaboration. The report is critical about the follow-up of the aforementioned 'Division of responsibility in collaboration in healthcare' guideline from 2010. Although this guideline was widely supported, agreements regarding transmural collaboration that should promote appropriate end-of-life care appear to be difficult to achieve.[22] More insight into the complexities of transmural collaboration in palliative care may contribute to more adequate transmural collaboration and thus to high-quality palliative care.

RESEARCH PROGRAM OF THE CONSORTIUM FOR PALLIATIVE CARE IN THE SOUTHWEST NETHERLANDS

Discontinuity in care due to insufficient transmural collaboration and exchange between different care settings is one of the major bottlenecks in the practice of palliative care. In a consortium-inspired research program 'Transmural collaboration in palliative care', funded by the Netherlands Organization for Health Research and Development

(ZonMw), the Consortium for Palliative Care in the southwest Netherlands aimed to improve transmural collaboration in the consortium region. Most of the studies described in this thesis were part of this research program.

At the start of this program, we conducted a number of survey studies to assess current experiences with palliative care and transmural collaboration, among patients, bereaved relatives, nurses and physicians working in different care settings. Subsequently, we set up a number of regional improvement projects in the field of transmural collaboration, in consultation with seven palliative care networks. Palliative care networks opted for an improvement project focusing on transmural consultation, a transmural care pathway or transmural information exchange. These improvement projects were accompanied by 'action research', in which we observed and analyzed processes related to the improvement projects. Within these improvement projects we also conducted some interview studies and a medical record review.

Interim findings of studies within the research program were disseminated in the participating networks at different time-points. Results that were important to the progress of the research program were:

1. Best practice models: at the start of the program we developed best practice models for information handovers in palliative care and transmural palliative care consultation, based on literature, guidelines and existing models. These best practice models are included as appendices 1 and 2, respectively (in Dutch).
2. The results of the survey studies among patients and bereaved relatives and among nurses and physicians. The (preliminary) results of all four survey studies were disseminated via several presentations and summaries for a general audience in the period October 2017 to March 2020. The final summary of these studies is included in this thesis as appendix 3 (in Dutch).

AIM, OVERVIEW OF STUDIES AND OUTLINE OF THIS THESIS

In order to contribute to the improvement of transmural collaboration between healthcare professionals in different care settings in palliative care, the aim of the studies presented in this thesis was twofold:

The first aim was to gain insight into the perspectives and experiences of nurses and physicians working in different care settings on transmural collaboration in palliative care and into their underlying attitudes towards transmural collaboration. The second aim was to gain insight into how transmural collaboration in palliative care can be efficiently organized. These overall aims have been addressed in a number of sub-studies with different objectives.

The first objective was to explore satisfaction with hospital care of patients with advanced illness. Acknowledging the importance of the patient perspective in palliative care, we performed a secondary analysis of data of the COMPASS study, a multicenter study on the effe***c***ts and c***o***sts of consultation tea***m***s for ***pa***lliative care in ho***s***pital***s*** in the Netherlands.

We studied the following research question (**Chapter 2**):

1.1 What are the underlying dimensions of satisfaction with care in hospitalized patients with advanced cancer in the Netherlands?

In the COMPASS study, a total of 105 patients had been recruited from nine hospitals, both university and general hospitals, in the period January 2013 to February 2015. We did an exploratory factor analysis with principal axis factoring in order to find underlying dimensions in patient satisfaction with care as measured with the INPATSAT-32. Regression models were used to assess the association of patient characteristics with satisfaction scores.

The second objective was to describe the quality of collaboration and information exchange in palliative care from the perspectives of nurses. The following research questions were addressed:

2.1 What are the experiences of nurses working in different care settings with inter-organizational collaboration between care settings in palliative care? (**Chapter 3**)
2.2 How do palliative care nurse champions in hospitals and home care perceive and fulfill their role and responsibilities? (**Chapter 4**)

To answer these questions, data were used from a survey and an interview study that were part of the consortium-wide research program. In the survey study, conducted in the period May to December 2017, a total of 933 nurses working in different care settings and representing different nursing levels participated. The survey was done with an online questionnaire. Nurses were asked for their general experiences with collaboration in palliative care and their experiences with handing over information in the case of the last deceased patient they had cared for. Besides descriptive statistics, Pearson's chi-square tests were performed to test for potential associations between quality scores of the nurses and characteristics of the respondents or patients.

In addition, in the period May to November 2018, semi-structured interviews were conducted with 10 nurses in two hospitals who were appointed as palliative care nurse champions in their ward, and 6 palliative care nurse champions working in a home care team in four different home care organizations. Palliative care nurses champions were asked for their role and responsibilities as palliative care nurse champion in their hospital ward or home care team, their place in their organization in relation to the palliative care expert team, and their role and responsibilities in inter-organizational collaboration. The interviews with the palliative care nurse champions were analyzed using the principles of thematic analysis.

The third objective was to identify how physicians in different care settings perceive their performance in communicating about a poor prognosis with patients and attending physicians in other care settings. In addition, we studied the quality of hospital discharge letters for patients with a limited life expectancy. This objective was addressed in the following research questions:

3.1 How do physicians in different care settings self-assess their performance in estimating a poor prognosis and communicating about this with patients and with attending physicians working in other care settings? (**Chapter 5**)

3.2 To what extent do hospital discharge letters for patients with a limited life expectancy include information about patient's poor prognosis and preferences for treatment and care? (**Chapter 6**)

In order to identify the perspectives of physicians, a survey study was conducted in the period July – December 2017, as part of the consortium-wide program. A total of 547 physicians (259 general practitioners, 205 hospital physicians and 83 nursing home physicians) participated. An invitation for the survey study was sent by mail and physicians could fill in either a paper copy of the questionnaire or a digital version. Physicians were asked how they self-assessed their performance in estimating prognosis (one year, three months, one week) and communicating poor prognosis to patients; how they communicated prognosis and related wishes for treatment and care with physicians from other care settings and how they perceived collaboration with physicians working in other care settings for patients with a poor prognosis in the past year. Following descriptive statistics, regression models were used to assess the association of respondent characteristics with their self-reported performance in adequately estimating a prognosis of less than a year, and the association with their self-reported performance in discussing wishes and expectations regarding treatment and care.

The quality of hospital discharge letters was assessed in a retrospective medical record study. We studied the records of 108 patients who had been admitted to a large teaching hospital in the period January 1 to July 1, 2017, had gone home upon their discharge and had died within one year after discharge. Data were collected on patient characteristics; general items, based on guidelines for information exchange, in the hospital discharge letter; and information regarding patients' limited life expectancy both in the medical record and in the hospital discharge letter. In this study, besides descriptive statistics, the association between presence of information on patients' limited life expectancy in the medical record or the hospital discharge letter and characteristics of patients was tested for statistical significance with Pearson's chi-square test.

The fourth objective was to examine facilitators and barriers in the process of developing and implementing an intervention aimed at promoting transmural collaboration in palliative care and to make recommendations for practice, policy and research. The research question was:

4.1 What facilitators and barriers affect the process of developing and implementing a transmural palliative care consultation service in four palliative care networks in the southwest region of the Netherlands? (**Chapter 7**)

In the period 2017 to December 2019, we performed a multiple case study in four palliative care networks in the research region. These networks had opted for the development of a transmural palliative care consultation service to improve transmural collaboration in their region, as part of the consortium-wide program. The researchers closely observed the process and participated in meetings of the project teams within these four networks. In the multiple case study, the Consolidated Framework for Implementation Research (CFIR), that identifies factors that influence an intervention's implementation, was used as a conceptual framework in the data collection and analysis. For each case, we listed all factual information within the appropriate domain and underlying construct of the CFIR. Then we identified elements that could potentially be considered as facilitator or barrier for developing and implementing a transmural consultation service and further investigated emerging facilitators and barriers. Subsequently, all findings were pooled together.

In **Chapter 8** of this thesis, an overview is given of some general methodological considerations regarding the studies included. Further, the main findings are discussed and put into perspective. This chapter is completed with a number of recommendations for clinical practice and for future research.

Funding

The main part of this thesis was financially supported by the Netherlands Organization for Health Research and Development (ZonMw, grant number 844001104).

However, the study on satisfaction with care of hospitalized patients with advanced cancer in the Netherlands (chapter 2) was based on the COMPASS study which was funded by Erasmus MC, University Medical Center Rotterdam (grant/award number: 2011-11112) and ZonMw (grant/award number: 11510031). The retrospective medical record review on quality of hospital discharge letters for patients at the end of life (chapter 6) was financially supported by the Research Center from the Maasstad Hospital ('Maasstad Ziekenhuis research voucher 2019.1 (19-02-2019)' Rotterdam), the Netherlands.

All these funding organizations had no role in the performance of the study and publications.

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Chapter 2

Satisfaction with care of hospitalized patients with advanced cancer in the Netherlands

Engel M.
Brinkman-Stoppelenburg A.
Nieboer D.
van der Heide A.

Eur J Cancer Care (Engl). 2018 Sep;27(5):e12874

ABSTRACT

Objective

We aimed to assess the level of satisfaction with hospital care of patients with advanced cancer and its association with quality of life and other patient characteristics.

Methods

Eligible patients were asked to fill out the EORTC INPATSAT-32 questionnaire, measuring patient satisfaction, and the EORTC QLQ-C15-PAL, measuring quality of life. Factor analysis was performed to identify underlying patterns in satisfaction. Multivariable regression analyses were used to assess associations of quality of life and other patient characteristics with satisfaction.

Results

A total of 105 patients participated in the study. The mean general satisfaction score was 72 (*SD* 21). Factor analysis identified three underlying dimensions: satisfaction with nurses (explaining 62.1% of the total variance), satisfaction with physicians (7.7%) and satisfaction with hospital services (5.3%). Associations were found between global health and general satisfaction (β=0.35, p=0.01), and between emotional functioning and satisfaction with hospital services (β=0.016, p<0.01). Further, diagnosis of breast cancer was associated with satisfaction with physicians (β=1.06, p<0.01), and dyspnea with satisfaction with hospital services (β=0.007, p=0.03).

Conclusions

Patients with advanced cancer are reasonably satisfied with hospital care. The INPATSAT-32 mainly measures satisfaction with nurses. Satisfaction with care and quality of life seems to represent distinct outcomes of hospital care in patients with advanced cancer.

INTRODUCTION

Patient satisfaction is an important outcome of patient-centered care, which is considered to be one of the key characteristics of high-quality care.[1-3] Therefore, patient satisfaction is an essential aspect of measuring quality of care.[4,5] Patient satisfaction can be described as the extent to which patients' healthcare experiences match with the level and quality of care they expect.[4,6] Patients have different backgrounds, experiences and expectations from their care. Patient satisfaction is highly dependent on such factors and may not always be associated with quality of care.[4,7-10] The key aspects to measure may differ according to the patient's disease, the care setting, and the type of intervention.[3] When measured adequately, patient satisfaction scores are supposed to provide a robust measure of quality of care.[11]

Patient satisfaction with end-of-life care refers to all relevant processes associated with healthcare delivery for patients with advanced illness.[4,8] To be useful, measurement of satisfaction with end-of-life care should address aspects that are important to patients and should be responsive to improvements in healthcare delivery.[3] Patient satisfaction with end-of-life care is a complex concept that is not easily distinguished from related concepts, such as quality of life and quality of dying.[3,5]

Cancer is one of the most common causes of death. End-of-life care therefore often concerns patients with cancer. In 2014, almost 43,000 persons died of cancer in the Netherlands, which represents 31% of the total number of deceased people in that year.[12] Bekelman et al.[13] found that in the Netherlands 77% of cancer patients were admitted to an acute care hospital in the last 180 days of life, which percentage is low compared with other European countries. In the last 30 days of life, the Netherlands has the lowest rate of hospitalizations (44%).[13] Ko et al.[14] found that 17% of Dutch patients with advanced cancer were admitted to hospital in the last week of life and died there.

Patient satisfaction with hospital care reflects the perception of the patient of the quality of care they receive during their hospitalization.[5,6] Most research on patient satisfaction with end-of-life care in the hospital has been conducted in specific settings, such as a palliative care unit or an oncology department[3,5,15-19] or in patients with a specific type of cancer, such as gynecologic cancer or lung cancer.[2,20,21] Little is known about satisfaction with in-hospital care of patients with advanced cancer.

The aim of this study was to explore satisfaction with hospital care of patients with advanced cancer, to study the underlying dimensions of satisfaction, and to explore the relation of satisfaction with patients' demographics, disease characteristics and quality of life.

METHODS

Study design

This cross-sectional study was part of the COMPASS study, a multicenter study on the effects and costs of consultation of expert teams for palliative care in hospitals in the Netherlands.[22] The study was performed in nine hospitals, both university and general hospitals.

Patients and data collection

Patients were recruited for the study in the period January 2013 – February 2015. Inclusion criteria were: admission to the hospital with advanced cancer, age 18 years or older, and the attending physician answering “no” to the Surprise Question: “Would you be surprised if this patient would die in the next year?”.[23] Eligible patients were identified by the attending physician; they received an information letter about the study and were informed by the attending nurse.

Questionnaires

After obtaining written informed consent, patients were invited to fill in the European Organisation for Research and Treatment of Cancer (EORTC) IN-PATient SATisfaction 32 (items) questionnaire (INPATSAT-32) and the EORTC Quality of Life Questionnaire Core 15 (items) Palliative care (QLQ-C15 PAL), on the 14th day after inclusion. The attending physician was asked to fill in a questionnaire about the patient’s diagnosis, performance status, comorbidities and life expectancy.

Satisfaction With Care (EORTC INPATSAT-32)

The EORTC developed the INPATSAT-32 questionnaire to assess satisfaction with hospital care of cancer patients. The INPATSAT-32 consists of 32 items assessing patients’ appraisal of the quality of hospital physicians (eleven items) and nurses (eleven items), as well as aspects of the organization of care and hospital environment (nine items), and general satisfaction (one item).[2,4] The INPATSAT-32 was conceptualized as having 11 multi-item scales and three single-item scales (Table 2) and uses a five-point response scale, from “poor” to “excellent”. The INPATSAT-32 has been validated and tested in a large, international sample of patients with cancer. The INPATSAT-32 has demonstrated excellent convergent validity and internal consistency, and high reliability.[4] The INPATSAT-32 general satisfaction single-item scale was the primary outcome measure in our study.

Quality of Life (EORTC QLQ–C15–PAL)

Quality of life measurement focuses on patient outcomes in the physical, psychological and the social domain.[24,25] The EORTC QLQ–C15–PAL questionnaire measures quality of life in palliative care and is an abbreviated 15-item version of the EORTC QLQ–C30. The QLQ–C15–PAL consists of 15 questions: two multi-item functional scales (emotional and physical functioning), two multi-item symptom scales (fatigue, pain), five single-item symptom scales (nausea and vomiting, dyspnea, insomnia, appetite loss, constipation), and one final question referring to overall quality of life (global health status) (Table 1). It uses a four-point response scale from 1 (not at all) to 4 (very much), with the exception of health status which was rated from 1 (very poor) to 7 (excellent).[26,27] The QLQ–C15–PAL has been demonstrated to have a good content validity as a "core palliative care questionnaire" that assesses common symptoms and problems of patients with advanced disease.[26]

Statistical analyses

Scores of the EORTC INPATSAT-32 for items within a scale were summed and divided by the number of items in the scale. Multi-item as well as single-item scale scores were then linearly transformed to scores ranging from 0 to 100, with a higher score representing a higher level of satisfaction.

The EORTC scoring manual was used to generate the QLQ-C15-PAL scores.[26] Scores range from 0 to 100. A higher score on global health, the emotional functioning scale or the physical functioning scale, indicates better global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

In order to explore underlying dimensions of satisfaction as measured with the INPATSAT-32 we looked for latent factors with an exploratory factor analysis (EFA) with principal axis factoring.[28-30] Direct Oblimin was used to rotate variables with the aim to find a structure with distinct factors, in which every factor includes related items with loadings as high as possible. General satisfaction and the resulting factors were used as outcomes in univariate and multivariable regression models. We performed univariate analysis to assess the association of patient characteristics with satisfaction scores, where $p<0.30$ was considered statistically significant. We subsequently performed multivariable regression analysis with variables that were significantly associated with satisfaction in the univariate analysis. All p-values were two-sided. Data were analyzed using the statistical program SPSS version 24.

RESULTS

Patient characteristics

One hundred and five patients participated in our study. Fifty-four percent of the participants were female. Patients' mean age was 67 (*SD* 10). Most patients (43%) had no comorbidities, 30% had a life expectancy of less than three months. Place of residence of most (96%) patients was their own home. The median duration of hospital admission was nine days (range 1-50). Most hospital admissions were unplanned (85%) (Table 1).

Patients' mean global health score was 59 (*SD* 19). The mean score for emotional functioning was 77 (*SD* 23) and for physical functioning it was 41 (*SD* 28). As for symptoms, patients scored on average highest (worst) on fatigue, with a mean score of 58 (*SD* 27), and appetite loss, with a mean score of 40 (*SD* 33) (Table 1).

Table 1 | Demographics, disease characteristics and quality of life (EORTC QLQ-C15-PAL) of hospitalized patients with advanced cancer (*n* = 105)

		Total (*n*=105) *n* (%)
Gender	Female	57 (54)
	Male	48 (46)
Age at admission (mean, sd)		67 (10)
Marital status	Single /unmarried/widowed	39 (37)
	Married	66 (63)
Place of residence	Home	99 (96)
	Other	4 (4)
Discharge destination	Home	82 (83)
	Nursing home / care home / hospice	12 (12)
	Other	5 (5)
Duration of current hospital admission in days (median, range)		9 (1-50)
Diagnosis	Gastro-intestinal cancer	44 (42)
	Urogenital cancer	21 (20)
	Breast cancer	15 (14)
	Lung cancer	15 (14)
	Other	10 (10)
Treatment status	Patient received anti-tumor therapy	45 (46)
	No options for anti-tumor therapy left	35 (35)
	Other	19 (19)

Table 1 | Demographics, disease characteristics and quality of life (EORTC QLQ-C15-PAL) of hospitalized patients with advanced cancer (*n* = 105) (continued)

		Total (*n*=105) *n* (%)
Comorbidity	No comorbidity	45 (43)
	1 comorbidity	34 (32)
	>1 comorbidity	26 (25)
Hospital admission was	Planned	15 (15)
	Unplanned	88 (85)
WHO performance status. The patient is....	(1) Able to carry out all normal activity without restrictions	7 (7)
	(2) Restricted in physically strenuous activity but ambulatory and able to carry out light work	37 (35)
	(3) Ambulatory and capable of all self-care but unable to carry out any work; up and about more than 50% of waking hours.	29 (28)
	(4) Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.	28 (27)
	(5) Completely disabled; cannot carry on any self-care; totally confined to bed or chair	4 (4)
Estimated prognosis at admission according to physician	6-12 months	34 (34)
	3-6 months	35 (35)
	< 3 months	30 (30)
Palliative care team consultation	Yes	16 (15)
	No	89 (85)
Type of hospital	University	20 (19)
	General	85 (81)
Quality of life[a] (mean, sd)		Total (n=105) Mean (SD)
Global health status	Global health	59 (19)
Functional scales	Emotional functioning	77 (23)
	Physical functioning	41 (28)
Symptoms	Fatigue	58 (27)
	Nausea and vomiting	16 (25)
	Pain	33 (29)
	Dyspnea	28 (31)
	Insomnia	29 (29)
	Appetite loss	40 (33)
	Constipation	23 (29)

[a] EORTC QLQ-C15-PAL: All items have scores ranging from 0 to 100. A higher score on global health status, the emotional functioning scale or physical functioning scale indicates a higher level of global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

Satisfaction with hospital care

The mean score for general satisfaction with hospital care was 72 (*SD* 21). Satisfaction was highest for nurses' technical skills (72, *SD* 21) and nurses' interpersonal skills (71, *SD* 23) Satisfaction was lowest for access to the hospital (parking facilities, transport options to the hospital) (59, *SD* 22) and "other hospital personnel" (60, *SD* 21) (Table 2).

Principal axis factoring yielded three components with eigenvalues exceeding 1, which explained 62,1 %, 7,7% and 5,3 % of the total variance, respectively (Table 2). After Oblimin rotation the pattern matrix showed three factors, representing "satisfaction with nurses and exchange of information", "satisfaction with physicians", and "satisfaction with hospital services" (Table 2).

Table 2 | Satisfaction of patients with advanced cancer with hospital care (EORTC INPATSAT-32) and factor loadings for the INPATSAT-32 subscales

		Factor Loadings[a]		
	Total n= 105	Eigenvalue (Λ) 8.931	Eigenvalue (Λ) 1.282	Eigenvalue (Λ) 1.031
INPATSAT-32 subscales	Mean (*SD*)	Factor 1	Factor 2	Factor 3
Satisfaction with physicians'[b]				
Technical skills	68 (22)		0.972	
Interpersonal skills	67 (24)		0.953	
Information	66 (24)		0.818	
Availability	62 (22)		0.747	
Satisfaction with nurses'				
Technical skills	72 (21)	0.877		
Interpersonal skills	71 (23)	1.021		
Information	67 (24)	0.829		
Availability	64 (25)	0.799		
Exchange of information	62 (20)	0.403		
Other hospital personnel Kindness and helpfulness	60 (21)			0.568
Waiting time	61 (21)			
Access (parking, means of transport,…)	59 (22)			0.853
Comfort /cleanness	62 (25)			0.743
General satisfaction	72 (21)	0.424		0.430

[a] Extraction method: Principal Axis Factoring and Oblimin rotation. Factor loadings under 0.40 are not shown.

[b] EORTC INPATSAT-32: all items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

Table 3 | The association between patient demographics, disease characteristics, quality of life (EORTC QLQ-C15-PAL) and general satisfaction (EORTC INPATSAT-32)

	General satisfaction IN-PATSAT 32[a]					
	Univariate linear regression			**Multivariable regression[b]**		
	B	CI	*p* Value	B	CI	*p* Value
Gender (male vs. female)	- 3.89	– 12.13 to 4.34	0.35			
Age at admission	0.24	-0.16 to 0.65	0.24	-0.05	-0.48 to 0.37	0.81
Marital status (single/unmarried vs. married)	3.19	-5.33 to 11.71	0.46			
Place of residence (other vs. home)	- 10.18	-31.34 to 10.97	0.34			
Discharge destination (Home = reference)			0.96			
Nursing home/care home/hospice	-1.35	-14.27 to 11.57	0.84			
Other	-2.19	-21.43 to 17.05	0.82			
Duration of current hospital admission[c]	0.21	-0.35 to 0.76	0.47			
Diagnosis (Gastro-intestinal cancer = reference)			0.63			
Urogenital cancer	1.19	-10.01 to 12.40	0.83			
Breast cancer	9.77	2.85 to 22.37	0.13			
Lung cancer	3.10	-9.52 to 15.71	0.63			
Other	-0.24	-15.00 to 14.51	0.98			
Treatment status (Patient received anti-tumor therapy = reference)			0.97			
No options for anti-tumor therapy left	-1.24	-10.89 to 8.41	0.80			
Other	-0.93	-12.53 to 10.67	0.87			
Comorbidity[d]						
No comorbidity						
1 comorbidity						
>1 comorbidity	4.11	-0.97 to 9.19	0.11	4.30	-1.13 to 9.73	0.12
Hospital admission was (planned vs. unplanned)	-6.59	-18.17 to 4.99	0.26	-12.54	-25.04 to 0.04	0.05
WHO performance status. The patient is....[d]						
(1) Able to carry out all normal activity without restrictions						
(2) Restricted in physically strenuous activity but ambulatory and able to carry out light work						
(3) Ambulatory and capable of all self-care but unable to carry out any work; up and about more than 50% of waking hours.						
(4) Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.						
(5) Completely disabled; cannot carry on any self-care; totally confined to bed or chair.	3.39	-0.63 to 7.40	0.10	3.43	-1.65 to 8.50	0.18

Table 3 | (Continued)

		General satisfaction IN-PATSAT 32[a]					
		Univariate linear regression			**Multivariable regression[b]**		
		B	CI	*p* Value	B	CI	*p* Value
Estimated prognosis at admission according to physician (6-12 months = reference)				0.77			
3-6 months		-3.65	-13.95 to 6.65	0.48			
< 3 months		-0.91	-11.54 to 9.72	0.87			
Palliative care team consultation (yes vs. no)		6.86	- 4.44 to 18.16	0.23	0.81	-11.03 to 12.64	0.89
Type of hospital (university vs. general)		-5.99	-16.34 to 4.36	0.25	-7.17	-19.61 to 5.28	0.26
Quality of life (EORTC QLQ C15-PAL) on day 14 after inclusion[e]							
Global health status	Global health	0.31	0.11 to 0.52	0.004	0.35	0.10 to 0.60	0.01
Functional scales	Physical functioning	0.08	-0.07 to 0.23	0.27	0.15	-0.06 to 0.36	0.16
	Emotional functioning	0.28	0.11 to 0.46	0.002	0.15	-0.06 to 0.36	0.16
Symptoms	Fatigue	-0.14	-0.30 to 0.02	0.08	0.05	-0.19 to 0.28	0.70
	Nausea and vomiting	-0.06	-0.2 to 0.11	0.51			
	Pain	-0.16	-0.30 to -0.02	0.03	-0.03	-0.21 to 0.14	0.70
	Dyspnea	0.09	-0.04 to 0.23	0.16	0.10	-0.04 to 0.24	0.16
	Insomnia	-0.05	-0.19 to 0.09	0.48			
	Appetite loss	-0,11	-0.24 to 0.01	0.07	-0.01	-0.16 to 0.15	0.94
	Constipation	-0.07	-0.21 to 0.07	0.32			

[a] Patient satisfaction with care was measured with EORTC INPATSAT-32: All items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

[b] Variables with $p< 0.30$ were included in the multivariable model. $F = 2.61$, $p = 0.005$, $R^2= 0.32$ (Adjusted $R^2 = 0.20$).

[c] Linear regression was performed as for continuous variables in order to show a possible tendency.

[d] Linear regression was performed as for ordinal variables in order to show a possible tendency.

[e] Quality of life was measured with the EORTC QLQ-C15-PAL: All items have scores from 0 to 100. A higher score on global health status, the emotional functioning scale or physical functioning scale indicates a higher level of global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

Associations between patient characteristics and satisfaction with hospital care

Based on significant univariate associations, patients' age, comorbidity, whether or not the hospital admission was planned, WHO performance status, palliative care team consultation, type of hospital, global health, physical functioning, emotional functioning, fatigue, pain, dyspnea and appetite loss were included in the multivariable analysis to assess determinants of patients' general satisfaction with care (Table 3). Likewise, place of residence, comorbidity, palliative care team consultation, global health, emotional functioning, pain and constipation were included in the multivariable analysis to assess determinants of satisfaction with nurses and exchange of information (Table 4).

Table 4 | The association between patient demographics, disease characteristics, quality of life (EORTC QLQ-C15-PAL) and satisfaction with nurses and exchange of information

	Satisfaction with nurses and exchange of information (underlying dimension) [a]					
	Univariate linear regression			**Multivariable regression**[b]		
	B	CI	*p* Value	B	CI	*p* Value
Gender (male vs. female)	- 0.14	-0.54 to 0.26	0.48			
Age at admission	0.01	-0.01 to 0.03	0.56			
Marital status (single/unmarried vs. married)	0.16	-0.25 to 0.57	0.44			
Place of residence (other vs. home)	-0.61	- 1.63 to 0.41	0.24	-0.69	-1.69 to 0.31	0.18
Discharge destination (Home = reference)			0.70			
Nursing home/care home/hospice	-0.21	-0.84 to 0.43	0.52			
Other	0.25	-0.70 to 1.19	0.61			
Duration of current hospital admission[c]	0.01	-0.02 to 0.03	0.59			
Diagnosis (Gastro-intestinal cancer = reference)			0.37			
Urogenital cancer	0.08	-0.45 to 0.62	0.76			
Breast cancer	0.57	-0.04 to 1.17	0.07			
Lung cancer	-0.01	-0.62 to 0.59	0.97			
Other	-0.16	-0.87 to 0.56	0.67			
Treatment status (Patient received anti-tumor therapy = reference)			0.81			
No options for anti-tumor therapy left	0.12	-0.35 to 0.58	0.62			
Other	-0.06	-0.62 to 0.50	0.83			
Comorbidity[d]						
No comorbidity						
1 comorbidity						
>1 comorbidity	0.17	-0.08 to 0.42	0.17	0.07	-0.18 to 0.32	0.57
Hospital admission was (planned vs. unplanned)	-0.08	-0.65 to 0.50	0.79			
WHO performance status. The patient is....[d]						
(1)Able to carry out all normal activity without restrictions						
(2)Restricted in physically strenuous activity but ambulatory and able to carry out light work						
(3)Ambulatory and capable of all self-care but unable to carry out any work; up and about more than 50% of waking hours.						
(4)Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.						
(5)Completely disabled; cannot carry on any self-care; totally confined to bed or chair.	0.10	-0.10 to 0.30	0.32			

Table 4 | (Continued)

		Satisfaction with nurses and exchange of information (underlying dimension) [a]					
		Univariate linear regression			**Multivariable regression**[b]		
		B	CI	*p* Value	B	CI	*p* Value
Estimated prognosis at admission according to physician (6-12 months = reference)				0.78			
3-6 months		-0.11	-0.61 to 0.38	0.65			
< 3 months		0.06	-0.45 to 0.57	0.81			
Palliative care team consultation (yes vs. no)		0.36	- 0.19 to 0.91	0.20	0.50	-0.09 to 1.09	0.10
Type of hospital (university vs. general)		-0.16	-0.66 to 0.35	0.54			
Quality of life (EORTC QLQ C15-PAL) on day 14 after inclusion[e]							
Global health status	Global health	0.012	0.001 to 0.022	0.03	0.010	-0.001 to 0.021	0.07
Functional scales	Physical functioning	0.003	-0.004 to 0.011	0.35			
	Emotional functioning	0.008	-0.001 to 0.017	0.08	0.004	-0.006 to 0.014	0.43
Symptoms	Fatigue	-0.002	-0.010 to 0.005	0.54			
	Nausea and vomiting	-0.001	-0.009 to 0.007	0.81			
	Pain	-0.005	-0.012 to 0.002	0.13	0.001	-0.007 to 0.009	0.85
	Dyspnea	0.001	-0.005 to 0.008	0.70			
	Insomnia	0.001	-0.006 to 0.008	0.71			
	Appetite loss	-0.003	-0.009 to 0.003	0.32			
	Constipation	-0.004	-0.011 to 0.003	0.29	-0.004	-0.011 to 0.003	0.30

[a] Patient satisfaction with care was measured with EORTC INPATSAT-32: All items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

[b] Variables with $p < 0.30$ were included in the multivariable model. $F = 1.72$, $p = 0.11$, $R^2 = 0.12$ (Adjusted $R^2 = 0.05$).

[c] Linear regression was performed as for continuous variables in order to show a possible tendency.

[d] Linear regression was performed as for ordinal variables in order to show a possible tendency.

[e] Quality of life was measured with the EORTC QLQ-C15-PAL: All items have scores from 0 to 100. A higher score on global health status, the emotional functioning scale or physical functioning scale indicates a higher level of global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

Age, diagnosis, comorbidity, type of hospital, global health, physical functioning, emotional functioning, fatigue, pain, appetite loss and constipation were included in the multivariable analysis to assess determinants of satisfaction with physicians (Table 5). Finally, patients' gender, WHO performance status, palliative care team consultation, type of hospital, global health, emotional functioning, fatigue, nausea and vomiting, pain, dyspnea and appetite loss were included in the multivariable analysis to assess determinants of satisfaction with hospital services (Table 6).

Table 5 | The association between patient demographics, disease characteristics, quality of life (EORTC QLQ-C15-PAL) and satisfaction with physicians

	Satisfaction with physicians (underlying dimension)[a]					
	Univariate linear regression			**Multivariable regression[b]**		
	B	CI	*p* Value	B	CI	*p* Value
Gender (male vs. female)	-0.01	-0.41 to 0.39	0.96			
Age at admission	0.01	-0.01 to 0.03	0.13	0.02	-0.00 to 0.04	0.08
Marital status (single/unmarried vs. married)	0.15	-0.27 to 0.56	0.49			
Place of residence (other vs. home)	0.31	- 0.74 to 1.36	0.56			
Discharge destination (Home = reference)			0.89			
Nursing home/care home/hospice	-0.11	-0.74 to 0.52	0.74			
Other	0.15	-0.79 to 1.09	0.76			
Duration of current hospital admission[c]	-0.01	-0.03 to 0.02	0.61			
Diagnosis (Gastro-intestinal cancer = reference)			0.29			0.03
Urogenital cancer	0.08	-0.46 to 0.62	0.76	0.25	-0.29 to 0.80	0.36
Breast cancer	0.53	-0.08 to 1.13	0.09	1.06	0.40 to 1.72	0.002
Lung cancer	-0.26	-0.87 to 0.34	0.39	-0.00	-0.62 to 0.62	0.99
Other	-0.10	-0.81 to 0.61	0.77	-0.01	-0.75 to 0.74	0.99
Treatment status (Patient received anti-tumor therapy = reference)			0.86			
No options for anti-tumor therapy left	-0.01	-0.46 to 0.43	0.95			
Other	0.14	-0.41 to 0.68	0.62			
Comorbidity[d]						
No comorbidity						
1 comorbidity						
>1 comorbidity	0.27	0.03 to 0.51	0.03	0.21	-0.05 to 0.47	0.11
Hospital admission was (planned vs. unplanned)	0.19	-0.38 to 0.77	0.51			
WHO performance status. The patient is....[d]						
(1) Able to carry out all normal activity without restrictions						
(2) Restricted in physically strenuous activity but ambulatory and able to carry out light work						
(3) Ambulatory and capable of all self-care but unable to carry out any work; up and about more than 50% of waking hours.						
(4) Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.						
(5) Completely disabled; cannot carry on any self-care; totally confined to bed or chair.	0.03	-0.17 to 0.23	0.79			

Table 5 | (Continued)

		Satisfaction with physicians (underlying dimension)[a]					
		Univariate linear regression			**Multivariable regression**[b]		
		B	CI	*p* Value	B	CI	*p* Value
Estimated prognosis at admission according to physician (6-12 months = reference)				0.59			
3-6 months		-0.25	-0.72 to 0.23	0.31			
< 3 months		-0.12	-0.62 to 0.38	0.63			
Palliative care team consultation (yes vs. no)		0.12	-0.44 to 0.67	0.68			
Type of hospital (university vs. general)		0.29	-0.21 to 0.80	0.26	0.40	– 0.20 to 1.00	0.19
Quality of life (EORTC QLQ C15-PAL) on day 14 after inclusion[e]							
Global health status	Global health	0.013	0.002 to 0.023	0.02	0.009	-0.003 to 0.021	0.12
Functional scales	Physical functioning	0.006	-0.001 to 0.013	0.10	0.005	-0.004 to 0.014	0.25
	Emotional functioning	0.009	0.000 to 0.018	0.05	0.003	-0.008 to 0.013	0.60
Symptoms	Fatigue	-0.006	-0.013 to 0.002	0.13	-0.003	-0.013 to 0.008	0.59
	Nausea and vomiting	0.000	-0.009 to 0.008	0.90			
	Pain	-0.004	-0.011 to 0.003	0.25	0.004	-0.005 to 0.012	0.39
	Dyspnea	0.002	-0.004 to 0.009	0.50			
	Insomnia	-0.001	-0.008 to 0.006	0.74			
	Appetite loss	-0.003	-0.009 to 0.003	0.29	-0.003	-0.010 to 0.004	0.37
	Constipation	-0.008	-0.015 to -0.001	0.02	-0.002	-0.009 to 0.005	0.64

[a] Patient satisfaction with care was measured with EORTC INPATSAT-32: All items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

[b] Variables with P< 0.30 were included in the multivariable model. F = 2.04, p = 0.03, R^2= 0.28 (Adjusted R^2 = 0.14).

[c] Linear regression was performed as for continuous variables in order to show a possible tendency.

[d] Linear regression was performed as for ordinal variables in order to show a possible tendency.

[e] Quality of life was measured with the EORTC QLQ-C15-PAL: All items have scores from 0 to 100. A higher score on global health status, the emotional functioning scale or physical functioning scale indicates a higher level of global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

The analyses showed that patient demographics and disease characteristics were not associated with patients' general satisfaction or its underlying dimensions, except for a diagnosis of breast cancer, which was associated with patients' satisfaction with physicians (β=1.06, p<0.01) (Table 3-6). Further, we found that better global health was associated with higher general satisfaction (β=0.35, p=0.01), and that better emotional functioning (β= 0.016, p<0.01) and more severe dyspnea (β= 0.007, p=0.03) were associated with higher satisfaction with hospital services.

Global health and other dimensions of quality of life were not associated with satisfaction with nurses and exchange of information or satisfaction with physicians.

Table 6 | The association between patient demographics, disease characteristics, quality of life (EORTC QLQ-C15-PAL) and satisfaction with hospital services

	Satisfaction with hospital services (underlying dimension)[a]					
	Univariate linear regression			**Multivariable regression**[b]		
	B	CI	*p* Value	B	CI	*p* Value
Gender (male vs. female)	- 0.23	-0.65 to 0.19	0.28	-0.25	-0.66 to 0.17	0.25
Age at admission	0.01	-0.01 to 0.03	0.43			
Marital status (single/unmarried vs. married)	0.11	-0.33 to 0.54	0.62			
Place of residence (other vs. home)	-0.23	-1.34 to 0.87	0.68			
Discharge destination (Home = reference)			0.98			
Nursing home/care home/hospice	-0.06	-0.74 to 0.62	0.86			
Other	-0.05	-1.06 to 0.97	0.92			
Duration of current hospital admission[c]	-0.01	-0.04 to 0.02	0.57			
Diagnosis (Gastro-intestinal cancer = reference)			0.82			
Urogenital cancer	0.012	-0.56 to 0.59	0.97			
Breast cancer	0.30	-0.35 to 0.95	0.36			
Lung cancer	0.09	-0.56 to 0.74	0.79			
Other	0.34	-0.42 to 1.10	0.37			
Treatment status (Patient received anti-tumor therapy = reference)			0.74			
No options for anti-tumor therapy left	0.05	-0.44 to 0.54	0.83			
Other	-0.18	-0.78 to 0.41	0.54			
Comorbidity[d]						
No comorbidity						
1 comorbidity						
>1 comorbidity	0.12	-0.15 to 0.38	0.38			
Hospital admission was (planned vs. unplanned)	-0.14	-0.75 to 0.46	0.64			
WHO performance status. The patient is....[d]						
(1) Able to carry out all normal activity without restrictions						
(2) Restricted in physically strenuous activity but ambulatory and able to carry out light work						
(3) Ambulatory and capable of all self-care but unable to carry out any work; up and about more than 50% of waking hours.						
(4) Capable of only limited self-care; confined to bed or chair more than 50% of waking hours.						
(5) Completely disabled; cannot carry on any self-care; totally confined to bed or chair	0.22	0.02 to 0.43	0.03	0.17	-0.03 to 0.37	0.10

Table 6 | (Continued)

		Satisfaction with hospital services (underlying dimension)[a]					
		Univariate linear regression			**Multivariable regression[b]**		
		B	CI	*p* Value	B	CI	*p* Value
Estimated prognosis at admission according to physician (6-12 months = reference)				0.48			
3-6 months		-0.31	-0.83 to 0.21	0.24			
< 3 months		-0.08	-0.63 to 0.46	0.76			
Palliative care team consultation (yes vs. no)		0.36	-0.22 to 0.94	0.22	0.11	-0.47 to 0.69	0.71
Type of hospital (university vs. general)		-0.57	-1.10 to -0.05	0.03	-0.38	-0.92 to 0.16	0.17
Quality of life (EORTC QLQ C15-PAL) on day 14 after inclusion[e]							
Global health status	Global health	0.013	0.003 to 0.024	0.02	0.006	-0.006 to 0.019	0.34
Functional scales	Physical functioning	0.001	-0.007 to 0.009	0.81			
	Emotional functioning	0.019	0.010 to 0.028	<0.001	0.016	0.006 to 0.027	0.002
Symptoms	Fatigue	-0.007	-0.015 to 0.001	0.08	0.001	-0.009 to 0.011	0.88
	Nausea and vomiting	-0.009	-0.017 to 0.000	0.04	-0.002	-0.011 to 0.007	0.69
	Pain	-0.009	-0.016 to - 0.002	0.01	-0.004	-0.012 to 0.004	0.33
	Dyspnea	0.005	-0.002 to 0.012	0.15	0.007	0.001 to 0.014	0.03
	Insomnia	-0.001	-0.008 to 0.006	0.73			
	Appetite loss	-0.005	-0.012 to 0.001	0.11	0.001	-0.006 to 0.008	0.70
	Constipation	-0.001	-0.009 to 0.006	0.69			

[a] Patient satisfaction with care was measured with EORTC INPATSAT-32: All items are scored from 0 to 100 where a higher score indicates a higher level of satisfaction.

[b] Variables with P< 0.30 were included in the multivariable model. F = 3.46, p = 0.001, R^2= 0.31 (Adjusted R^2 = 0.22).

[c] Linear regression was performed as for continuous variables in order to show a possible tendency.

[d] Linear regression was performed as for ordinal variables in order to show a possible tendency.

[e] Quality of life was measured with the EORTC QLQ-C15-PAL: All items have scores from 0 to 100. A higher score on global health status, the emotional functioning scale or physical functioning scale indicates a higher level of global health or better functioning. Inversely, a higher score on a symptom indicates more severe symptoms or problems.

DISCUSSION

We found that patients with advanced cancer were reasonably satisfied with the care they received during their admission to the hospital: the mean score on general satisfaction was 72. Satisfaction was highest for nurses' technical and interpersonal skills and lowest for access to the hospital and other hospital personnel. Factor analysis yielded three underlying dimensions: satisfaction with nurses and exchange of information, satisfaction with physicians, and satisfaction with hospital services. We found that the INPATSAT-32 mainly measures satisfaction with nurses and exchange of information.

The satisfaction scores in this study overall seem to be in accordance with scores found in other studies in patients with cancer.[15,17,21,31] Bredart et al.[31] found scores ranging from 61 (physicians' availability) to 78 (nurses' interpersonal skills) among breast cancer patients (19% of the respondents had a metastatic stage), and Skret-Magierlo et al.[21] found highest scores on technical skills of physicians (70) and nurses (67), and the worst score on access to the hospital (51) among patients with endometrial cancer. The dimensions we found as explaining a large part of the variance in satisfaction scores, nursing care and physician care, were confirmed in other studies to represent the most relevant dimensions of satisfaction.[2,19] Plotti et al.[2] found that expert care for patients with gynecological cancer was associated with significantly higher scores on satisfaction with physicians' information provision, nurses' technical skills, nurses' information provision, and general satisfaction than standard care. Bredart et al.[19] found that specialized care for patients with different types of cancer was associated with significant higher scores on satisfaction with nurses' availability than standard care.

Other studies explored the important and complex role of nurses in cancer care and patient satisfaction.[10,32,33] These studies described or implemented specific nursing interventions that are assumed to improve cancer patients' satisfaction with care. Kullberg et al.[32] found that, after implementing a specific nurse handover procedure in an oncological inpatient setting, patients from the intervention ward scored higher on satisfaction with exchange of information between the caregivers compared with patients from the control wards. Suhonen et al.[10] described differences between European countries in hospitalized cancer patients' perceptions of individualized nursing care that is assumed to improve patient satisfaction and other outcomes. Patients' perceptions of individuality and differences between countries in this study[10] illustrate the complexity of the development of nursing care that responds to the variety of needs of cancer patients. Walczak et al.[33] evaluated the efficacy of a nurse-facilitated communication program for patients with advanced cancer to improve end-of-life care and found that patient satisfaction with this program in the intervention group was high.

Association of patient demographics and disease characteristics with satisfaction

In multivariable analyses, we found no significant associations between patient demographics and satisfaction with hospital care. In other studies, older patients with cancer were found to be more satisfied than younger patients.[15,34] In univariate analysis, we also found a positive association between age and general satisfaction, and between age and satisfaction with physicians.

Multivariable analysis showed a positive association between having a diagnosis of breast cancer and satisfaction with physicians. One explanation can be that the five-year survival of patients with breast cancer is high as compared to other types of cancer.[12] Nguyen et al.[15] found that patients treated for head and neck cancer were less satisfied with physicians' provision of information, and hospital environment as compared to those treated for prostate cancer. Hannon et al.[34] found no association between different types of cancer and patient satisfaction with end-of-life care.

Association of quality of life with satisfaction

Quality of life was to a limited extent associated with satisfaction. Global health was positively associated with general satisfaction, but not with any of the underlying dimensions of satisfaction.

Emotional functioning and dyspnea were associated with satisfaction with hospital services. In the literature, better global health[15,35] has been reported to be associated with higher satisfaction scores with hospital care too. Nguyen et al.[15] found that a decrease of global health in cancer patients, during and after treatment, led to a decrease in satisfaction scores, mainly in the evaluation of physicians. Aboshaiqah et al.[24] found that better emotional functioning was associated with higher general satisfaction with hospital care.

With regard to symptoms, a study in patients with gynecological malignancies showed no association between symptom severity and satisfaction with treatment.[36] Vedel et al.[9] found that for patients in palliative care it was important they could discuss symptoms with physicians or nurses, regardless of whether symptoms were relieved or not.

The question has been raised if scores on (dimensions of) quality of life and general satisfaction represent the same general feeling of "happiness", which is easily influenced by factors unrelated to quality of care.[5,11] In our study, dimensions of quality of life were to a limited extent associated with satisfaction, which suggests that patients' satisfaction with end-of-life care reflects a dimension of quality of care that only partly overlaps with quality of life.

This study has several strengths: it was conducted in nine hospitals in the Netherlands, both university and general hospitals. All patients had a primary diagnosis of cancer, but there was a variation in types of cancer, number of comorbidities and treatment status. Besides the variation in demographics and disease characteristics, all patients had advanced cancer with a limited prognosis of less than a year.

A limitation is the total number of 105 patients. Although the recruitment rate was low, the size of the sample was consistent with comparable studies. Another limitation is that for each patient quality of life and patient satisfaction were measured on the same day (on the 14th day after inclusion). Drawing robust causal inferences is therefore not possible.

Conclusion

Understanding which patient demographics, disease characteristics and dimensions of quality of life are related with satisfaction with hospital care in patients with advanced cancer is important for guiding improvement in hospital care. We found that patients with advanced cancer in the Netherlands are reasonably satisfied with hospital care. Satisfaction with hospital care in patients with advanced cancer as measured with the INPATSAT-32 mainly represents satisfaction with nurses and exchange of information. Global health was the only dimension of quality of life that was associated with general satisfaction. The underlying dimensions satisfaction with nurses and satisfaction with physicians, represent aspects of quality of care distinct from dimensions of quality of life. As nursing care and exchange of information seem to be the main underlying dimension of patient satisfaction, our findings may help to develop recommendations to address the needs of hospitalized patients with advanced cancer and improve end-of-life care.

Acknowledgements

We are most grateful to all patients who kindly agreed to participate in the study, and we thank physicians, nurses and other care providers from the participating hospitals for their help in collecting data.

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Chapter 3

Quality of collaboration and information handovers in palliative care: a survey study on the perspectives of nurses in the Southwest Region of the Netherlands

Engel M.
van der Ark A.
Tamerus R.
van der Heide A.

Eur J Public Health. 2020 Aug 1; 30(4):720-727

ABSTRACT

Background

When patients receiving palliative care are transferred between care settings, adequate collaboration and information exchange between health care professionals is necessary to ensure continuity, efficiency and safety of care. Several studies identified deficits in communication and information exchange between care settings. Aim of this study was to get insight in the quality of collaboration and information exchange in palliative care from the perspectives of nurses.

Methods

We performed a cross-sectional regional survey study among nurses working in different care settings. Nurses were approached via professional networks and media. Respondents were asked questions about collaboration in palliative care in general and about their last deceased patient. Potential associations between quality scores for collaboration and information handovers and characteristics of respondents or patients were tested with Pearson's chi-square test.

Results

A total of 933 nurses filled in the questionnaire. Nurses working in nursing homes were least positive about inter-organizational collaboration. Forty-six per cent of all nurses had actively searched for such collaboration in the last year. For their last deceased patient, 10% of all nurses had not received the information handover in time, 33% missed information they needed. An adequate information handover was positively associated with timeliness and completeness of the information and the patient being well-informed, not with procedural characteristics.

Conclusion

Nurses report that collaboration between care settings and information exchange in palliative care is suboptimal. This study suggests that health care organizations should give more attention to shared professionalization towards inter-organizational collaboration among nurses in order to facilitate high-quality palliative care.

INTRODUCTION

In the last months of life, the majority of patients are at least once transferred between different care settings.[1] Most transfers in the last 3 months of life involve an admission to or discharge from a hospital.[1,2] Adequate transfers of patients between care settings in palliative care are associated with lower rates of symptom crises and unplanned hospitalizations, decreased numbers of hospital deaths, and supportive needs being better met.[3,4] Adequate transfers are thus crucial for patient experiences of care in the last phase of life.[4]

Adequate transfers require adequate inter-organizational collaboration, to ensure continuity, efficiency and safety of care.[5-8] Inter-organizational collaboration has been defined as ‘a cooperative, inter-organizational relationship that is negotiated in an ongoing communicative process, and which relies on neither market nor hierarchical mechanisms of control’.[9] Auschra emphasizes that each inter-organizational collaboration underlies a dynamic, context-dependent, and history-laden process.[9]

During the last decade it has been increasingly recognized that the quality of collaboration between primary care and hospital care is often not optimal.[10] Several studies have been done on collaboration between the hospital setting and other health care providers,[5,11-13] especially in the field of chronic disease care.[6,10] Patients and family caregivers have been found to need and expect multidisciplinary and inter-organizational collaboration, but too often feel that health care professionals lack a collaborative attitude.[4,14]

Following Kodner and Spreeuwenberg,[15] Auschra categorized barriers to the integration of care in inter-organizational settings in five relevant domains, ranging from the macro to the micro level: the administrative domain, the funding domain, the (inter)organizational domain, the service delivery domain and the clinical domain.[9] The micro level as defined by Auschra involves the clinical domain, including aspects such as common professional languages; agreed understandings, practices and standards for specific diseases; and ongoing communication with patients. It also involves the service delivery domain, which is affected by factors such as staff training, interpersonal relationships between professionals, and the distribution of responsibilities and tasks. Auschra suggested several barriers for integration of care at the micro level, among which differences in professionalization, lack of trust, and lack of communication and information exchange.[9]

An important practical aspect of collaboration is the handover of information upon the transfer of patient from one care setting to another.[16] Inadequate handovers involve the risk of miscommunication, misunderstanding and the omission of critical information.[5-7,16,17] Research on information exchange has mostly focused on shift-to-shift handovers of nurses working on the same ward.[17-21] Other studies have identified deficits in information exchange between hospital and community care providers.[16,22] Information flows have been found to be inadequate and the content of written and verbal transfer information to be incomplete. Palliative care is often provided by different care organizations, and thus requires adequate information transfer to ensure that patients' needs are met. Den Herder-van der Eerden et al.[4] examined integrated palliative care initiatives in five European countries and found that informational continuity seemed to be relatively poor in all initiatives.

Nurses play a key role in inter-organizational collaboration and information exchange in palliative care, but little is known about their experiences. Therefore, we studied the following research questions:

i. What are the experiences of nurses working in different care settings with inter-organizational collaboration in palliative care?
ii. What are the experiences of nurses working in different care settings with information handovers between care settings in palliative care?

METHODS

Study design

This cross-sectional survey study was part of a larger study on continuity in palliative care in the Southwest Region of the Netherlands. The study was performed among nurses working in all care settings where palliative care is provided: care homes or nursing homes, home care, hospices, hospitals or other settings.

Study population

The study population consisted of nurses in the Southwest Region of the Netherlands working in different care settings that regularly provide palliative care. Nurses were approached via several professional networks for palliative care, professional newsletters and social media, in the period May to December 2017. We aimed for participation of a broad range of nurses. Inclusion criteria were that the respondent was practicing as a nurse with education level, according to International Standard Classification of Education (ISCED) ranging from level 3-6, and regularly provided palliative care. Nurses were invited to fill in a digital version of the questionnaire or they could ask the researchers for a paper copy.

Questionnaire

A new questionnaire was developed for this study by the research group, because available instruments did not meet our goals. We used relevant literature [23,24] and previously used questionnaires to formulate questions.[25,26] The first part of the questionnaire included questions on the respondents' work setting, age, gender, education level, working experience, being trained in palliative care and degree of urbanization of work setting.[27] The questionnaire further focused on (i) nurses' general experiences with collaboration in palliative care and (ii) their experiences with handing over information in the case of the last deceased patient they had cared for.

The part of the questionnaire on collaboration contained one question about how important inter-organizational collaboration is for the nurse, which could be answered on a four-point scale ranging from 'very important' to 'not important at all'. The survey contained general questions about nurses' collaboration with care providers from other care settings, which could be answered on a four-point scale ranging from 'always' to 'never'. Further, questions were asked about the last deceased patient nurses had cared for, socio-demographic and disease characteristics of this patient, whether the patient came from another setting, whether the nurse had received any information about the patient, and, if yes, how and what had been the impact. Statements about this information handover could be answered on a five-point scale ranging from 'totally agree' to not agree at all'. Our results entail the answers to questions about inter-organizational collaboration and information handovers between care settings.

We used two numerical scales (range 0-10) to assess the general quality of collaboration and the quality of the information handover for the last deceased patient, respectively, with a higher score representing a higher perceived quality. A full draft of the questionnaire was tested for face validity and readability among 10 nurses in different settings. Their comments were incorporated in the final version of the questionnaire.

Statistical analyses

Scores for quality of collaboration and handover of information were categorized into 'inadequate' (scores ≤ 5) and 'adequate' (scores ≥ 6). Potential associations of these dichotomized quality scores with characteristics of the respondents or patients were tested for statistical significance with the Pearson's chi-square test. The association between scores for quality of collaboration and quality of information handovers was analyzed using the Pearson correlation coefficient. All tests were two-tailed with a significance level of 0.05. Data were analyzed using the statistical program SPSS version 24.

RESULTS

Nurses characteristics

Nine hundred and thirty three nurses filled in the questionnaire. Nurses' work settings were categorized in five main groups. Of all respondents, 39% were working in home care, 18% in a hospice, 14% in a care home or nursing home, 13% in a hospital and 16% in another or in more than one setting. Sixty-eight per cent were highly educated. Most of the nurses (84%) had more than 5 years licenced nursing experience. Seventy-five per cent had received some form of training in palliative care. Fifty-four per cent worked in a strongly urbanized area, 17% in a moderately urbanized area and 24% in a rural area (table 1).

Table 1 | Characteristics of nurses by care setting

		Nurse worked in:				
		Total[a]	Care home /nursing home[b]	Home care	Hospice	Hospital
		N = 933	*N* = 130	*N* = 364	*N* = 164	*N* = 122
		n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Age (mean, SD)		45.8 (11.8)	44.9 (11.4)	46.5 (11.4)	47.6 (11.2)	39.7 (12.4)
Gender	Female	881 (94)	121 (93)	352 (97)	156 (95)	111 (91)
	Male	52 (6)	9 (7)	12 (3)	8 (5)	11 (9)
Education level[c]	Higher education level[d]	636 (68)	53 (41)	226 (62)	129 (79)	120 (98)
	Intermediate education level	295 (32)	77 (59)	136 (37)	35 (21)	2 (2)
Number of years licensed as nurse	0-2 years	79 (8)	10 (8)	31 (9)	11 (7)	16 (13)
	3-4 years	67 (7)	14 (11)	27 (7)	9 (6)	9 (7)
	5-10 years	126 (14)	17 (13)	54 (15)	10 (6)	28 (23)
	More than 10 years	661 (71)	89 (69)	252 (69)	134 (82)	69 (57)
Trained in palliative care[e]	Yes	696 (75)	95 (73)	248 (68)	157 (96)	77 (63)
	No	237 (25)	35 (27)	116 (32)	7 (4)	45 (37)
Degree of urbanization of work setting[f]	Extremely/strongly urbanized[g]	503 (54)	68 (52)	182 (50)	90 (55)	79 (65)
	Moderately urbanized	158 (17)	26 (20)	75 (21)	20 (12)	13 (11)
	Hardly/not urbanized	225 (24)	32 (25)	100 (28)	46 (28)	9 (7)

a: In this total, also a group of 153 nurses that worked in another/more than one setting is included.

b: Residential care homes and nursing homes in the Netherlands are facilities for vulnerable old and other persons, where medical care is provided by on-site (nursing home) or off-site physicians, mostly general practitioners.[41]

c: Missings: n = 2 (0%)

d: ISCED, International Standard Classification of Education: higher education level refers to higher professional (nurse) education (ISCED levels 4-6). Intermediate professional (nurse) education refers to upper secondary (nurse) education (ISCED level 3).[42]

e: Trained in palliative care: 'Yes' refers to any self-reported additional education in palliative care after degree (training in palliative care organized by own organization, basic training in palliative care organized by regional network palliative care, postgraduate continuing professional education).

f: Missings: n = 47 (5%).

g: Degree of urbanization is based on zip code of work setting, related to environmental address density [extremely urbanized (address density of 2500 or more addresses/km2); strongly urbanized (1500-2500 addresses/km2); moderately urbanized (1000-1500 addresses/km2); hardly urbanized (500-1000 addresses/km2); not urbanized (<500 addresses/km2)].[27]

Inter-organizational collaboration

Out of 933 respondents, 781 answered questions about their collaboration with other care professionals during the last year. Most nurses were rather positive: 77% indicated that in their experience professionals had ‘always’ or ‘often’ collaborated as one team in order to provide patients and their relatives with adequate care. Eighty-three per cent indicated that adequate collaboration between professionals had ‘always’ or ‘often’ improved the quality of care (table 2).

Furthermore, 46% of the nurses ‘always’ or ‘often’ actively searched themselves for collaboration with professionals from outside their own organization. Eighteen per cent regularly participated in meetings with care providers from outside their own organization. The percentage of hospice nurses participating in such meetings was highest (27%) and the percentage was lowest among care home or nursing home nurses (7%) (table 2).

Nurses’ mean quality score for collaboration with care providers from outside their own organization was 6.8 (SD 1.5). Nurses in care homes or nursing homes had the lowest mean score (6.0) and home care nurses had the highest mean score (7.1). Thirteen per cent of the nurses judged the quality of collaboration to be inadequate (score≤5), and 86% judged it to be adequate (score≥6; table 2). We found a significant difference in the appreciation of the quality of collaboration between nurses working in different care settings (χ^2, $p < 0.001$). Nurses who regularly participate in meetings to discuss individual patient care with care providers from outside their own organization, rated the quality of collaboration more often as adequate (χ^2, $p < 0.001$) than nurses who did not participate in such meetings. Further, nurses who indicated that there is a standard procedure or form to inform other care settings if a patient is transferred, more often rated the quality of collaboration as adequate (χ^2, $p < 0.01$) than nurses who did not have such a standard procedure or form. We found no significant association between nurses’ quality scores for collaboration and their age, gender, education level, numbers of years licenced as nurse, being trained in palliative care or degree of urbanization of work setting.

Transfer of information

In total, 506 out of 933 nurses (54%) indicated that they had received at least one handover of information upon the transfer of the last deceased patient they had cared for (table 3). Most patients for whom an information handover was received were 80 years or younger (74%) and had a diagnosis of cancer (76%) (table 3). Communication was partly or not possible with 29% and 13% of these patients, respectively. Symptom burden was relatively high: 56% of these patients suffered moderately or severely from three or more symptoms (table 3).

Table 2 | Experiences of nurses with inter-organizational collaboration[a]

		Nurse worked in:				
		Total[b]	Care home/ nursing home	Home care	Hospice	Hospital
		N = 781 *n* (%)	*N* = 97 n (%)	*N* = 310 *n* (%)	*N* = 144 *n* (%)	*N* = 96 *n* (%)
How important is collaboration with care providers from outside your own organization for you?[c]	Very/reasonably important[d]	719 (92)	72 (74)	299 (96)	134 (93)	89 (93)
How would you rate the quality of collaboration with care providers outside your own organization[e]	Mean (SD)[e]	6.8 (1.5)	6.0 (2.2)	7.1 (1.2)	6.8 (1.3)	6.7 (1.4)
	Inadequate (≤ 5)	104 (13)	30 (31)	26 (9)	18 (13)	15 (16)
	Adequate (≥ 6)	668 (86)	66 (68)	279 (90)	125 (87)	81 (84)
How often did it occur during the last year ….						
… that all care providers worked together as one team to provide a patient and his/her relatives with adequate care	Always/often[f]	604 (77)	84 (87)	230 (74)	114 (79)	75 (78)
… that the quality of care for a patient improved due to adequate collaboration between care providers.	Always/often[f]	649 (83)	74 (76)	264 (85)	127 (88)	71 (74)
… that the quality of care for a patient deteriorated due to inadequate collaboration between care providers	Always/often[f]	97 (12)	9 (9)	39 (13)	20 (14)	8 (8)
… that you searched for collaboration with care providers outside your own organization.	Always/often[f]	359 (46)	21 (22)	184 (59)	54 (38)	34 (35)
… that you trusted that all care providers who were involved in caring for a patient delivered good care.	Always/often[f]	642 (82)	81 (84)	257 (83)	124 (86)	75 (78)
Do you regularly participate in meetings to discuss individual patient care with care providers from outside your own organization[c]	Yes	143 (18)	7 (7)	56 (18)	39 (27)	11 (11)
Is there a standard procedure/form to inform other care settings if a patient is transferred[c]	Yes	544 (70)	64 (66)	210 (68)	102 (71)	89 (93)

a: Number of nurses that answered general questions about inter-organizational collaboration, i.e. collaboration in a broader sense than information transfer: *n* = 781

b: In this Total, also a group of 134 nurses that worked in another/more than one setting is included.

c: Missings: did not exceed 1.3%

d: Nurses could answer on a four-point scale: 'very important'/'reasonably important'/'a little bit important'/ 'not important'. Very important/reasonably important answers were combined in this table.

e: Nurses were asked to give a score on a scale from 1 to 10, with a higher score representing better quality.

f: Nurses could answer on a four-point scale: 'always'/'often'/'sometimes'/'never.' Always / often answers were combined in this table.

Table 3 | Characteristics of the last deceased patient for whom the nurse had received one or more information handovers, by care setting where the patient came from[a]

		Patient came from:			
		Total	Hospital	Home	Other care setting[b]
		N = 506 *n* (%)	*N* = 322 *n* (%)	*N* = 128 *n* (%)	*N* = 56 *n* (%)
Care setting where nurse who received handover worked	Care home/nursing home	65 (13)	31 (10)	15 (12)	19 (34)
	Home care	202 (40)	142 (44)	47 (37)	13 (23)
	Hospice	103 (20)	63 (20)	29 (23)	11 (20)
	Hospital	39 (8)	24 (8)	11 (9)	4 (7)
	Other/more than one setting	97 (19)	62 (19)	26 (20)	9 (16)
Information handover received for this patient?[c]	Yes, once	404 (80)	259 (80)	107 (84)	38 (68)
	Yes, more than once	102 (20)	63 (20)	21 (16)	18 (32)
Patient characteristics					
Gender	Female	281 (56)	176 (55)	74 (58)	31 (55)
	Male	225 (44)	146 (45)	54 (42)	25 (45)
Age	Younger than 40	20 (4)	9 (3)	2 (2)	9 (16)
	40-60 years	116 (23)	86 (27)	26 (20)	4 (7)
	60-80 years	238 (47)	159 (49)	60 (47)	19 (34)
	Older than 80	132 (26)	68 (21)	40 (31)	24 (43)
Diagnosis (multiple options possible)	Cancer	382 (76)	256 (80)	99 (77)	27 (48)
	Heart disease	59 (12)	30 (9)	20 (16)	9 (16)
	Asthma/COPD	46 (9)	29 (9)	10 (8)	7 (13)
	Diabetes	31 (6)	20 (6)	5 (4)	6 (11)
	Dementia	43 (9)	14 (4)	14 (11)	15 (27)
	Other	197 (39)	120 (37)	48 (38)	29 (52)
Phase in which nurse took care of patient (multiple options possible)	Two/three months before patient died	220 (44)	151 (47)	45 (35)	24 (43)
	Last month before patient died	224 (44)	147 (46)	55 (43)	22 (39)
	Last week before patient died	221 (44)	130 (40)	60 (47)	31 (55)
	In dying phase	87 (17)	52 (16)	20 (16)	15 (27)
	Bereavement care	90 (18)	56 (17)	20 (16)	14 (25)
	Other[d]	34 (7)	19 (6)	5 (4)	10 (18)
Communication	Possible	295 (58)	213 (66)	67 (52)	15 (27)
	Partly possible	144 (29)	83 (26)	37 (29)	24 (43)
	Not possible	67 (13)	26 (8)	24 (19)	17 (30)
Presence of symptoms[e]					
Pain	Rather/very[f]	304 (60)	203 (63)	73 (57)	28 (50)
Dyspnoea	Rather/very[f]	167 (33)	106 (33)	40 (31)	21 (38)
Fatigue	Rather/very[f]	445 (88)	289 (90)	113 (88)	43 (77)
Fear	Rather/very[f]	193 (38)	120 (37)	49 (38)	24 (43)
Depressive feelings	Rather/very[f]	137 (27)	90 (28)	31 (24)	16 (29)

Table 3 | Characteristics of the last deceased patient for whom the nurse had received one or more information handovers, by care setting where the patient came from[a] (continued)

		Patient came from:			
		Total	Hospital	Home	Other care setting[b]
		N = 506 *n* (%)	*N* = 322 *n* (%)	*N* = 128 *n* (%)	*N* = 56 *n* (%)
Number of symptoms	0 or 1 symptom	75 (15)	41 (13)	24 (19)	10 (18)
	2 symptoms	150 (30)	95 (30)	38 (30)	17 (30)
	3 symptoms	146 (29)	96 (30)	35 (27)	15 (27)
	≥4 symptoms	135 (27)	90 (28)	31 (24)	14 (25)

a: Number of last deceased patients they cared for, for whom a nurse received one or more information handovers: *n* = 506 (100%)

b: Information handover came from another setting than hospital or home (i.e. care/nursing home, hospice or other care setting).

c: Respondents were asked if they had received an information handover for the last deceased patient they had cared for. It was explained to them that it could be an information handover once or more than once, and that is was supposed to be an information handover from another organization and not an information handover in the context of 'end of shift handovers'. In total, 506 nurses answered yes to this question and answered questions about this patient.

d: In total, 26 out of 34 nurses indicated under the answer 'Other' that they cared for this patient longer than 3 months some of them up till years.

e: Respondents were asked what symptoms in their last deceased patient were present in the phase that they cared for this patient.

f: Nurses could answer on a five-point scale: 'not at all' 'a little bit' /'do not know'/'rather'/'very'. Rather/very answers were combined in this table.

In total, 448 out of 506 nurses (89%) answered questions about the last handover they had received for this patient: 69% had received it from a hospital setting, 25% from a home care setting and 6% from another care setting (table 4). Nurses mean score for the quality of the last information handover was 7.0 (SD 1.4). Eighty-nine per cent judged the quality as adequate (score≥6) and 11% judged it as inadequate (score≤5; table 4). Twelve per cent of the nurses who had received an information handover from a hospital assessed the quality as inadequate compared with 7% of the nurses who had received an information handover from a home setting and 12% of the nurses who had received an information handover from another setting. Ninety per cent of the nurses (totally) agreed that the information had been available in time. Sixty-seven per cent of the nurses (totally) agreed that the information handover contained all the information they needed and 76% agreed that the patient was well informed about his or her disease and prospects (table 4). Information was mostly handed over on a standard paper form (52%) or digital form (27%). Seventeen per cent of the nurses had received a 'warm handover of information' (with personal contact). Fourteen per cent of the nurses had received a specific palliative care handover, either on paper or digitally (table 4). Seventy-five per cent of the nurses agreed that information had been quickly available and

Table 4 | Experiences of nurses with the exchange of information upon the transfer of the last deceased patient they had cared for[a]

		Patient was transfered from:			
		Total	Hospital	Home	Other care setting
		N = 448 *n* (%)	*N* = 310 *n* (%)	*N* = 112 *n* (%)	*N* = 26 *n* (%)
How would you rate the quality of this information handover?[b]	Mean (SD, range)	7.0 (1.4, 1-10)	6.9 (1.4, 1-10)	7.3 (1.5, 1-10)	7.2 (1.3, 4-9)
	Inadequate (≤ 5)	48 (11)	37 (12)	8 (7)	3 (12)
	Adequate (≥ 6)	400 (89)	273 (88)	104 (93)	23 (88)
The information was available at the moment I started caring for the patient.	(Totally) agree[c]	402 (90)	275 (89)	103 (92)	24 (92)
The information handover contained all the information I needed.	(Totally) agree[c]	298 (67)	197 (64)	83 (74)	18 (69)
Way of information handover (multiple options possible)	Standard digital handover	120 (27)	95 (31)	16 (14)	9 (35)
	Standard paper handover	232 (52)	176 (57)	42 (37)	14 (54)
	Specific digital palliative care handover	22 (5)	14 (5)	8 (7)	0 (0)
	Specific paper palliative care handover	40 (9)	30 (10)	9 (8)	1 (4)
	‘Warm’ handover with personal contact	76 (17)	34 (11)	32 (29)	10 (39)
	Handover through email	31 (7)	14 (5)	14 (13)	3 (12)
	Unknown	19 (4)	15 (5)	4 (4)	0 (0)
The patient was well-informed about his or her disease and perspectives.	(Totally) agree[c]	342 (76)	226 (73)	97 (87)	19 (73)
Information was quickly available and transferable in unforeseen situations.	(Totally) agree[c]	335 (75)	223 (72)	90 (80)	22 (85)
Did the information exchange affect the quality of care for this patient?[d]	Yes, in a positive sense	255 (57)	172 (56)	72 (64)	11 (42)
	Yes, in a negative sense	23 (5)	20 (7)	2 (2)	1 (4)
	No	152 (34)	104 (34)	36 (32)	12 (46)
	Other	17 (4)	13 (4)	2 (2)	2 (8)
For the patient and family it was clear who was available to help them with questions or problems.	(Totally) agree[c]	386 (86)	256 (83)	106 (95)	24 (92)
For me it was clear who was available to help me with questions about care for the patient or family.	(Totally) agree[c]	409 (91)	276 (89)	108 (96)	25 (96)

a: Number of nurses that received one or more information handovers for the last deceased patient they cared for, and that answered questions about this (last) received information handover: *n* = 448 (100%)

b: Nurses were asked to give a score on a scale from 1 to 10, with a higher score representing better quality.

c: Nurses could answer on a five-point scale ‘totally agree’/’agree’/’neutral’/’not agree’/’not agree at all’. Totally agree/agree answers were combined in this table.

d: Missings: n=1

transferable in unforeseen situations. Fifty-seven per cent of the nurses reported that the information handover had positively affected the quality of care, 5% of the nurses reported that the information handover had negatively affected the quality of care (table 4).

We found that the quality of the handover of information was more often rated as adequate for patients with whom less communication was possible (χ^2, $p = 0.02$). Out of 402 nurses who (totally) agreed that the information handover was timely available, 92% scored the quality of the information handover as adequate compared with 70% of those who did not agree (χ^2, $p < 0.001$). An adequate score for the quality of the information handover was also positively associated with the information having been complete (χ^2, $p < 0.001$), the patient being well informed about their disease and prospects (χ^2, $p<0.001$), and all information being quickly available in unforeseen situations (χ^2, $p < 0.001$). We also found a positive association between the score for the quality of information handover and the score for the quality of collaboration ($r = 0.13$, $p < 0.01$, $n = 409$). We found no significant association between nurses' quality scores for information handover and patients' age, disease or symptom burden; the way of information handover, the care setting where the receiving nurse worked, the degree of urbanization of work setting or consultation of health care professionals outside her own organization.

DISCUSSION

Professionalization towards collaboration in palliative care

In our study, the large majority of nurses indicated that collaboration with care providers from other care organizations is important to them, but they were modestly positive about the quality of such collaboration, with 13% rating it as inadequate. Somewhat less than half of the nurses indicated to regularly search for inter-organizational collaboration and a minority participates in inter-organizational meetings to discuss patient care. Overall, about one in five nurses feel that the quality of care may suffer from poor collaboration.

Poor collaboration between health care professionals from different settings and professions has been associated with differences in professionalization between health care professionals. Professionalization is described as a process that serves to secure and protect exclusive areas of knowledge, skills and expertise of professionals in the health care system.[28] Auschra has suggested that different professions may have divergent cultural assumptions and professional values, and may follow different procedures.[9] Such variance can cause conflicts within inter-organizational collaborations.[9,28,29] In a systematic review of research on views from patients, carers and health care professionals on the provision of palliative care for non-cancer patients by primary care providers, Oishi & Murtagh[30] found that the role of different health care providers was perceived as unclear and that there was lack of collaboration between professionals. Alvarado & Liebig[31] found that in community-based palliative care disturbances in collaboration between family doctors and nurses are mainly caused by different professional values regarding palliative care and dying.

In our study, nurses working in care homes or nursing homes were least positive about inter-organizational collaboration. Most care homes or nursing home nurses (almost) never searched for collaboration with care providers outside their own organization. Several studies have assessed nursing home care providers' professional views regarding palliative and terminal care. In a focus group study in a municipal nursing home in Germany, Bükki et al.[32] found that interprofessional collaboration in end-of-life care was perceived as problematic by all professions, due to understaffing, ethical conflicts and lack of training. In a large survey study among long term care providers in Canada, Leclerc et al.[33] found that one in four respondents felt not comfortable sharing experienced difficulties in palliative care with colleagues. Following the literature on inter-organizational collaboration,[34] we assume that for nurses in care homes or nursing homes inter-organizational collaboration is even more complex than interprofessional collaboration within their own organization, although we do not know the reasons from the care home or nursing home nurses in our study for their moderately low rating of quality of collaboration with care providers from other settings.

As for home care nurses, their score for the quality of collaboration was the highest and their attitude toward collaboration was most positive. They also most often perceive collaboration with care providers outside their own organization as important and most often actively search for this collaboration. Our results support findings from other studies that collaboration with other care providers is an important aspect of the professionalization of home care nurses, and especially of those who provide palliative care.[35,36]

Only 38% of nurses working in inpatients hospice settings actively searched for inter-organizational collaboration, which may demonstrate that they feel that such collaboration is less necessary while hospice is the final care setting for almost all admitted patients.

We found that although many hospital nurses are often confronted with admission or discharge of patients with a limited life expectancy,[1] only 35% of them actively searched for collaboration with care providers outside their own hospital in the last year. Professional attitudes towards collaboration in palliative care with care providers from other care settings seem to differ between nurses from different care settings.

Information handovers

Nurses were moderately positive about the quality of information handovers, with handovers from home care settings scoring better than handovers from hospitals. We found few specific palliative care handovers. In accordance with other studies, timeliness and completeness of the information were strongly associated with positive evaluations of handovers.[4,6,13,22,37-39] The way of information handover was not associated with the appreciation of handovers. Our finding that handovers from hospital were more often standard digital or paper handovers and less often 'warm' handovers than handovers from home care is thus no explanation for the different appreciation of handovers. Other studies have found the opposite: no verbal information from home care nurses when patients are admitted to the hospital, while there is often a telephone call combined with written information upon patients' discharge from hospital.[22,38] However, whereas usually several nurses take alternately care of one patient, it can be questioned to what extent a 'warm' handover contributes to adequate information transfer, because verbal information is reliant on memory and details of the information may be omitted or forgotten.[22]

The appreciation of information handovers was positively associated with patients being well-informed about their disease and perspectives. One explanation for this could be that extensive information handover is less needed for patients who are well-informed and capable of giving information and expressing their care needs themselves. It may also be that in case the patient is well-informed, patient's care needs upon the transfer are more often congruent with patients' and nurses' expectations. Other studies also found that for high-quality palliative care patients must be involved by informing them about their disease and perspectives.[40] Several authors suggest that a comprehensive discharge procedure with extra information in case of complex patients may improve information transfer.[13,16,39] We did not find an association between use of specific palliative care forms and nurses' appreciation of handovers. However, whereas den Herder-van der Eerden et al.[4] found that patients and relatives felt burdened when they had to take care of information handovers themselves, such comprehensive and specific palliative care handovers may nevertheless be important for the wellbeing of patients and relatives.

Our study provides insight in the experiences with inter-organizational collaboration and information handovers of a large number of nurses working in various settings. A limitation is that nurses were openly invited to participate via several networks and media. Therefore we could not calculate a response rate and there is a possibility that selection bias occurred because respondents may have had more affinity or experience with palliative care than non-respondents. This could mean that nurses who have more affinity with palliative care were more critical and therefore rated the quality of inter-organizational collaboration and information transfer lower than non-respondents. We expect our findings to be generalizable to other parts of the Netherlands and Europe although we are not sure about the international generalizability because of differences in health care systems and education of care providers. Finally, the cross-sectional nature of our study limits the possibility to make robust causal inferences.

In conclusion, our findings show that on the micro-level professional boundaries between nurses from different care settings seem to hinder inter-organizational collaboration in palliative care. Further, our findings suggest that more shared professionalization towards inter-organizational collaboration in palliative care between nurses from different care settings may facilitate adequate collaboration and high-quality palliative care. In health care organizations more attention should be paid to this shared professionalization between nurses working in different care settings. Efforts to improve inter-organizational collaboration between nurses that regularly provide palliative care should take into account the complexity of inter-organizational collaboration.

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Chapter 4

Palliative care nurse champions' views on their role and impact: a qualitative interview study among hospital and home care nurses

Engel M.
van Zuylen L.
van der Ark A.
van der Heide A.

BMC Palliat Care. 2021 Feb 18; 20(1): 34

ABSTRACT

Background

One of the strategies to promote the quality of palliative care in non-specialized settings is the appointment of palliative care nurse champions. It is unclear what the most effective model to implement the concept of nurse champions is and little is known about palliative care nurse champions' own views on their role and responsibilities. This paper aims to describe views of palliative care nurse champions in hospitals and home care on their role, responsibilities and added value.

Methods

In 2018, a qualitative interview study was conducted with 16 palliative care nurse champions in two hospitals and four home care organizations in the southwest of the Netherlands. The framework approach was used to analyze the data.

Results

Most palliative care nurse champions described their role by explaining concrete tasks or activities. Most nurse champions perceive their main task as disseminating information about palliative care to colleagues. A few nurses mentioned activities aimed at raising awareness of palliative care among colleagues. Most nurses were to a limited extent involved in collaboration with the palliative care expert team. Hospital nurse champions suggested that more support from the palliative care expert team would be helpful. Most nurse champions feel little responsibility for organizational tasks and inter-organizational collaboration. Especially hospital nurses found it difficult to describe their role.

Conclusion

The role of palliative care nurse champions in hospital and home care varies a lot and nurses have diverging views on palliative care in these settings. Comprehensively fulfilling the role of palliative care nurse champion is a challenge. Careful selection, training, support and task descriptions for nurse champions are needed to make the concept of nurse champions work in palliative care.

BACKGROUND

Palliative care is an approach that improves the quality of life of patients with an advanced incurable illness and their families. Palliative care is mostly offered in non-specialized care settings by healthcare professionals for whom palliative care is not their main expertise.[1-3] One of the strategies to promote the quality of palliative care in non-specialized settings is the appointment of palliative care nurse champions.[1-5]

The concept of nurse champions or link nurses is applied to a range of nursing specialties, such as infection prevention and control,[6-11] tissue viability,[12,13] diabetes[14,15] and palliative care.[1,3-5,16-18] The roles and responsibilities of nurse champions vary greatly.[7] Sometimes they are mainly expected to disseminate knowledge on their focus area to colleagues.[7] In other cases they are expected to raise awareness of patients' specific care needs[1,4] or to have a leading role in the implementation of innovative care interventions.[19] Nurse champions often collaborate in a network.[2,7,19] It is unclear what the most effective model for the concept of nurse champions is.[3,7] Both in hospitals and in primary care, the model of palliative care nurse champions has been found to have much potential for contributing to high-quality palliative care.[1] In recent literature authors emphasize the potentially important role of palliative care nurse champions in adequate use of generalist palliative care versus specialist palliative care.[1,4,20] Other studies found that in hospital and in home care the palliative care nurse champion (in studies on home care also referred to as specialized palliative care community nurse) provides direct clinical care and also has an important role in transferring knowledge to other healthcare professionals.[2,21] However, several authors state that the role of palliative care nurse champion in both care settings needs more clarification, including in what phase in the illness trajectory and for what reasons they should be involved in patient care, and what their role is in relation to the palliative care expert team.[1,21] Whereas the majority of patients with an advanced incurable illness are at least once transferred between different care settings,[22] palliative care nurse champions may also play an important role in promoting adequate transfers and inter-organizational collaboration.[23-26]

Several studies found barriers to the effectiveness of nurse champion programs: nurse champions may fail to attend meetings due to a high work load,[4,27] be unable to disseminate knowledge to fellow staff[27] or have insufficient skills or experience for the position of nurse champion.[4,27] Little is known about palliative care nurse champions' own views of their role and responsibilities. The aim of this study was to describe the views of palliative care nurse champions in hospitals and home care on their role, responsibilities and added value. Therefore, we studied the following research questions:

1. How do palliative care nurse champions in hospitals and home care perceive and fulfill their role and responsibilities?
2. What do palliative care nurse champions in hospitals and home care need to adequately fill in their role and responsibilities?
3. How do palliative care nurse champions perceive their role and responsibilities in inter-organizational collaboration and transfers of patients?

METHODS

This interview study was part of a larger study on quality of palliative care in the Southwest Region of the Netherlands. We applied an explorative qualitative research approach using semi-structured interviews to assess palliative care nurse champions 'lived experience' of their role and responsibilities.[28] We conducted individual interviews in order to explore individual views and experiences.

Setting and participants

Two hospitals expressed their interest in participating in this study. In order to gain insight into the role of palliative care nurse champions in a diversity of care settings, we also asked other care organizations to participate. These care organizations differ in the type of care provided (only home care or also residential care), size of the work area and organizational model. Convenience sampling was used in different care settings that were interested in participating in the study. Participants were nurses who had the role of palliative care nurse champion within an inpatient ward in one of two hospitals or one of four care organizations, one organization only providing home care, the other three also providing care in care homes and nursing homes. All palliative care nurse champions in the two hospitals (n=9 and 12, respectively) were approached directly by email, palliative care nurse champions in the four care organizations were invited by local contact persons (i.e. n=1 to 4 nurse champions per organization). Sixteen palliative care nurse champions agreed to be interviewed: five nurses working in one hospital and five in the other hospital, and six home care nurses working in four different care organizations. The interviews were conducted in participants' workplace. Interviews in hospital lasted an average of 30 minutes and in home care organizations an average of 45-60 minutes. The palliative care nurse champions were all Registered Nurses, but had varying experience in palliative care. Seven nurse champions had completed extra training in palliative care at ISCED level 4 or 5. In the Netherlands, for the nursing specialty palliative care this is usually a one year course. In this course nurses learn to adjust interventions to the palliative care needs of patients and their loved ones; to provide information and advice to patients on a wide range of questions and uncertainties, and to deal with complex situations; to collaborate in a multidisciplinary team and provide advice to colleagues on complex care needs. Once nurses have completed this course they may call themselves palliative care nurses, although this is not a formal qualification in the Netherlands. Further, three nurses had completed a basic training in palliative care and six nurses had not followed extra training in palliative care (Table 1).

Table 1 | Characteristics of respondents

Characteristics	Number of respondents (n=16)
Gender	
Women	16
Work setting	
Hospital	10
Cardiology and neurology ward	1
Cardiovascular ward	2
Coronary Care Unit and Emergency department	1
Oncology/hematology ward	3
Pulmonology ward	2
Urology ward	1
Home care organization	6
Profession	
Registered nurse	16
Training in the field of palliative care	
Extra palliative care training at ISCED level 4 or 5 [a]	7
Basic training of one to three (half-)day courses, or e-learning	1
Minor in palliative care during nursing education	2
No extra training in palliative care	6
Years working as palliative care nurse champion	
< 1 year	2
1 - 5 years	7
6 - 10 years	4
> 10 years	3

[a] ISCED, International Standard Classification of Education: level 4 or 5 refers to higher professional (nurse) education.

Data collection

The interviews were conducted from May until November 2018. We developed an original topic guide to structure the interviews. Topics included participants' perspectives on their role and responsibilities as palliative care nurse champion, how they perceived their collaboration with the palliative care expert team and their experiences with inter-organizational collaboration in palliative care (see Supplementary file 1). Data were collected by ME.

Data analysis

Interviews were audio-recorded and transcribed. During and after the interview also field notes were made. The data were analyzed using the principles of the Framework approach, a modified form of thematic analysis that is designed to provide a systematic and transparent approach to data management and analysis.[29] Line-by-line coding of each transcript was completed using the software program NVivo 12. Codes were grouped in categories and underlying themes. We used a deductive approach, using an initial framework drawing on existing literature about the role of palliative care nurse champions. This initial framework consisted of the following elements: role in clinical practice, role in relation to the palliative care expert team, role in inter-organizational collaboration. The process of constant comparison was undertaken so that the early stages of analysis informed subsequent data collection and we would find additional information throughout the research process where possible. For example, we coded answers referring to their care for patients having palliative care needs in their ward. Subsequently, we identified subthemes related to their role in clinical care and from these subthemes we moved to elements of their role. The field notes were used as supporting material for the analysis.

We aimed for thematic saturation which was determined by consensus of the researchers that no new themes in relation to the research questions had emerged in the last interviews. Special attention was paid to commonalities and differences between individual interviews and across settings. To enhance the trustworthiness and credibility of the data analysis, we used member checking, reflexivity and audit trail. Member checking was done by sending each respondent a summary of the transcript and asking whether this summary properly reflected the interview. Respondents' feedback was added to the transcript. Reflexivity involved the use of memo writing and regular meetings with the research team to discuss the analysis. Audit trail involved extensive documentation of the research process.

Further, the research team all have experience in providing palliative care and/or doing research in palliative care. ME is a nurse non-practicing, MSc and PhD student. LvZ is (practicing) MD and professor in hospital palliative care, AvdA is MSc and junior researcher in palliative care, AvdH is MD and professor of medical care and decision making at the end of life. The researchers were and are not affiliated to any of the hospitals or care organizations involved and did not know the nurses who were approached. For reporting our findings we followed the COREQ guidelines.[30]

RESULTS

Findings from the interviews relate to the palliative care nurse champions' activities and responsibilities in patient care, their position in the care organization in relation to the palliative care expert team and their role and responsibilities in inter-organizational collaboration (Table 2).

Table 2 | Summary of palliative care nurse champions' role

Elements of palliative care nurse champions' role	Subtheme
Activities and responsibilities in patient care in a non-specialized care setting	- View on palliative care - Own knowledge of palliative care - Description of role, responsibility and added value in the ward/team
Position in the care organization in relation to the palliative care expert team	- Accessibility and frequency of asking advice regarding a patient with one or more complex problems from the palliative care expert team in this ward/ team - Experiences with providing advice - Position in relation to the palliative care expert team - Barriers/facilitators in collaboration with the palliative care expert team - Role in collaboration with the palliative care expert team
Role and responsibilities in inter-organizational collaboration	- Experience with inter-organizational collaboration - Importance attached to inter-organizational collaboration - Role in inter-organizational collaboration and information transfers - Perspective on quality of nursing/medical/ medication handovers for patients transferred from or to other care settings - Communication with regard to patients being transferred from or to other care settings

Activities and responsibilities in patient care in a non-specialized care setting

When they were asked about their role as palliative care nurse champion, hospital nurses reported varying numbers of patients who need palliative care in their ward. Numbers ranged from a small minority (cardiovascular ward) to about half of the patients (oncology/hematology ward), to almost all patients (pulmonology ward). They also reported that, as far as they knew, their role of palliative care nurse champion is not formalized. In general they described their role as being responsible for keeping their knowledge on palliative care up-to-date and informing colleagues in their ward about new insights and developments. According to most hospital nurses their role was either on hold or interwoven with their regular work as a nurse.

> *"Because this is a lung oncology ward, you don't really think about palliative care, because almost all we do is palliative care. If there is a really difficult case, and we start talking about it, it often turns out that we are already doing very well. When a physician wants to give a patient some chemo, we often say: that does not seem the right thing for this patient. Nurses are more often consulted. Physicians trust us in these things." (Hospital nurse 2, trained in palliative care on International Standard Classification of Education (ISCED) level 5)*

Most hospital nurses consider palliative care to be one of many areas for which nurse champions are appointed, and they could not indicate when they had actually started being a palliative care nurse champion. They get no extra hours or salary for activities related to this role. Hospital nurses who had had training in palliative care at ISCED level 4 or 5 (three out of five in hospital one, two out of five in hospital two) reported that they felt they could do much more, for example update guidelines or provide training. Reasons for not being able to do so included a high workload and insufficient appreciation of their palliative care expertise in the hospital. Some also reported that they miss the support of the palliative care expert team.

The views of home care nurses about which patients in their practice need palliative care vary somewhat. Some nurses mentioned patients with a life expectancy shorter than three months, others suggested that patients with a longer life expectancy or patients who are in a stable phase of their illness (e.g. Alzheimer's disease) may also need palliative care. As a result, the numbers of patients needing palliative care in their clinical practice ranged from one patient in two months to at least one patient each week.

Three out of six home care nurses reported that there is some kind of formal role description for palliative care nurse champions in their organization and that they have a few hours per week for activities related to this role. The other home care nurses had no clear role description, but felt that their role is clear to themselves and their colleagues.

Home care nurses more than hospital nurses tended to report that they consciously chose palliative care as their focus, sometimes because of personal experiences. Two out of six home care nurses did a special training in palliative care at ISCED level 4 or 5. Sharing knowledge about palliative care within the organization is considered a very important aspect of their task as nurse champion by most home care nurses. They also see a pioneering role for themselves. They could often clearly indicate when they had started and describe their tasks as nurse champion. These tasks included visiting all patients in the palliative or terminal phase of their illness, having a coaching role towards colleagues, participating in multidisciplinary home care meetings, visiting general practitioners to promote palliative care, providing training to colleagues. Unlike hospital nurses most home care nurses feel appreciated in their role by colleagues and by their organization.

> *"I am starting a new working group that will meet every six weeks, to improve collaboration with, for example, [name of local hospital]. And discuss information from within the network [local network palliative care] and other organizations. To distribute information and to ensure that knowledge reaches the right people. These things must come to life now." (Home care nurse 1, did e-learning and several courses in palliative care)*

Position in the care organization in relation to the palliative care expert team

All hospital nurses are familiar with the palliative care expert team and most consider the team easily accessible. In one hospital four out of five nurses indicated that colleagues in their ward seldom ask the expert team for advice, because they think that they have sufficient palliative care expertise themselves.

> *"We have the palliative care expert team to fall back on, to ask for advice. We are used to doing it ourselves, of course." (Hospital nurse 2, trained in palliative care on ISCED level 5)*

In the other hospital, most nurses indicated that the palliative care expert team is regularly consulted. Some nurses indicated that they would appreciate more collaboration with the palliative care expert team, but that they were awaiting an initiative from the team.

> *"I miss some kind of connection between the palliative care team and the ward. Not when it comes to patient care. [.…] But in addition to discussing a specific patient I would like to talk a bit more about education, how we are doing, do we need training [...]. Especially when it concerns geriatric patients." (Hospital nurse 6, no extra training in palliative care)*

Most home care nurses are familiar with the regional palliative care expert team, but they seldom ask the team for advice. They did not express a need for more collaboration, although some think that adding a home care nurse to the palliative care expert team could have added value.

Role and responsibilities in inter-organizational collaboration

Hospital nurses collaborate with many different care providers within the hospital. Almost all hospital nurses reported that they seldom collaborate with care providers outside the hospital. Such collaboration may involve visiting symposia or transfer of information in patient care. Hospital nurses indicated that they do not have time for more collaboration and do not see the added value. They assume that their manager or the palliative care expert team will address potential problems in such collaboration. Almost all hospital nurses assessed the quality of the handover of information upon the transfer of patients with a limited life expectancy as adequate and complete.

> *"I think that transfer nurses [in the hospital] are already doing a lot to ensure that people can go home well, by ensuring that care at home is properly arranged. And also the materials needed. And the rest is actually up to us. I believe that where there is no care at home and people are regularly admitted [to hospital], I often aim for continuity home visits. So that at least someone occasionally visits those people [In the Netherlands, in some regions, patients with a limited life-expectancy who not yet need home care, may receive 'continuity home visits' from trained home care nurses. These nurses monitor how the patient is doing and, if necessary, organize home care or other care in consultation with the patient]." (Hospital nurse 7, trained in palliative care on ISCED level 5)*

Home care nurses reported to collaborate with many other care providers: general practitioners (GPs), nursing specialists, physiotherapists, dieticians, occupational therapists, mental healthcare providers, informal care providers. However, their collaboration with hospital staff is limited.

> *"We have no consultations with the hospital. We sometimes go to the hospital to see if people are really terminal. But it is unclear how should we register that. Then it seems I'm even more unproductive [In the Netherlands, a visit to the hospital of a patient who is not (yet) registered for home care is not eligible for reimbursement]." (Home care nurse 5, trained in palliative care on ISCED level 5)*

The organization and financing of care do not facilitate more collaboration. Further, home care nurses suggest that care providers in the hospital have a perspective on palliative care that is completely different from their own. They think that in the home care situation nurses look at the whole person and environment and adapt care to the needs of the patient, whereas in hospital care is determined by care providers.

Home care nurses reported that they often only receive a standard paper or digital handover from the hospital for patients who are discharged, and that they often miss information about patients' diagnosis, prognosis, treatment plan and patients' specific care needs. They have adapted to inadequate information handovers and often ask information they need from patients and their relatives themselves. Only one of them searched actively for collaboration with the hospital.

> *"Next week I will for the first time attend a multidisciplinary meeting in [name of local hospital]. I have invited myself for this and had to insist for six weeks. It concerns a very complex patient. Otherwise the hospital will simply announce that or ask if we can take over care for this patient. I think that during the intake collaboration is already possible." (Home care nurse 1, did e-learning and several courses in palliative care)*

A few hospital nurses indicated that they also contribute to the transfer of medical information: they encourage physicians to call the patient's general practitioner to inform them about the patient, especially in case of a discharge just before the weekend.

DISCUSSION

This study shows that palliative care nurse champions vary in how they perceive and fill in their role and responsibilities. Most nurses described their role as palliative care nurse champion by explaining concrete tasks or activities. Most nurses perceive their main task to be disseminating information about palliative care to colleagues, whereas some home care nurses also mentioned raising awareness, e.g. by visiting general practitioners to promote palliative care, having a coaching role towards colleagues and promoting palliative care in general. Hospital nurses seemed to be more modest about their added value than home care nurses, which may be the result of more hierarchical relationships in hospital[31] and a greater focus on cure than in home care.[20,32]

Our findings are consistent with results from other studies, that also found that nurse champions consider passing on information and knowledge to colleagues an important strategy to influence practice.[3,5,10,16,33] Home care nurses more often than hospital nurses reported that they disseminate knowledge in a structured way, for example by providing training to colleagues. They do not seem to receive much guidance on this part of their role, although this has been demonstrated to be important.[33] In a controlled before and after study in a hospital, Witkamp et al.[4] found that the introduction of palliative care nurse champions who were trained in raising ward staff's awareness of palliative care needs, resulted in more communication about patients' imminent death.

In general, nurses in our study indicated limited collaboration with the palliative care expert team. Several studies emphasize the important supportive role of expert teams in palliative care nurse champion networks.[1,4] Besides this supportive role of the expert team, nurse champions may also facilitate the role of the expert team, by promoting that care providers consult the expert team when appropriate[1,10,18] and by assisting the expert team in providing basic palliative care education.[1,18] Nurses in our study did not actively engage in these activities, nor were they supported to do so.

Both hospital and home care nurses in general felt little responsibility towards inter-organizational collaboration and adequate transfer of information. Inter-organizational collaboration in palliative care is known to be complex and often non-optimal.[26,34-37] Based on the literature[3,4,38] and given the complexity of inter-organizational collaboration in palliative care, one may wonder to what extent a more active leadership role in striving for better inter-organizational collaboration in palliative care may be expected from nurse champions.

Nurse champions are also expected to take up an active role in implementing guidelines or in introducing new interventions.[1,4,38] In our study especially hospital nurses reported that they have little or no time for such activities and do not feel sufficiently appreciated to be able to take up this role. This confirms findings from other studies where nurse champions also mentioned a high workload[4,5,10,27,31] and lack of appreciation.[5,16,31]

The lack in taking up a leadership role may also be related to nurses' personal characteristics, such as their level of interest in palliative care,[3-5] having leadership capacities[4,38] and their ability to be assertive and enthusiastic.[3,5]

Palliative care is a relatively complex area with many unresolved issues, such as the identification of patients who need palliative care, the assessment of care needs in different domains, multidisciplinary and inter-organizational collaboration, and the responsibilities of generalist versus specialist palliative care.[39,40] It can be questioned whether, in this complex area, nurses are able to take up a comprehensive role as palliative care nurse champion, especially if they are insufficiently supported. In their qualitative systematic review of studies on the nurse's role in palliative care, Sekse et al. found that the nurses' many activities make it difficult to describe their role and responsibilities in palliative care.[41] Sekse et al. argue that there is an urgent need to clarify nurses' role and impact in palliative care.[41] The same is true for palliative care nurse champions. Our finding that especially hospital nurses with training on ISCED level 4 or 5 indicated they feel they could contribute more than they currently do may suggest that the potential of palliative care nurse champions is not fully used. Our findings add to the existing literature that, in order to support nurse champions in contributing to high-quality palliative care, the concept of palliative care nurse champion in hospital and home care needs more clarity.

Strengths and limitations of the study

A strength of our study is that the qualitative data obtained provide a valuable insight into the views of palliative care nurse champions on their role. Trustworthiness of the findings is increased by member's check and reflexivity. The fact that our questions were somewhat general and that especially in the hospitals the time available for the interviews was often limited, leaving little time for asking in-depth questions, can be considered a limitation. Therefore, we cannot be sure that saturation of the information about our research questions was reached. In order to justify the number of respondents, we also assessed the information power of the interviews conducted. With regard to the items that in interaction determine the information power of a study sample,[42] we assessed 1. our study aim as rather narrow; 2. the sample as highly specific; 3. the theoretical background about the role of palliative care nurse champions as establishing foundation for the findings; 4. the focus of the interviews as rather clear; 5. the analysis strategy moving from within-case analysis to gradually more cross-case analysis. As we did an exploratory study, the information power seems adequate[42] to offer new insights about the role of palliative care nurse champions in hospital wards and home care. Finally, caution is advised regarding transferability of our findings to other parts of the Netherlands and Europe because of differences in health care systems and in the training of nurses in the field of palliative care.

Conclusion

Our findings show that palliative care nurse champions in hospital wards and home care think differently about their role and tasks. Nurses have diverging views on palliative care in these settings. Both palliative care nurse champions in hospital and home care have the potential to increase the quality of palliative care. However, because of the complexity of palliative care, the role of nurse champion may involve a great challenge for nurses. Therefore, nurse champions should be carefully selected, trained and supported, and their role should be formalized. Care organizations should properly embed palliative care nurse champions in their organization, offer them ongoing education and ensure that they are structurally supported by the management and by the palliative care expert team.

Acknowledgements

The authors wish to thank the care organizations in which the study was conducted for their cooperation and the palliative care nurse champions who participated in the study.

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Supplementary file 1

Topic guide for interviews with palliative care nurse champions in hospital and home care

1. How would you describe your role as a palliative care nurse champion in your ward/ home care team/organization?

a. Can you tell me something about how you became involved in this position?
b. Have you completed additional training in palliative care? If so, what training, was it appropriate, do you miss knowledge or skills?
c. What are your tasks and responsibilities? (in patient care, in your team, in the organization).

2. Can you describe the discharge process of a patient …

o (for hospital nurses) going home from your ward (so transfer to the general practitioner and home care)?
o (for home care nurses) coming home after hospital admission?

3. With which care providers outside your hospital ward/home care team do you regularly collaborate?

a. What does this collaboration look like? With whom, how often, about what, are there fixed agreements?
b. What are your experiences with that collaboration?
c. How is your role as a palliative care nurse champion when collaborating with other care providers different from the role of colleagues?

4. Is there a difference in collaboration between health care professionals regarding patients with a limited life-expectancy and patients not having a limited life-expectancy? Is there a difference in information handover after patient‘s discharge from hospital to home?

5. About the quality of nursing information handovers:

o (for hospital nurses) In general, do you have the impression that the recipient (general practitioner, home care nurses) is sufficiently informed so that care can be continued properly? Do recipients ever contact you for clarification?
o (for home care nurses) In general, do you, when a patient with palliative care needs is discharged from hospital to home, receive sufficient information to be able to continue care properly? Do you contact hospital nurses if you have any questions or need for clarification?

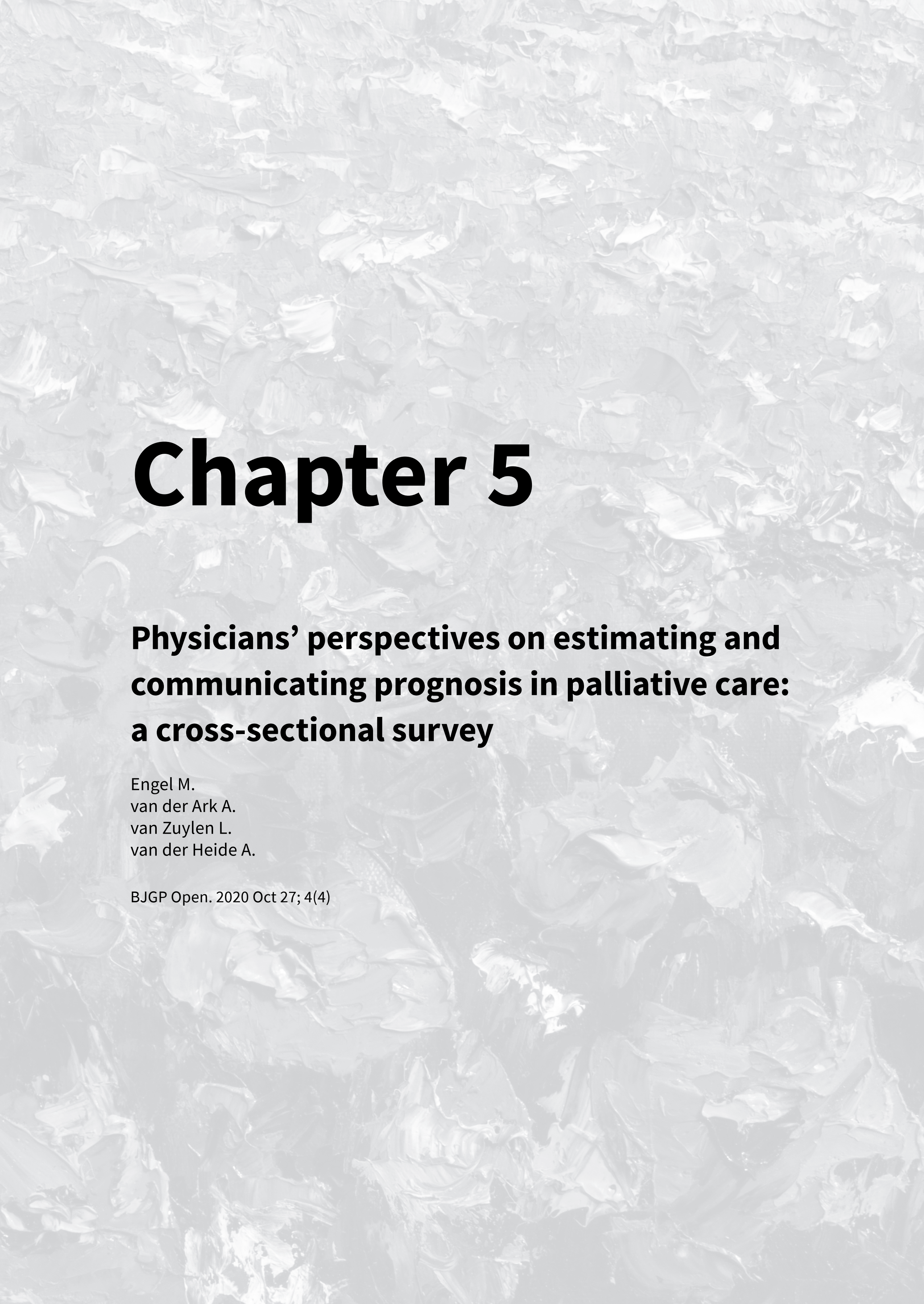
6. Is the palliative care expert team easily accessible for you? Is the palliative care expert team ever consulted in your ward/team? If so, what are your experiences with such consultations and the advice provided?

7. When would you contact the palliative care expert team? Do you have meetings with the palliative care expert team?

8. Can you tell me about the preconditions for fulfilling your position as palliative care nurse champion: available hours, management, training?

9. What is going well in the collaboration with healthcare providers within/outside your ward/team (also with other organizations) regarding patients with palliative care needs? Where is room for improvement?

10. How do you perceive your role as palliative care nurse champion in patient care? (in care of your patients, but also your role more generally in the ward/your team, your role with regard to information exchange, training of colleagues). What do you miss/need to properly fulfil your role?



Chapter 5

Physicians’ perspectives on estimating and communicating prognosis in palliative care: a cross-sectional survey

Engel M.
van der Ark A.
van Zuylen L.
van der Heide A.

BJGP Open. 2020 Oct 27; 4(4)

ABSTRACT

Background

Advance care planning (ACP) can help to enhance the care of patients with limited life expectancy. Despite physicians' key role in ACP, the ways in which physicians estimate and communicate prognosis can be improved.

Aim

To determine how physicians in different care settings self-assess their performance in estimating and communicating prognosis to patients in palliative care, and how they perceive their communication with other physicians about patients' poor prognosis.

Design & setting

A survey study was performed among a random sample of GPs, hospital physicians (HPs) and nursing home physicians (NHPs) in the southwest of the Netherlands (*n* = 2212).

Method

A questionnaire was developed that had three versions for GPs, HPs, and NHPs. Each specialism filled in an appropriate version.

Results

A total of 547 physicians participated: 259 GPs, 205 HPs, and 83 NHPs. In the study, 61.1% of physicians indicated being able to adequately estimate whether a patient will die within 1 year, which was associated with use of the Surprise Question (odds ratio [OR] = 1.65, P = 0.042). In the case of a prognosis of <1 year, 75.0% of physicians indicated that they communicate with patients about preferences regarding treatment and care, which was associated with physicians being trained in palliative care (OR = 2.02, P = 0.007). In cases where patients with poor prognosis are discharged after hospital admission, 83.4% of HPs indicated that they inform GPs about these patients' preferences compared with 29.0% of GPs, and 21.7% of NHPs who indicated that they are usually adequately informed about the preferences.

Conclusion

The majority of physicians indicated that they believe they can adequately estimate patients' limited life expectancy and that they discuss patients' preferences for care. However, more physicians should be trained in communicating about patients' poor prognosis and care preferences.

INTRODUCTION

To improve the care of patients with a life-limiting disease, it is essential to identify their preferences with regard to medical treatment and care. This process of identifying goals and preferences is thought to prevent overtreatment as well as undertreatment, and is referred to as ACP.[1-3] ACP has been shown to improve concordance between patients' own preferences and actual care, and to increase patient satisfaction with care.[4,5] A key element of ACP involves physicians estimating prognosis – especially in the case of poor prognosis – and communicating this to the patient, provided the patient is thought to be able to cope with such information.[3] Indeed, research has shown that, to some degree, all patients with a life-limiting illness want to know about the course of their illness and their likely prognosis. Such information helps them indicate their preferences with regard to treatment and care.[2,4-7]

In daily practice, ACP is complex. Patients usually receive care from multiple health care professionals from different care settings.[8] Especially in the final months of their life, the majority of patients are at least once transferred between different care settings, which often involves an unplanned hospital admission.[9] While estimating prognosis and discussing it with the patient are important at all stages of the illness trajectory of patients with a limited life expectancy,[10] both HPs and non-HPs are engaged in this part of clinical practice.[10,11] In the Netherlands, HPs, GPs and NHPs have an important role in initiating or continuing palliative care.[11-13] To ensure that patients' needs are met and their preferences are honored, physicians should also adequately communicate prognosis and related preferences to physicians from other care settings.

In palliative care, patients' desire for information has been shown to contrast with a failure by physicians to predict prognosis.[12,14,15] Studies have also shown that even if they are able to predict poor prognosis, GPs and HPs are reluctant to discuss poor prognosis and preferences regarding related treatment and care with patients and their relatives.[16-21] Other studies have identified deficits in information exchange and communication between physicians, including those working in different care settings.[22-26] Information exchange and communication are aspects of inter-organizational collaboration, which has been defined as *'a cooperative, inter-organizational relationship that is negotiated in an ongoing communicative process, and which relies on neither market nor hierarchical mechanisms of control'.*[27]

How physicians in different care settings self-assess their performance in estimating a poor prognosis and discussing it with patients has poorly been studied. Further, little attention has been paid to the experiences of physicians communicating about these issues with physicians in other care settings who are involved in the patient's care. Therefore the following research questions were studied:

1. How do physicians in different care settings self-assess their performance in estimating a poor prognosis and discussing it with patients in palliative care?
2. How do physicians in different care settings perceive their communication about patients' poor prognosis and preferences regarding treatment and care with attending physicians working in other care settings?
3. In case of a poor prognosis, how do physicians assess the quality of collaboration with physicians working in other care settings?

METHODS

Study design

This cross-sectional survey study was part of a larger study on continuity in palliative care in the southwest region of the Netherlands. The study was performed among physicians working in primary care, hospitals and nursing homes.

Study population

The study population consisted of a random sample of physicians (*n* = 2212) from a full professional registry (IQVIA database OneKey), working in different care settings in the research region. GPs, HPs and NHPs were included. Exclusion criteria were: junior doctors, and specialties that have relatively little to do with palliative care, such as ophthalmologists. A random stratified sample was taken; that is 50% (*n* = 716) of all registered GPs, 50% (*n* = 1271) of all registered HPs from most specialties, and all (*n* = 225) registered NHPs. In July 2017, physicians were invited to fill in either a paper copy of the questionnaire or a digital version. Additionally physicians were invited to participate in the study via institutes for training physicians in palliative care, and via professional newsletters.

Questionnaire

A questionnaire was developed for this study with three versions (for GPs, HPs and NHPs) to enable adequate formulation of the same questions and statements for each specialism. Questions were formulated based on earlier research about estimating prognosis[28,29] and collaboration among HPs and GPs.[22] Further, previously developed questionnaires were used.[30-32]

The general part of the questionnaire included questions on the responder's work setting, sex, age, practice experience (number of deceased patients in their practice per year), training in palliative care, self-reported use of the Surprise Question ('Would you be surprised if this patient would die in the next year?'),[14] and degree of urbanization of their work setting.

The questionnaire further focused on 1) physicians' self-assessment of their performance in estimating prognosis (1 year, 3 months, 1 week) and communicating poor prognosis to patients; 2) communicating prognosis and related wishes for treatment and care with physicians from other care settings (HPs were asked for their communication with GPs, and GPs and NHPs were asked for their communication with HPs); and 3) perceived collaboration with physicians working in other care settings for patients with a poor prognosis in the past year (HPs were asked for their collaboration with GPs, and GPs and NHPs were asked for their collaboration with HPs). The questionnaire also contained open questions about experienced bottlenecks in collaboration with care providers from other organizations. Ten physicians tested a full draft of the questionnaire to assess the applicability (comprehension, formulation, and length of time). Their comments were incorporated in the final version of the questionnaire.

Statistical analyses

The score on the numerical scale for quality of collaboration was categorized into 'inadequate' (scores ≤ 5) and 'adequate' (scores ≥6). In order to explore the potential association of responder characteristics with their self-reported performance in adequately estimating a prognosis of <1 year, a univariable regression analysis was performed. Those variables for which the association had a $P<0.30$ in the univariable analysis were entered in a multivariable analysis. Potential associations of responder characteristics with their self-reported performance in discussing wishes and expectations regarding treatment and care were explored similarly. Data were analyzed using the statistical program IBM SPSS Statistics (version 25). From the answers to open questions, after having coded them to themes, a few direct quotes were selected to illustrate the findings.

RESULTS

Physician characteristics

The questionnaire was filled in by 547 physicians: 259 GPs (36.2% of GPs in sample), 205 HPs (16.1%) and 83 NHPs (36.9%). Of all responders, 51.7% indicated that they had ≥10 patients in their practice die per year. On the issue of training, 36.4% indicated that they had received extra training in the field of palliative care, ranging from any basic training after degree to specialist palliative care training. Of all responders, 19.7% reported use of the Surprise Question. Forty-seven per cent worked in a strongly urbanized area, 22.3% in a moderately urbanized area and 24.9% in a rural area (*Table 1*).

Table 1 | Characteristics of physicians

		Physicians by care setting			
		Total	**GP**	**HP**	**NHP**[a]
		***N*=547,**	***n* = 259,**	***n* = 205,**	***n* = 83,**
Characteristic		**n (%)**	***n* (%)**	***n* (%)**	***n* (%)**
Sex[b]	Female	256 (46.8)	126 (48.6)	89 (43.4)	41 (49.4)
	Male	280 (51.2)	131 (50.6)	111 (54.1)	38 (45.8)
Age, years[c]	< 40	146 (26.7)	69 (26.6)	67 (32.7)	10 (12.0)
	40-50	155 (28.3)	75 (29.0)	62 (30.2)	18 (21.7)
	>50	237 (43.3)	114 (44.0)	72 (35.1)	51 (61.4)
Number of patients die per year[d]	< 5	82 (15.0)	27 (10.4)	54 (26.3)	1 (1.2)
	5-10	163 (29.8)	107 (41.3)	45 (22.0)	11 (13.3)
	10-20	151 (27.6)	84 (32.4)	37 (18.0)	30 (36.1)
	>20	132 (24.1)	38 (14.7)	58 (28.3)	36 (43.4)
Training in the field of palliative care[d]	Extra training[e]	199 (36.4)	118 (45.6)	39 (19.0)	42 (50.6)
	No extra training or unknown	329 (60.1)	133 (51.4)	159 (77.6)	37 (44.6)
Self-reported use of Surprise Question[f,g]	Always or often[h]	108 (19.7)	59 (22.8)	32 (15.6)	17 (20.5)
	Sometimes or never	400 (73.1)	192 (74.1)	154 (75.1)	54 (65.1)
Degree of urbanization work setting[i]	Extremely or strongly urbanized	257 (47.0)	96 (37.1)	126 (61.5)	35 (42.2)
	Moderately urbanized	122 (22.3)	49 (18.9)	47 (22.9)	26 (31.3)
	Hardly or not urbanized	136 (24.9)	112 (43.2)	6 (2.9)	18 (21.7)

[a] Nursing homes in the Netherlands are facilities for vulnerable old and other persons, where medical care is provided by on-site nursing home physicians.[44] [b] Missing: *n* = 11 (2.0%). [c] Missing: *n* = 9 (1.6%). [d] Missing: *n* = 19 (3.5%). [e] Responder is specialist in palliative care by 'specialist palliative care' education, is working as a hospice physician, or reports other expertise in palliative care. [f] 'Surprise Question': Would you be surprised if this patient would die in the next year? [g] Missing: *n* = 39 (7.1%). [h] Physicians could answer on a four-point scale: 'always', 'often', 'sometimes', 'never'. 'Always' or 'often' and 'sometimes' or 'never' answers were combined in this table. [i] Missing: *n* = 32 (5.9%). [j] Degree of urbanization is based on ZIP code of work setting, related to environmental address density;[45] 1) extremely urbanized (environmental address density of ≥2500 addresses per km^2); 2) strongly urbanized (1500-2500 addresses per km^2); 3) moderately urbanized (1000-1500 addresses per km^2); 4) hardly urbanized (500-1000 addresses per km^2); 5) not urbanized (<500 addresses per km^2). HP = hospital physician. NHP = nursing home physician.

Estimating and communicating prognosis with patient

Of all physicians, 61.1% stated that they can 'always' or 'often' adequately estimate if a patient will die within 1 year. When a patient is estimated to have a prognosis of <1 year, the majority of all physicians (75.0%) indicated that they 'always' or 'often' will discuss with the patient his or her wishes and expectations regarding treatment and care. On the issue of whether the physician would have a conversation with the patient about his or her worries, psychosocial aspects and/or meaning of life questions, 43.4% of HPs answered 'always' or 'often' compared with 73.0% of GPs and 71.1% of NHPs (*Table 2*). In univariable regression analysis, it was found that self-reported use of the Surprise Question had a statistically significant association with physicians' self-reported performance in adequately estimating a prognosis of <1 year (P = 0.025). Based on P<0.30

Table 2 Estimating and communicating prognosis with the patient

	Physicians by care setting			
	Total	**GP,**	**HP,**	**NHP,**
	***N*=547,**	***n* = 259,**	***n* = 205,**	***n* = 83,**
Statement	**n (%)**	**n (%)**	**n (%)**	**n (%)**
I can adequately estimate if a patient will die within a year.[a b]	334 (61.1)	163 (62.9)	121 (59.0)	50 (60.2)
I think it is important to consider whether a patient will possibly die within a year.[c]	416 (76.1)	197 (76.1)	157 (76.6)	62 (74.7)
If I expect a patient to die within a year, I will discuss his or her wishes and expectations regarding treatment and care.[d]	410 (75.0)	197 (76.1)	147 (71.7)	66 (79.5)
If I expect a patient to die within a year, I will have a conversation about his or her worries, psychosocial aspects and / or meaning of life questions.[e]	337 (61.6)	189 (73.0)	89 (43.4)	59 (71.1)
I can adequately estimate if a patient will die within 3 months.[f]	365 (66.7)	188 (72.6)	127 (62.0)	50 (60.2)
I think it is important to consider whether a patient will possibly die within 3 months.[g]	507 (92.7)	253 (97.7)	180 (87.8)	74 (89.2)
If I expect a patient to die within 3 months, I will discuss his or her wishes and expectations regarding treatment and care.[h]	501 (91.6)	249 (96.1)	176 (85.9)	76 (91.6)
If I expect a patient to die within 3 months, I will have a conversation about his or her worries, psychosocial aspects and / or meaning of life questions.[i]	444 (81.2)	246 (95.0)	130 (63.4)	68 (81.9)
I can adequately estimate if a patient will die within a week.[j]	416 (76.1)	206 (79.5)	145 (70.7)	65 (78.3)
I think it is important to consider whether a patient will possibly die within a week.[k]	512 (93.6)	250 (96.5)	187 (91.2)	75 (90.4)
If I expect a patient to die within a week, I will discuss his or her wishes and expectations regarding treatment and care.[l]	505 (92.3)	249 (96.1)	180 (87.8)	76 (91.6)
If I expect a patient to die within a week, I will have a conversation about his or her worries, psychosocial aspects and / or meaning of life questions.[m]	469 (85.7)	240 (92.7)	159 (77.6)	70 (84.3)

[a] Physicians could answer on a four-point scale: 'always', 'often', 'sometimes', 'never'. Only combined 'always' or 'often' answers are shown. [b] Missing total: *n* = 21 (3.8%) (GP: *n* = 6, HP: *n* = 8, NHP: *n* = 7). [c] Missing total: *n* = 15 (2.7%) (GP: *n* = 1, HP: *n* = 6, NHP: *n* = 8). [d] Missing total: *n* = 20 (3.7%) (GP: *n* = 3, HP: *n* = 10, NHP: *n* = 7). [e] Missing total: *n* = 25 (4.6%) (GP: *n* = 7, HP: *n* = 10, NHP: *n* = 8). [f] Missing total: *n* = 22 (4.0%) (GP: *n* = 6, HP: *n* = 8, NHP: *n* = 8). [g] Missing total: *n* = 17 (3.1%) (GP: *n* = 3, HP: *n* = 7, NHP: *n* = 7). [h] Missing total: *n* = 23 (4.2%) (GP: *n* = 5, HP: *n* = 11, NHP: *n* = 7). [i] Missing total: *n* = 21 (3.8%) (GP: *n* = 3, HP: *n* = 11, NHP: *n* = 7). [j] Missing total: *n* = 23 (4.2%) (GP: *n* = 6, HP: *n* = 10, NHP: *n* = 7); [k] Missing total: *n* = 17 (3.1%) (GP: *n* = 1, HP: *n* = 9, NHP: *n* = 7). [l] Missing total: *n* = 21 (3.8%) (GP: *n* = 3, HP: *n* = 11, NHP: *n* = 7); [m] Missing total: *n* = 26 (4.8%) (GP: *n* = 6, HP: *n* = 13, NHP: *n* = 7). HP = hospital physician. NHP = nursing home physician.

in univariate analysis, age (P = 0.188), practice experience (P=0.071) and self-reported use of the Surprise Question (P = 0.025) were included in the multivariable analysis. A statistically significant association was only found with use of the Surprise Question (OR = 1.65, 95% confidence interval [CI] = 1.018 to 2.688, P = 0.042). It was also found that both training in palliative care (P = 0.001) and self-reported use of the Surprise Question (P = 0.027) were statistically significantly associated with physicians' self-reported performance in discussing wishes and expectations regarding treatment and care with the patient in the case that a patient had a prognosis of <1 year. In a multivariable analysis, a statistically significant association was only found with training in palliative care (OR = 2.02, 95% CI = 1.210 to 3.384, P = 0.007).

When a patient is estimated to have a prognosis of <3 months or <1 week, 66.7% and 76.1% of all physicians respectively stated that they can 'always' or 'often' adequately estimate this. More than nine in 10 physicians will then 'always' or 'often' discuss with the patient his or her wishes and expectations regarding treatment and care (*Table 2*).

Communicating prognosis and collaboration with physicians working in other care settings

In cases where it is determined in the hospital that a patient has a serious incurable disease, 94.1% of the HPs indicated that they would 'always' or 'often' inform the GP. The study found 86.1% of GPs and 59.0% of NHPs indicated that they have 'always' or 'often' been adequately informed about this by HPs (*Table 3*).

In cases where a patient with a limited life expectancy is discharged after an unplanned admission to the hospital, 77.1% of HPs indicated that they 'always' or 'often' inform the GP about the prognosis of the patient, compared with 43.6% of GPs and 28.9% of NHPs who indicated that they are 'always' or 'often' adequately informed about this. With regard to wishes and agreements of or with the patient about treatment and care, 83.4% of HPs indicated that they 'always' or 'often' adequately inform the GP about this, compared with 29.0% of GPs and 21.7% of NHPs who indicated that they are 'always' or 'often' adequately informed about this (*Table 3*).

Physicians' mean score for quality of their collaboration with physicians from other care settings with regard to care for patients with a limited life expectancy was 7.2 (standard deviation [SD] 1.2). NHPs had the lowest mean score (6.2) en HPs the highest mean score (7.5). Of all physicians, 30.5% indicated that poor collaboration with physicians from other care settings 'always' or 'often' hinders them in providing adequate care to patients with a limited life expectancy (*Table 3*).

Table 3 | Communicating prognosis with physicians working in other care settings, and perceived quality of collaboration

	Physicians by care setting		
	GP,	**HP,**	**NHP,**
Statement (GP/NHP or HP variant)	***n* = 259**	***n* = 205**	***n* = 83**
	***n* (%)**	***n* (%)**	***n* (%)**
GP/NHP: In case it is determined in the hospital that a patient has a serious incurable disease, I am adequately informed about this.[a, b]	223 (86.1)	193 (94.1)	49 (59.0)
HP: In case it is determined in the hospital that a patient has a serious incurable disease, I inform the GP adequately.			
GP/NHP: Collaboration with care providers from the hospital is important for me to be able to provide good care.[c]	233 (90.0)	190 (92.7)	74 (89.2)
HP: Collaboration with the GP is important for me to be able to provide good care.			
GP/NHP: In case a patient known to have a limited life expectancy is admitted to hospital unscheduled, I am informed about this within 48 hours.[d]	187 (72.2)	127 (62.0)	29 (34.9)
HP: In case a patient known to have a limited life expectancy is admitted to hospital unscheduled, I inform the GP adequately.			
GP/NHP: In case a patient with a limited life expectancy is discharged after being admitted to hospital under my responsibility, I am informed about this within 24 hours.[e]	186 (71.8)	187 (91.2)	55 (66.3)
HP: In case a patient with a limited life expectancy is discharged after being admitted to hospital under my responsibility, I inform the GP adequately.			
GP/NHP: In case a patient with a limited life expectancy is discharged after an unplanned admission to hospital, I (GP or NHP) receive adequate information from the hospital about[f]:			
HP: In case a patient with a limited life expectancy is discharged after an unplanned admission to hospital, I (HP) inform the GP adequately about:			
… the medical situation of the patient	217 (83.8)	193 (94.1)	52 (62.7)
… the psychosocial situation of the patient	39 (15.1)	127 (62.0)	11 (13.3)
… the prognosis of the patient	113 (43.6)	158 (77.1)	24 (28.9)
… the medication that patient uses	221 (85.3)	187 (91.2)	77 (92.8)
… wishes and agreements of or with patient about treatment and care	75 (29.0)	171 (83.4)	18 (21.7)
GP/NHP: In case a patient dies in hospital during admission, I am informed.[g]	223 (86.1)	187 (91.2)	26 (31.3)
HP: In case a patient dies in hospital during admission, I inform the GP about this within 24 hours.			

Table 3 | Communicating prognosis with physicians working in other care settings, and perceived quality of collaboration (continued)

		Physicians by care setting		
		GP,	**HP,**	**NHP,**
GP/NHP: In case a patient dies outside the hospital, I ensure that the treating HP is informed about this.[h]		142 (54.8)	31 (15.1)	40 (48.2)
HP: In case a patient dies outside the hospital, I am informed about this.				
GP/NHP: Poor collaboration with the HP hinders me in providing good care to patients with a limited life expectancy.[i]		86 (33.2)	41 (20.0)	40 (48.2)
HP: Poor collaboration with the GP hinders me in providing good care to patients with a limited life expectancy.				
Quality of collaboration with the hospital (was asked to GP and NHP) or with the GP (was asked to HP) for patients with a limited life expectancy in the past year.[j]	Mean (SD)[k]	7.3 (1.0)	7.5 (1.1)	6.2 (1.3)
	Inadequate (≤5)	10 (3.9)	6 (2.9)	21 (25.3)
	Adequate (≥6)	245 (94.6)	190 (92.7)	62 (74.7)

[a] Physicians could answer on a four point scale: 'always', 'often', 'sometimes', 'never'. Only combined 'always' or 'often' answers are shown. [b] Missing total: $n = 14$ (2.6%) (GP: $n = 4$, HP: $n = 4$, NHP: $n = 6$). [c] Missing total: $n = 9$ (1.6%) (GP: $n = 5$, HP: $n = 4$, NHP: $n = 0$). [d] Missing total: $n = 22$ (4.0%) (GP: $n = 5$, HP: $n = 10$, NHP: $n = 7$).

[e] Missing total: $n = 25$ (4.6%) (GP: $n = 8$, HP: $n = 10$, NHP: $n = 7$). [f] Missing total for '…the medical situation of the patient': $n = 14$ (2.6%) (GP: $n = 4$, HP: $n = 10$, NHP: $n = 0$). '…the psychosocial situation of the *patient'*: $n = 13$ (2.4%) (GP: $n = 2$, *HP:* $n = 11$*,* NHP: $n = 0$*)*. '…the prognosis of the patient'*:* $n = 20$ (3.7%) (GP*:* $n = 5$, HP: $n = 15$, NHP: $n = 0$). '…the medication that patient uses': $n = 15$ (2.7%) (GP: $n = 4$, HP: $n = 11$, NHP: $n = 0$). '…wishes and agreements of/with patient about treatment and care': $n = 19$ (3.5%) (GP: $n = 7$, HP: $n = 10$, NHP: $n = 2$). [g] Missing total: $n = 24$ (4.4%) (GP: $n = 6$, HP: $n = 11$, NHP: $n = 7$). [h] Missing total: $n = 19$ (3.5%) (GP: $n = 2$, HP: $n = 10$, NHP: $n = 7$). [i] Missing total: $n = 12$ (2.2%) (GP: $n = 4$, HP: $n = 8$, NHP: $n = 0$). [j] Missing total: $n = 13$ (2.4%) (GP: $n = 4$, HP: $n = 9$, NHP: $n = 0$). [k] Physicians were asked to give a score for the quality of collaboration with physicians from outside their own organization on a scale from 1 to 10 with a higher score representing a higher assessment of quality; an inadequate score was ≤5, an adequate score was ≥6. HP = hospital physician. NHP = nursing home physician. SD = standard deviation.

In answers to open questions, 421 out of 547 respondents reported ≥1 bottlenecks in their collaboration with care physicians from other care settings; 34 physicians mentioned that they experienced few or no bottlenecks. If physicians reported bottlenecks, most mentioned themes were: communication and exchange of information (*Table 4*).

Table 4 | Open answers: experienced bottlenecks in collaboration between GPs/NHPs (their perspectives) and HPs, and between HPs (their perspectives) and GPs[a]

	Physicians by care setting		
	GP, *n* = 259	**HP, *n* = 205**	**NHP, *n* = 83**
Communication and/or consultation, *n*	120 Quote: *'Too little communication, would like to be called by hospital about diagnosis, discharge, prognosis etc, now I know sometimes nothing, neither about the wishes of the patient than I know nothing.' (GP 95)*	98 Quote: *'Especially the difficult accessibility of general practitioners both in and outside working hours is a problem. In addition, not all details of the GP are known and readily available.' (HP 116)*	47 Quote: *'Communication about the seriousness of the situation and limited treatment possibilities is sometimes not provided. The nursing home must then still bring the bad news.' (NHP 82)*
Exchange of information, *n*	102 Quote: *'Too late information: patient is with me after hospital visit without me being informed, and wants to talk to me about decisions to be made. Especially a problem in case of interim changes.'(GP 31)*	21 Quote: *'Not always feedback from a general practitioner when care is transferred, only then suddenly contact again in an emergency situation.' (HP 122)*	46 Quote: *'Rarely enough information about the patient's wishes around end of life.' (NHP 66)*
No or few bottlenecks, *n*	15	17	2

[a] 421 responders reported ≥1 bottlenecks in collaboration with physicians from other care settings. Open answers were coded to themes, with a maximum of four themes for one answer. Some examples of quotes are given in the table. HP = hospital physician. NHP = nursing home physician.

DISCUSSION

Summary

The results of this study suggest that the majority of physicians believe they can adequately estimate a patient's limited life expectancy, and, in cases where prognosis is poor, discuss the patient's wishes with the patient. However, this study also suggests that information transfer and communication concerning patients' wishes for treatment and care can be improved. Multivariable analysis showed a statistically significant association between use of the Surprise Question and physicians' self-reported performance in adequately estimating a prognosis of <1 year, and between training in palliative care and self-reported performance in discussing preferences regarding treatment and care in case where a patient has a prognosis of <1 year.

Strengths and limitations

A strength of our study is that a random sample was surveyed from a professional registry of GPs, HPs and NHPs in the research region. A limitation is that the questions about estimating and communicating prognosis were somewhat general, which may have resulted in the physicians' responses representing their views on the subject rather than their actual behavior. It is expected that the findings can be generalizable to other parts of the Netherlands and Europe, although caution is advised because of differences in healthcare systems and in the education of care providers. Finally, the cross-sectional nature of the study limits our possibility of making robust causal inferences.

Comparison with existing literature

A significant association was found between use of the Surprise Question and physicians' self-reported performance in adequately estimating a prognosis of <1 year. In general, the process of estimating prognosis and communicating this to patients has been found to be complex. Studying nuances of this process appears to be difficult given the great diversity in patients and disorders, and in care settings.[10,21] In a systematic review of predictions of survival in palliative care, White *et al.* found no sub-group of physicians that consistently performed better in estimating prognosis.[10] The finding that physicians using the Surprise Question reported better performance in adequately estimating a prognosis of <1 year, supports studies that mention the Surprise Question as a simple and feasible tool helping physicians to adequately identify patients with palliative care needs. [14,15,33] Nevertheless, the Surprise Question has a rather low specificity and positive predictive value, which means that many patients unexpectedly live longer than 1 year[15,33]. The main purpose of estimating patients' prognosis is not necessarily to inform the patient about their estimated life expectancy in years, months or weeks. Rather, the emphasis is on communicating with the patient about their deteriorating situation.[3,14,34] Nevertheless, in cases where a physician expects a patient to die within a year, 21.4% of the physicians surveyed here indicated that they would not talk to the patient about their wishes and expectations. Possible explanations for this finding are that these physicians consider it the role of an attending physician working in another care setting,[11] that physicians feel that the patient cannot cope with such information [19,20] or restraint on the part of physicians regarding the value of ACP.[11,35]. The finding could also be related to the healthcare reimbursement system in the Netherlands: only since 2018 can HPs request reimbursement for an '*extensive consultation for careful consideration of treatment options, together with the patient and/or his/her representative*' (translated from Dutch).[36]

On the other hand a significant association was found between being trained in palliative care and discussing preferences regarding treatment and care in case a patient has a prognosis of <1 year. This finding supports findings from other studies.[13,21] Thoonsen *et al.* found that 1 year after the start of a training program on how to provide structured anticipatory palliative care, GPs performed significantly better in estimating a limited life expectancy and in providing multidimensional care.[13] In a review and synthesis of best practices in communication about serious illness care goals, Bernacki *et al.* found that training of HPs is one of the most promising interventions to promote conversations with patients about preferences regarding end-of-life care.[21]

In general, when physicians were asked about their collaborations with physicians from other care settings for patients with a limited life expectancy in the past year, they were moderately positive, with HPs giving the highest mean score for the quality of collaboration, and NHPs the lowest. Considerable differences were found in experiences between the hospital and non-hospital physicians: while HPs often stated that they adequately inform the GP about patients with a limited life expectancy, GPs and NHPs often indicated that they are not adequately informed. It was also found that, in the experience of GPs and NHPs, the handover from the HP often lacks information regarding prognosis and patients' wishes for treatment and care. Other studies have also found such deficits.[8,37-39]. With regard to palliative care, den Herder-van der Eerden *et al.*[8] and Seamark *et al.*[39] concluded that the information exchange between health care providers from different care settings in palliative care is relatively poor.

There are a number of explanations for the differences that were found between physicians. First, HPs may overestimate the frequency and content of their own communication with patients. A second explanation could be that HPs do not document this information adequately. Other studies found that around 30% of treatment and care preferences – as expressed by the patient – were documented in the medical record.[17,40] This indicates that the proportion of HPs in the study who communicate with patients about poor prognosis and related preferences is probably higher than the proportion who document this adequately in the medical record. This lack of documentation probably leads to inadequate information in the medical handover.

A third possible explanation is that it is unclear for the HP exactly when patients' wishes and expectations should be communicated, and to what extent this is part of their role and responsibilities.[11,17] This may have to do with differences in professionalization regarding ACP. Professionalization is described as a process that serves to secure and protect exclusive areas of knowledge, skills and expertise of professionals in the health care system.[41] This means that physicians in different care settings have different professional values and follow different procedures.[27,41,42] Other studies have found differences in terminology and in attitudes towards palliative care and ACP between physicians working in different care settings.[28,40,43]

Implications for practice

In conclusion, the findings suggest that more shared professionalization towards ACP and communicating prognosis in palliative care may facilitate collaborative partnership in ACP between physicians working in different care settings. To achieve this, first, professional physicians' associations should, in mutual consultation, give direction to the coordination of roles and responsibilities related to ACP. Second, education and training in practice require more attention for communicating poor prognosis and related preferences with patients and with other physicians.

Acknowledgements
The authors wish to acknowledge the physicians who gave feedback on drafts of the questionnaire and who participated in the study. They also wish to extend their thanks to Sanne Tamerus MSc, research assistant, for her research support and for her work on the database, and to Sally Hill MSc, medical writer and language consultant, for editing parts of the manuscript.

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Chapter 6

Quality of hospital discharge letters for patients at the end of life: a retrospective medical record review

Engel* M.
van der Padt-Pruijsten* A.
Huijben A.M.T.
Kuijper T.M.
Leys M.B.L.
Talsma A.
van der Heide A.

* Both authors contributed equally.

Eur J Cancer Care (Engl). 2021 Oct 26: e13524 (Published online first before inclusion in an issue)

ABSTRACT

Objective

For patients who are discharged to go home after a hospitalization, timely and adequately informing their general practitioner is important for continuity of care, especially at the end of life. We studied the quality of the hospital discharge letter for patients who were hospitalized in their last year of life.

Methods

A retrospective medical record review was performed. Included patients had been admitted to the hospital during the period January 1 to July 1, 2017; had died within a year after discharge.

Results

Data were collected from records of 108 patients with cancer or other diseases. For 57 patients (53%), the discharge letter included information that related to their limited life expectancy (e.g. agreements about treatment limitations), whereas the patient's limited life expectancy was addressed in the medical record in 76 cases (70%). We found related information in discharge letters for 36 patients (66%) who died <3 months compared to 21 patients (40%) who died 3-12 months after hospitalization ($p<0.01$).

Conclusion

For patients with a limited life expectancy going home after a hospitalization, one out of two hospital discharge letters lacked any information addressing their limited life expectancy. Specific guidelines for medical information exchange between care settings are needed.

INTRODUCTION

For patients receiving care in different care settings, information exchange between these settings is important for their safety and for the continuity of care. Such exchange could e.g. involve the transfer of information from an emergency department to a hospital ward,[1,2] from an Intensive Care Unit to a hospital ward,[3] between attending physicians in hospital wards,[4,5] and between hospital care providers and care providers at home.[6] Hospital discharge letters are an important means to ensure continuity of care when patients are admitted and subsequently discharged from the hospital.[7,8] Several studies have identified deficits in information exchange between hospital physicians and general practitioners.[7,9-12] To improve communication during and after a patient's hospitalization between hospital physicians and general practitioners, professional physicians' associations have developed guidance for information exchange. This has resulted in several standards and guidelines.[13-15] In the Netherlands, the Dutch Association of Medical Specialists and the Dutch Association of General Practitioners jointly developed a guideline for information exchange between general practitioners and medical specialists (HASP).[16,17] Essential elements of information exchange in case hospitalized patients are discharged to go home are[16,18]:

- a structured hospital discharge letter that includes information on: reason for admission, comorbidities, assessments, diagnosis and treatment, clinical situation of the patient at the moment of discharge and recommendations about the continuation of care for the general practitioner;
- this hospital discharge letter should be sent within 24 hours after discharge.

Guidelines to exchange information between hospital physicians and general practitioners for patients with complex problems, e.g. patients with cancer or older frail patients, include some additional elements. In the HASP, for example, for patients who had a (new) diagnosis of cancer a time out procedure is recommended to consider all treatment options. No information is given about information exchange addressing end of life care for patients with advanced cancer or another life limiting disease.

Cancer is one of the most common causes of death. In the Netherlands, in 2018 a total of 46.657 persons died from cancer which was almost one third (30%) of the total of deceased persons in that year.[19] Therefore end-of-life care often concerns patients with cancer. Transitions between care settings of patients with cancer and other diseases in the last 6 months of life are common.[20-22] Most transfers in the last three months of life involve admission to or discharge from a hospital.[22] A timely and adequate hospital discharge letter is even more crucial for these patients, because treatment goals and preferences for care may change in the last phase of life.[23-25] Knowledge about the patient's medical condition and about decisions and agreements regarding medical treatment can support the general practitioner in addressing the patient's care needs.[8] Other studies found that the majority of all patients with cancer would prefer to talk with their general practitioner about end of life issues and also value support from their general practitioner in making treatment decisions.[26] Stegmann et al. found that patients with incurable cancer preferred their healthcare professional to take the initiative for this conversation.[27] These findings make adequate information exchange and communication regarding treatment goals and preferences of patients with a limited life expectancy even more important.

Therefore, we performed a retrospective medical record review to examine the timeliness and quality of the hospital discharge letter for patients with a limited life expectancy who are discharged after a hospitalization. We assessed how many days after discharge the hospital discharge letter was sent to the general practitioner. We also studied whether the hospital discharge letter included information about the patient's prognosis and agreements with the patient and family about treatment, care and medication, and compared this to whether and how these topics were described in the patient's medical record.

METHODS

Design and study population

We conducted a retrospective medical record study in the Maasstad Hospital, a large teaching hospital in Rotterdam, the Netherlands. Records of patients of age 18 years or older were included if the patient had been admitted to the hospital at least once during the period January 1, 2017 to July 1, 2017 and had died within a year after discharge from the hospital; had one of the following diagnoses: incurable malignancy, heart failure, kidney failure, or lung failure; and had gone home upon discharge from the hospital. We selected records that included a hospital discharge letter to the patient's general practitioner. In case the patient had been admitted more than once during the study period, we collected data on the last hospitalization that preceded death. We defined 'home' as the place where the patient used to live before the hospital admission. Exclusion criteria were: a stay in the hospital of less than 24 hours; death during the hospitalization.

A total of 1283 patients were admitted at least once to the hospital during the study period. From these 1283 patients, a total of 277 patients had died within one year after their (last) hospital discharge, according to the municipal death registry. For 242 out of these 277 deceased patients, the hospital's administration system indicated that a discharge letter had been sent to their general practitioner. Patients did not receive a copy of the letter. These 242 patients were randomly assigned a sequential study number and odd numbers were selected for this study. Out of 121 selected patients, 13 were excluded because they turned out not to comply with the inclusion criteria: the discharge letter was not found in the hospital medical record or patients had not gone home upon their discharge (Figure 1). Two data collectors were trained in collecting data for this study using a self-developed questionnaire.

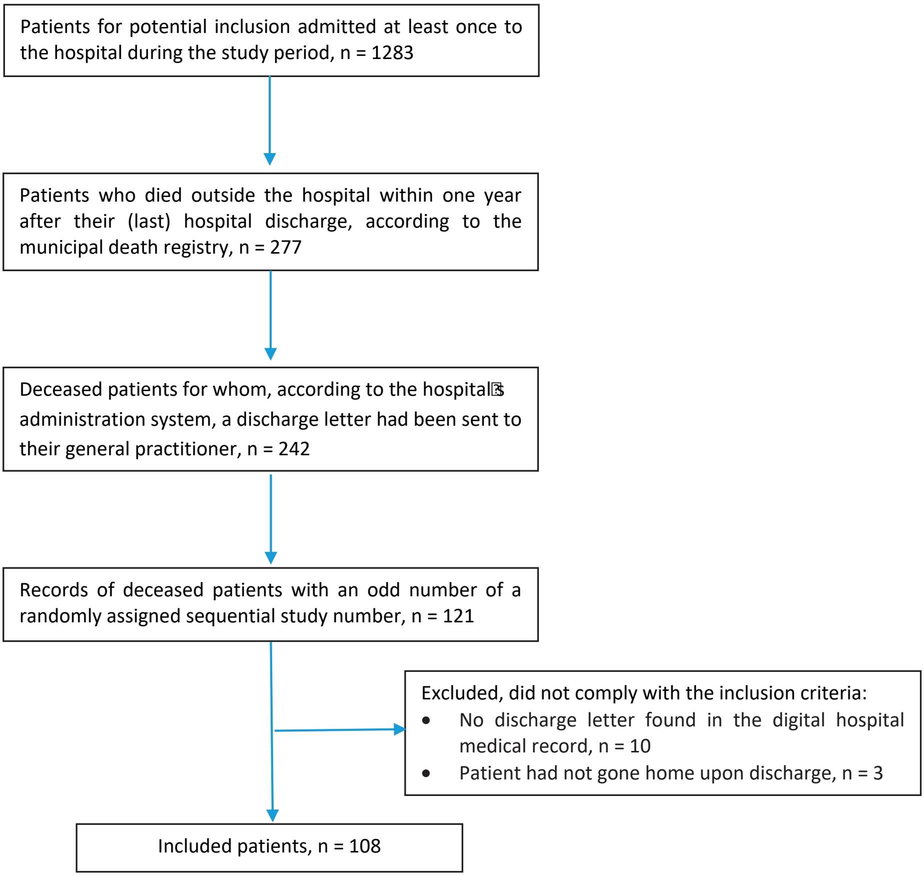

Figure 1 | Flow chart of inclusion

Data collection

We developed a questionnaire for the data collection based on guidelines for hospital discharge letters[9,12,16] and on literature about continuity of care of patients in the last phase of life.[28-30]

We collected data on the following patient characteristics: gender, age at death, diagnosis, whether the hospital admission had been planned, reason for the hospital admission, duration of the hospital admission in days, discharge destination, months of survival of the patient after the hospital admission.

The hospital discharge letter was checked for presence of following items: the date the patient was admitted to the hospital, the duration of the hospital admission, the patient entry route for hospitalization, the discharge destination, a concise conclusion or diagnosis, the care and interventions during the hospitalization, guidance for care at home, use of medication at the time of discharge, medication that was stopped during the hospitalization and (outpatient) clinical follow-up appointments.

We also checked whether patients' limited life expectancy was addressed during the hospitalization, by looking for notes on these items in their medical file: indications of the patient's limited life expectancy, discussions and agreements with patient and family about preferences for treatment and care, for example documentation of a do-not-resuscitate order (DNR-order), advance care directives completed by the patient or information whether the palliative care expert team had been involved.

Furthermore, we assessed when the hospital discharge letter had been sent and whether the hospital physician had contacted the patients' general practitioner by telephone before the patient's discharge.

Data analysis

The results are presented by descriptive statistics. The association between presence of information on patients' limited life expectancy in the medical record or the hospital discharge letter and characteristics of patients was tested for statistical significance with Pearson's chi-square test. Data were analyzed using the statistical program SPSS version 25.

RESULTS

Patient characteristics

One hundred and eight patients were included in our study. The median age when they died was 74, and 53% were male. Fifty-four percent of patients had incurable cancer (17% lung cancer, 6% hematologic or lymphoid cancer, 31% another type of solid tumor), 22% had lung failure, 12% heart failure and 12% another diagnosis. For 82% of the patients their hospital admission was unplanned and for 84% symptom management was the reason for hospital admission. Fifty-one percent of all patients died within three months after their hospital admission (Table 1).

Table 1 | Patients' demographics and disease characteristics

		Total (n=108) n (%)
Gender	Male	57 (52.8)
	Female	51 (47.2)
Age at death	18 - 40 years	0 (0.0)
	40 - 60 years	11 (10.2)
	60 - 80 years	64 (59.3)
	≥ 80 years	33 (30.6)
Diagnosis	Cancer	58 (53.7)
	Lung failure (COPD, interstitial lung disease)	24 (22.2)
	Heart failure	13 (12.0)
	Kidney failure	11 (10.2)
	Other	2 (1.9)
Hospital admission was	Unplanned	89 (82.4)
	Planned	19 (17.6)
Reason for hospitalization	Symptom management	91 (84.3)
	Other	17 (15.7)
Duration of hospital admission in days (median, range)		6 (1-32)
Discharge destination	Home	96 (88.9)
	Nursing home	2 (1.9)
	Other (e.g. home of family member)	10 (9.3)
Survival after hospital admission	0 - 3 months	55 (50.9)
	3 - 6 months	20 (18.5)
	6 - 9 months	19 (17.6)
	9 - 12 months	14 (13.0)

Timeliness of the discharge letter

For 6% of all patients the hospital discharge letter was sent within two days upon discharge, for 29% between 2 and 6 days, for 23% between 7 and 13 days, and for 38% it was sent 14 days or more after discharge. For three patients the discharge letter was sent before discharge, for two patients the date the discharge letter was sent was unclear. For six patients the hospital physician had contacted the patient's general practitioner by telephone to notify that the patient was coming home after a hospital admission.

General information in the hospital discharge letter

All discharge letters included information about the date patient was admitted to hospital, and most included information on the duration of the hospital admission (94%), the discharge destination (87%), a concise diagnosis or conclusion (94%), and the care and interventions during the hospitalization (81%). Guidance for care at home (63%), a description of the entry route through which the patient was admitted to the hospital (32%), and information on outpatient follow-up appointments (68%) were less often present (table 2). Furthermore, for 87% of all patients the letter included information about the medication used and for 71% of all patients it included information about medication that was stopped during the hospitalization (Table 2).

Table 2 | Information present in the hospital discharge letter

Items addressed in the hospital discharge letter	n=108 (%)
Date patient was admitted to hospital	108 (100.0)
Duration of hospital admission	101 (93.5)
Patient entry route for hospitalization†	35 (32.4)
Discharge destination	94 (87.0)
A concise diagnosis or conclusion	101 (93.5)
Care and interventions during the hospitalization	87 (80.6)
Guidance for care at home	68 (63.0)
Current medication use	94 (87.0)
Medication stopped during the hospital admission‡	77 (71.3)
Any (outpatient) follow-up appointments or treatments	73 (67.6)

†For 35 patients (32.4%) the information in the discharge letter about the entry route for hospitalization was clear, for 24 patients (22.2%) it was not clear, for 49 patients (45.4%) the discharge letter included no information about the patient's entry route for hospitalization.

‡For 19 patients (17.6%) medication was stopped during the hospital admission, but this was *not* mentioned in the discharge letter. For 12 patients (11.1%) no medication was stopped during the hospital admission, and no information was mentioned in the discharge letter.

Information on patients' limited life expectancy in the medical record and the hospital discharge letter

We found information regarding a limited life expectancy in the medical record for 76 (70%) of all patients, whereas for 57 (53%) of patients this information was found in the hospital discharge letter (table 3). For 28 (26%) of all patients the limited life-expectancy was explicitly mentioned in the medical record, compared with 21 (19%) of all patients for whom we found such information in the hospital discharge letter. Whether preferences for treatment and care had been discussed with the patient and/or family, was documented in the medical record of 52 (48%) of the patients, compared with 28 (26%) of the patients for whom the hospital discharge letter included this information. Information regarding agreements that had been made with the patient and/or family about treatment limitations or discontinuation of treatment was documented in the medical record of 69 (64%) of all patients, compared with 55 (51%) of the hospital discharge letters. Whether any advance care directives were completed by the patient was documented in the medical record of 2 (2%) of the patients compared with 1 (1%) of the hospital discharge letters. For 32 (30%) of all patients no information about a limited life-expectancy was found in the medical record and for 51 (47%) no such information was found in the hospital discharge letter. Furthermore, information about involvement of the palliative care expert team was present in both the medical record and the discharge letter for 5% of all patients.

Table 3 | Extent to which patients' limited life expectancy was addressed in the medical record and hospital discharge letter

Items addressed	In hospital medical record	In hospital discharge letter
	n = 108 n (%)	
Any information about patients' limited life expectancy	76 (70.4)	57 (52.8)
Prognosis:		
o Yes, by indicating a life expectancy of max. days /weeks/months/one year	2 (1.9)	0 (0.0)
o Yes, by indicating that care was oriented at symptom control or palliative needs	26 (24.1)	21 (19.4)
o No	48 (44.4)	36 (33.3)
Discussion of preferences for treatment and care with patient and/or family	52 (48.1)	28 (25.9)
If yes, items discussed†:		
o Potential treatment limitation or discontinuation	38 (35.2)	
o Symptom control/comfort care	21 (19.4)	
o Palliative sedation	4 (3.7)	
o Euthanasia	1 (0.9)	
Agreements made with patient and/or family about treatment limitations	69 (63.9)	55 (50.9)
If yes, items addressed in agreement†:		
o Do-Not-Resuscitate	63 (58.3)	46 (42.6)
o No artificial respiration	57 (52.8)	45 (41.7)
o No ICU admission	53 (49.1)	42 (38.9)
o Comfort care only	14 (13.0)	4 (3.7)
o Other‡	6 (5.6)	9 (8.3)
o Advance care directive(s) completed by patient	2 (1.9)	1 (0.9)

†Multiple answers possible.
‡'Other' includes: no antitumor treatment, no treatment of infections, no dialysis, no blood transfusion, no defibrillation, no readmission to the hospital, no life-prolonging treatment.

Information about the limited life expectancy was present in the medical record of 50 patients (91%) who died within three months and for 26 patients (49%) who died after more than three months (p<0.01). In the hospital discharge letter this information was present for 36 patients (66%) who died within three months after their hospital admission and for 21 patients (40%) who died after more than three months (p<0.01) (table 4). In the hospital discharge letter, we also more often found information about a limited life expectancy for patients with cancer compared to patients with other diseases, but this difference was not statistically significant (p=0.090). The extent to which patients' limited life expectancy was addressed in the medical record and discharge letter was not associated with other patient characteristics.

Table 4 Extent to which patients' limited life expectancy was addressed in medical record and the hospital discharge letter according to patient characteristics

		Hospital medical record included information on patients' limited life expectancy			Hospital discharge letter included information on patients' limited life expectancy		
		Yes n (%)	No n (%)	p-value*	Yes n (%)	No n (%)	p-value*
Age at death				0.416			0.508
	Up to 80 years (n=75)	51 (68.0)	24 (32.0)		38 (50.7)	37 (49.3)	
	80 years and older (n=33)	25 (75.8)	8 (24.2)		19 (57.6)	14 (42.4)	
Diagnosis				0.616			0.090
	Cancer (n=58)	42 (72.4)	16 (27.6)		35 (60.3)	23 (39.7)	
	Non-cancer (n=50)	34 (68.0)	16 (32.0)		22 (44.0)	28 (56.0)	
Hospital admission was				0.062			0.125
	Unplanned (n=89)	66 (74.2)	23 (25.8)		50 (56.2)	39 (43.8)	
	Planned (n=19)	10 (52.6)	9 (47.4)		7 (36.8)	12 (63.2)	
Reason for hospitalization				0.086			0.116
	Symptom management (n=91)	67 (73.6)	24 (26.4)		51 (56.0)	40 (44.0)	
	Other (n=17)	9 (52.9)	8 (47.1)		6 (35.3)	11 (64.7)	
Duration of hospital admission in days				0.520			0.408
	1 to 6 days (n=59)	40 (67.8)	19 (32.2)		29 (50.9)	30 (50.8)	
	7 days and longer (n=49)	36 (73.5)	13 (26.5)		28 (57.1)	21 (42.9)	
Survival after hospital admission				0.000			0.007
	0 - 3 months (n=55)	50 (90.9)	5 (9.1)		36 (65.5)	19 (34.5)	
	3 - 12 months (n=53)	26 (49.1)	27 (50.9)		21 (39.6)	32 (60.4)	

*Pearson's chi-squared test

DISCUSSION

We studied the quality of hospital discharge letters for patients who went home after a hospitalization within one year before they died. In our population, half of the patients were diagnosed with incurable cancer and one third had lung or heart failure. Most patients were admitted to the hospital for symptom management. For most patients in our study, many items as suggested in guidelines were documented in the hospital discharge letters, e.g. concise conclusion or diagnosis (94%) and current medication (87%). However, there is room for improvement for the items 'clinical care plan' (81%) and 'suggestion for care plan at home' (63%). A major area of concern is the time of sending the discharge letter. In our study, the discharge letter was sent within two days after discharge for only 6% of all patients, whereas guidelines in the Netherlands prescribe that this should be done within 24 hours after discharge.[12,16]

For two thirds of all patients (70%), hospital physicians had documented information about patients' limited life expectancy, such as poor prognosis, discussed preferences for treatment and care, and agreements about treatment limitations (e.g. DNR-orders) in the medical record. However, in half of all patients, this information was not addressed in the hospital discharge letter.

Several studies have emphasized the importance of adequate care transitions for patients with a limited life expectancy going home after a hospital admission.[6,31,32] The discharge process and information exchange between health care professionals in the hospital and at home are known to be complex and often suboptimal. Studies on continuity of care are mainly qualitative and describe the perspectives of health care professionals or patients and their family or relatives. Only a few studies focus on the actual content or timeliness of the information exchange in discharge letters for patients with several diseases, more or less clearly also including patients with a limited life expectancy.[6,12]

It is obvious that not all patients can be recognized as having a limited life expectancy, and that, for example, a do-not resuscitate order is not always related to a limited life expectancy. However, adequate information exchange is also important for patients with a limited life expectancy of more than three months, because it can contribute to high-quality palliative care.[26,27] In our study for one in four patients their limited life expectancy was documented in the medical record but lacking in the discharge letter. Other studies also found deficits in the exchange of information between care settings regarding patients with palliative care needs.[6,28,33] In a survey about estimating and communicating about patients' poor prognosis, it was found that 83% of 205 hospital physicians indicated that they usually inform general practitioners about agreements regarding treatment and care for patients with a limited life expectancy who are discharged from hospital, whereas only 29% of 259 general practitioners indicated that they are usually adequately informed about such patients.[34]

We found that information on preferences for treatment and care that had been discussed with the patient and/or family was often lacking in hospital discharge letters, even if it was documented in the medical record. This finding supports results from several other studies in which it was found that documentation by hospital physicians of what is discussed with hospitalized patients about preferences for treatment and care is poor.[17,35]

Information about patients' limited life expectancy was more often found in the medical record and hospital discharge letter for patients who died within three months after hospital admission than for patients who died after more than three months. Other studies also found that physicians tend to find it difficult to estimate or discuss a limited life-expectancy of more than 3 months.[34,36] Other reasons for not documenting such information could be that the hospital physician feels that the patient cannot cope with such information,[37,38] uncertainty of prognostication and about these conversations[6,39,40] or that the hospital physician does not perceive this to be his or her responsibility.[6,30,41] Nowadays, patients in the Netherlands and other countries often have access to (part of) their electronic record themselves. In addition, sharing of electronic records between healthcare services is also increasing. Therefore, it is even more important that information in the medical record is discussed with the patient and their relatives and that related information is adequately documented. Furthermore, several studies show that patients, family carers and health care professionals all value adequate exchange of information about a poor prognosis and preferences for treatment and care.[28,42-44]

Strengths and limitations

A strength of this study is that it is one of the few studies in which the hospital discharge letter and the medical record were studied from randomly chosen patients with cancer or other diseases who died within one year after hospital admission. Another strength is that we had very few missing data. Limitations are that this is a single-site study and that we did not study nursing information handovers for these patients. Another limitation is that we may have missed information that was communicated or transferred between the hospital physician and general practitioner but not documented in the medical record. We expect that our findings are representative for the Netherlands and possibly for other countries in Europe, although caution is advised because of differences in health care systems and in the role of the general practitioner.

Clinical implications

Based on our findings, attention is needed for the importance of a timely and adequate transfer of information for patients with a limited life expectancy who are discharged after a hospital admission. Guidelines for the exchange of information between hospital physicians and general practitioners do not offer specific guidance for patients with a limited life expectancy. Therefore, it may be helpful to add a specific section in guidelines for information exchange between hospital physicians and general practitioners for patients in the last phase of life. The hospital discharge letter for these patients should at least contain information about the patient's prognosis, whether preferences for treatment and care were discussed with the patient and/or family, whether agreements about treatment limitation were made (e.g. DNR-order), a clinical care plan and a suggestion for a care plan at home. An example of a Dutch intervention to improve accurate and timely information exchange from hospitals to other health care settings, is the Transfer Intervention Procedure (TIP).[12] This intervention is also based on the Joint Commission International Standards in which the importance of effective communication among caregivers and continuity of care is addressed.[15] It includes a structured discharge procedure for all patients admitted to a hospital; in TIP, specific information could be added for patients with a limited life expectancy.[12] Standardized discharge procedures, such as TIP, may improve the timeliness and content of the hospital discharge letter,[12] but more research on the effects of these procedures is needed. Further, in education and training of hospital physicians more attention should be paid to a timely and adequate information transfer regarding patients with a limited life expectancy who are discharged after a hospital admission.

In conclusion, for patients with a limited life expectancy going home after a hospitalization, one out of two hospital discharge letters lacked information that is important for the general practitioner in providing adequate care during the last phase of life. The quality of the hospital discharge letter for patients in the last phase of life should be improved, e.g. by better training hospital physicians and by improving procedures and guidelines for medical information exchange between care settings.

Research ethics and patient consent

This study was conducted in accordance with the Declaration of Helsinki. According to Dutch legislation, written informed consent of the patients was not required because data were gathered after the patients' death by healthcare professionals of the hospital and processed anonymously. The study was approved by Medical research Ethics Committees United (MEC-U) on March 5, 2019 (Registration No W19.052). Subsequently, on April 10, 2019, the Board of Directors of the Maasstad Hospital gave permission to conduct this study in their hospital.

Acknowledgements

The authors would like to thank T. van der Graaf of the Team Business Intelligence of the Maasstad Hospital for initial patient selection. They would also like to thank C. van

Leijen, D.L.A. Sprokkereef and T.J. van Niekerk-Boneveld for data collection and entry. Further they wish to extend their thanks to the Palliative Care Network Rotterdam & surroundings for their support of this study and financial contribution to a program aimed to improve the exchange of information for patients with a limited life expectancy between hospital physicians of the Maasstad Hospital, Rotterdam, The Netherlands, and general practitioners.

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Chapter 7

Development and implementation of a transmural palliative care consultation service: a multiple case study in the Netherlands

Engel M.
Stoppelenburg A.
van der Ark A.
Bols F.M.
Bruggeman J.
Janssens-van Vliet E.C.J.
Kleingeld-van der Windt J.H.
Pladdet I.E.
To-Baert A.E.M.J.
van Zuylen L.
van der Heide A.

BMC Palliat Care. 2021 Jun 5; 20(1): 81

ABSTRACT

Background

In the Netherlands, healthcare professionals attending patients in the last phase of life, can consult an expert palliative care team (PCT) in case of complex problems. There are two types of PCTs: regional PCTs, which are mainly consulted by general practitioners, and hospital PCTs, which are mainly consulted by healthcare professionals in the hospital. Integration of these PCTs is expected to facilitate continuity of care for patients receiving care in different settings. We studied facilitators and barriers in the process of developing and implementing an integrated transmural palliative care consultation service.

Methods

A multiple case study was performed in four palliative care networks in the southwest Netherlands. We aimed to develop an integrated transmural palliative care consultation service. Researchers were closely observing the process and participated in project team meetings. A within-case analysis was conducted for each network, using the Consolidated Framework for Implementation Research (CFIR). Subsequently, all findings were pooled.

Results

In each network, project team members thought that the core goal of a transmural consultation service is improvement of continuity of palliative care for patients throughout their illness trajectory. It was nevertheless a challenge for hospital and non-hospital healthcare professionals to arrive at a shared view on goals, activities and working procedures of the transmural consultation service. All project teams experienced the lack of evidence-based guidance on how to organize the service as a barrier. The role of the management of the involved care organizations was sometimes perceived as unsupportive, and different financial reimbursement systems for hospital and out-of-hospital care made implementation of a transmural consultation service complex. Three networks managed to develop and implement a transmural service at some level, one network did not manage to do so.

Conclusions

Healthcare professionals are motivated to collaborate in a transmural palliative care consultation service, because they believe it can contribute to high-quality palliative care. However, they need more shared views on goals and activities of a transmural consultation service, more guidance on organizational issues and appropriate financing. Further research is needed to provide evidence on benefits and costs of different models of integrated transmural palliative care consultation services.

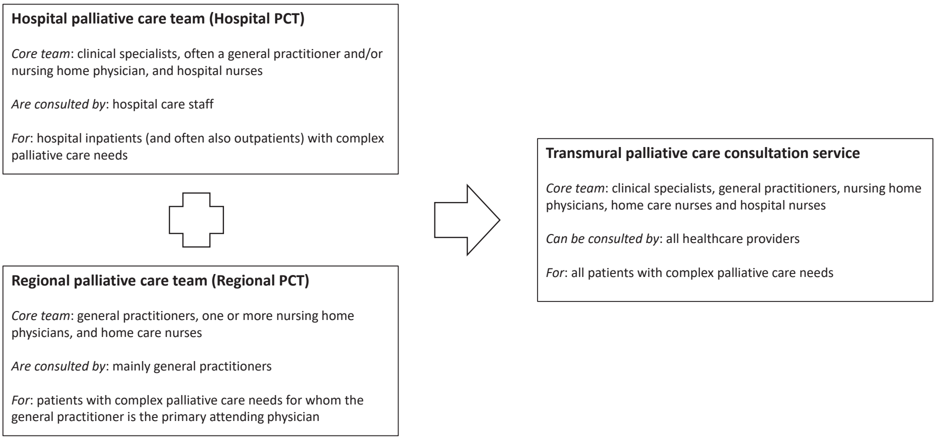
BACKGROUND

Patients with a limited life-expectancy due to progressive illness or frailty often need care from different care providers in different care organisations.[1] The majority are at least once transferred between different care settings during the last months of life.[2] Adequate transmural care and collaboration between healthcare professionals from different organizations is therefore important.[3-5] Transmural care should be attuned to the needs of the patient and provided on the basis of co-operation and co-ordination between general and specialist caregivers, with shared overall responsibility and specification of delegated responsibilities.[6] Transmural care typically involves collaboration between healthcare professionals working in and outside the hospital setting.[7,8] During the last decade it has been increasingly recognized that the quality of collaboration between healthcare professionals from different care organizations is often not optimal.[9-11]

In the Netherlands, one of the strategies to promote transmural collaboration in palliative care is the establishment of so-called regional palliative care networks by the Dutch Ministry of Health, Welfare and Sport.[12,13] In these networks, care organizations such as hospitals, care and nursing homes, home care organizations, general practitioners, hospices and volunteers work together to optimize the provision of palliative care within a specific region. Networks have a basic structure that includes a steering group or management team consisting of representatives from participating care organizations, and a patient care-oriented member group consisting of healthcare professionals. Each palliative care network has appointed a network coordinator.[14] In total there are 65 palliative care networks, covering the whole country.[14]

One of the main tasks of palliative care networks is to facilitate the integration of generalist palliative care, provided by physicians and nurses and other healthcare professionals in all care settings, and specialist palliative care, for more complex cases.[15-17] Within networks, generalist care providers attending patients with complex problems can consult a regional expert palliative care team (PCT). PCTs typically include palliative care specialists from several disciplines. They provide advice to the physician or nurse attending the patient, but do not take over care.[18] Regional PCTs can be consulted by healthcare professionals in all settings, but the majority of requests for advice come from general practitioners.[19] Hospital PCTs were originally intended to improve the quality of hospital palliative care and most hospital PCTs can only be consulted for inpatients.[20] In the Netherlands, regional PCTs have been established since 2004.[21] The first hospital PCT was established in 1993,[22] with a strong rise in the number of hospital PCTs between 2014 and 2017. Currently, there are 34 regional PCTs and every hospital has its own hospital-based PCT.[19,20,23]

Integration of regional and hospital-based PCTs into a transmural palliative care consultation service may facilitate continuity of care for patients receiving care in different settings. However, such integration has proven to be complex and there is no evidence-based or experience-based best model available. To better understand how a transmural palliative care consultation service can be implemented, we studied the facilitators and barriers that affected the process of developing and implementing a transmural palliative care service in four palliative care networks in the southwest region of the Netherlands. The main models of palliative care consultation services in the Netherlands are presented in Figure 1.



Hospital palliative care team (Hospital PCT)

Core team: clinical specialists, often a general practitioner and/or nursing home physician, and hospital nurses

Are consulted by: hospital care staff

For: hospital inpatients (and often also outpatients) with complex palliative care needs

Regional palliative care team (Regional PCT)

Core team: general practitioners, one or more nursing home physicians, and home care nurses

Are consulted by: mainly general practitioners

For: patients with complex palliative care needs for whom the general practitioner is the primary attending physician

Transmural palliative care consultation service

Core team: clinical specialists, general practitioners, nursing home physicians, home care nurses and hospital nurses

Can be consulted by: all healthcare providers

For: all patients with complex palliative care needs

Figure 1 | Main models of palliative care consultation services in the Netherlands
The general procedure for consultation is: a nurse has the role of front guard, performs an initial exploration of the problem, and, if possible, immediately provides the advice. In case medical expertise is needed, the nurse asks a physician to discuss the case with the applicant and to provide an advice. In case expertise from outside the core team is needed, a dedicated group of healthcare professionals from other disciplines can be involved.

METHODS

Study design and setting

In an inventory of challenges in palliative care as experienced in eight palliative networks in the southwest region of the Netherlands, transmural collaboration was unanimously identified as the main issue. Based on this finding, networks were invited to participate in an action research program on transmural collaboration in palliative care. Within this program, four independent palliative care networks opted for the bottom-up development of a transmural palliative care consultation service within their network. Experiences in these four networks were used for this multiple case study, with researchers (ME and AvdA) closely observing the process and participating in meetings of the project teams. A multiple case study design allows for comparisons to be made across a number of cases and can serve ‘to generate in-depth, multi-faceted understanding of a complex issue in its real-life context’.[24] The development and implementation of the transmural consultation service in four network regions were considered as four cases. An action research approach was used for data collection and data analysis. Action research is context-bound and participative, and aims at improving practice. It is a continuous learning process in which the researcher learns and also shares newly generated knowledge with those who may benefit from it.[25]

In general, a regional PCT consists of general practitioners, one or more nursing home physicians, a hospice physician and home care nurses with palliative care expertise. A hospital based PCT consists of several medical specialists, often a general practitioner and/or nursing home physician, and hospital nurses with palliative care expertise. In each network a project team was formed. The size and composition of the project teams varied. Some project teams consisted mainly of palliative care experts working for either the existing regional or hospital PCT, others also included representatives from the participating organizations’ management. The total number of meetings of the project teams within a period of about 30 months varied between 5 and 18 (table 1).

Data collection

The process of the development and implementation of a transmural palliative care consultation service started early 2017 and, for this analysis, ended in December 2019. We collected mostly qualitative data in all four networks, during meetings of the project teams and of the PCTs.

In concordance with our action research approach, the data collection was open and responsive to the needs of the project teams.[25] The researchers collected data during observations of meetings, informal conversations and documents. During the meetings, the researchers made minutes and field notes on processes of communication and collaboration between project team members and within PCT’s, and on the barriers and facilitators they perceived. They also took notes of individual contacts with project team members, and collected project plans and other information related to the development and implementation of the transmural palliative care consultation service. Project teams were regularly provided with feedback and the research team regularly discussed which data should be further elaborated.

The Consolidated Framework for Implementation Research (CFIR), that identifies factors that influence an intervention’s implementation, was used as a conceptual framework in the data collection and analysis.[26-28] The CFIR includes five major domains, each consisting of a number of constructs[26,28]:

Table 1 | Characteristics of regional palliative care networks (networks), palliative care teams and project teams

Network characteristics	**A**	**B**	**C**	**D**
Number of inhabitants in network region in 2017	415.000	460.000	380.000	425.000
Number of deceased patients in network region in 2017	3958	4286	3722	4275
Number of hospitals in network region	1	1	2	2
Number of member organizations	10	20	23	28
Geographical characteristics	A medium-sized city with surroundings	A medium-sized city with surroundings	Three rural sub-regions, with medium-sized cities as well as rural regions	Two sub-regions: a medium-sized city with surroundings and a rural region
Palliative care team (PCT) characteristics				
Baseline situation in 2017	One hospital PCT and one regional PCT (based in another region)	One hospital PCT and one regional PCT	Two hospital PCTs and one regional PCT	Two hospital PCTs and one regional PCT
	No earlier attempts to develop one transmural palliative care consultation service	At the start of the current program, both teams had already prepared a business plan for further integration of the hospital PCT and regional PCT	At the start of the current program, the hospital PCTs and regional PCT already shared consultants. No earlier attempts to develop one transmural palliative care consultation service	No earlier attempts to develop one transmural palliative care consultation service
Hospital PCT				
· Number of consultations in **2017**	56	33	For one hospital: unknown, for the other hospital: <3	Unknown
Regional PCT				
· Number of consultations in **2017**	<10*	11	26	47
Project team characteristics				
Total number of members of the project team	10	14	11	11
Members of the project team				
Physicians				
- General practitioner	1	1	1	2

Table 1 | Characteristics of regional palliative care networks (networks), palliative care teams and project teams (continued)

Network characteristics	A	B	C	D
- Hospital physician	-	3	2	1
- Nursing home physician	1	2	2	2
Nurses or nursing managers				
- Home care nurse	1	1	-	-
- Hospice nurse	1	-	-	-
- Hospital nurse	2	2	2	2
- Nursing home nurse	1	1	1	-
Others:				
· Project team coordinator	1	1	1	1
· Network coordinator	1	1	1	1
· Representative of the Netherlands Comprehensive Cancer Organization (IKNL)	-	1	-	1
· Researcher	1	1	1	1
Number of meetings of the project team	14	18	9	5 and several meetings of sub-teams

* This network had no regional PCT. Healthcare providers could consult a regional PCT in a nearby region.

1. Intervention: the features of the intervention that is implemented. Constructs within this domain are, for example, the relative advantage of implementing the intervention versus an alternative solution, and perceived difficulties of the intervention.
2. Inner setting: the features of the implementing organization. Constructs within this domain are, for example, the implementation climate: the degree to which stakeholders perceive the current situation as needing change, the level of priority attached to the intervention, organizational incentives, the degree to which goals are clearly communicated, and readiness for implementation.
3. Outer setting: the features of the external context or environment. This domain includes, for example, relevant external policies and incentives.
4. Characteristics of individuals involved in the implementation. This domain includes, for example, individuals' knowledge and beliefs about the intervention and individuals' identification with 'their' organization and its goals.
5. Implementation process: the strategies or tactics used for the implementation of the intervention, such as planning, executing, reflecting, and evaluating.

Data analysis

Data from observations, conversations, meetings and documents were analyzed using the five major domains of the CFIR, to get insight into the characteristics of each case, including barriers and facilitators. For each case, we listed all factual information within the appropriate domain and underlying construct of the CFIR. Within this information, we identified elements that could potentially be considered as facilitator or barrier for developing and implementing a transmural consultation service. Emerging facilitators and barriers were further investigated in an iterative process of data collection and data analysis. Finally, for each case we had a list of facilitators and barriers within each domain of the CFIR. Subsequently, all findings were pooled together. All steps in the analytical process were initially performed by the researcher who collected the data within a case (ME or AvdA), in collaboration with the project team involved. Their initial findings were regularly discussed by the research team until consensus on the interpretation of the findings was reached.

RESULTS

Characteristics of networks and PCTs

The four palliative care networks participating in this study were comparable in terms of geographical size and annual number of deaths within the network region (table 1). The number of member care organizations varied from ten to twenty-eight. At the start of the project, each network included two or three PCTs, one regional and one or two hospital-based.

In the following account of the results of the project, we distinguish the perspectives and experiences of project team members, who had the task of developing a model for the transmural consultation service (Figure 1), from those of the healthcare professionals working for the service. For each of the domains from the CFIR, the facilitators and barriers found are summarized in table 2.

Intervention characteristics

In all networks, project team members agreed that the core added value of a transmural consultation service is the improvement of the continuity of palliative care for patients throughout their illness trajectory, regardless of the care setting. Continuity of palliative care can also be a challenge when patients are transferred from one care setting to another, for example for patients going home after a hospital admission, where GPs may not be adequately informed about patients’ needs, their prognosis or agreements about care and treatment. Some project team members thought that transmural collaboration can also increase the awareness of healthcare professionals in different settings of the availability of an expert consultation service and serve as a vehicle for other activities in the field of palliative care, such as education or transmural collaboration.

Table 2 | Facilitators and barriers that affected the process of developing and implementing a transmural palliative care consultation service

Domain	Constructs	Main findings
Intervention characteristics	The relative advantage of implementing the intervention	***Facilitators**:* Healthcare professionals perceived the added value of the intervention as · improving continuity of care for patients with a limited life expectancy, regardless of the care setting; · a potential vehicle function for other activities in the field of palliative care; · promoting more transmural collaboration between palliative care experts from hospital and from primary care.
	Perceived difficulties of the intervention	***Barriers**:* · Healthcare professionals had different views on goals and activities of the transmural palliative care consultation service. · Scientific evidence for a complex intervention such as a transmural palliative care consultation service is scarce. · Where the researchers presented scientific evidence that supported (part of) the complex intervention, project teams often questioned presented findings and doubted whether these were applicable in their case.
Inner setting	The implementation climate: the level of priority attached to the intervention, organizational incentives, the degree to which goals are clearly communicated	***Facilitators**:* · Networks identified transmural collaboration as an important challenge. · Initial support from the management of involved care organizations was perceived as supportive. ***Barriers**:* · Healthcare professionals experienced limited positive stimuli from involved care organizations. · Involved care organizations sometimes had limited interest/doubts/resistance regarding the development of a transmural consultation service, because they felt there was insufficient evidence to demonstrate its benefits and cost-effectiveness. · Project teams experienced a lack of 'best practices' or other guidance in how to organize the service.
	Readiness for implementation	***Facilitators**:* · Networks voluntarily opted to participate in the project. ***Barriers**:* · The management of involved care organizations sometimes turned out to be reluctant when concrete efforts were required. · Registration of transmural consultations in patients' medical files was found to be complex because of different registration systems within and outside the hospital.

Table 2 | Facilitators and barriers that affected the process of developing and implementing a transmural palliative care consultation service (continued)

Domain	Constructs	Main findings
Outer setting	Relevant external policies and incentives	***Facilitators**:* · Project team members considered the Netherlands Quality Framework Palliative Care and the Multidisciplinary Standards for Oncological Care in the Netherlands (SONCOS norms) for hospitals as very supportive. ***Barriers**:* · Healthcare professionals and other participants involved expressed a need for national guidance, but also wanted to adapt the intervention to the local situation. · Separate funding streams for the financing of intra- and extramural palliative care consultations made the administrative part of the transmural consultation service complex. · On top of the regular reimbursement, extra financial support was needed, but often lacking.
Characteristics of individuals involved in the implementation	Individuals' knowledge and beliefs about the intervention	***Facilitators**:* · Palliative care experts participating in the transmural palliative care consultation service experienced collaboration and mutual exchange of information as important. ***Barriers**:* · Professionals from different care organizations having different views on palliative care, working procedures and about who was in control over the initiative made collaboration sometimes more complex. · (After implementation:) Several extra efforts being required from healthcare professionals participating in the transmural palliative care consultation service, without diminishing their regular tasks, made healthcare professionals reluctant to do, for example, extra tasks for the transmural consultation service such as attending meetings. · Different participants (healthcare professionals, coordinators, managers) asked for different motivators for the actions needed.
	Individuals' identification with 'their' organization	***Facilitators**:* · Project team members wanted to share their clinical expertise and experience within the project team and/or the transmural consultation service. ***Barriers**:* · Identification of project team members with other than their own care organization in the palliative care network was limited. · Roles and responsibilities of project team members regarding the development of transmural procedures were not clear.
Implementation process	Planning Executing Reflecting Evaluating	***Facilitators**:* Professionals from different care organizations were dedicated and enthusiastic about the initiative. ***Barriers**:* · Professionals had difficulties to arrive at a problem definition, a concrete goal and appropriate actions. Professionals perceived limited/no guidance on how to write a project plan and how to develop and implement a transmural consultation service in the relatively complex area of palliative care.

> *In network A, during a meeting in which the project team discussed the main bottlenecks related to continuity of care in their network, they mentioned as a common problem that patients with complex palliative care needs living at home, are often hospitalized more than once in the last months of their life. One reason seems to be that hospital physicians find it difficult to actively give responsibility to the general practitioner for palliative care during this phase. Further, general practitioners and community nurses do not always know how to fulfill their role in palliative care. A transmural consultation service was expected to help solve this bottleneck in the continuity of care by advising all involved physicians on the best care for a patient and by supporting care providers in the organization of palliative care at home.*

It was considered important that the transmural consultation service includes healthcare staff from different care settings and different disciplines, to be able to address diverse medical and nursing problems; if necessary, other disciplines should be available for problems in other domains. An actively involved hospital physician, who lobbies for support from the hospital management, turned out to be a facilitator for the development of the service. Some members of the project teams wanted to build their project plan on scientific evidence, because they thought that would help to get support from their management. However, scientific evidence for a complex intervention such as a transmural consultation service is scarce. In addition, where the researchers presented scientific evidence that supported (part of) the complex intervention, project teams often questioned presented research findings and doubted whether these findings were applicable in their case.

Inner setting

In three networks, participants perceived the project as bottom-up initiated. In the fourth network project team members perceived the project as top-down initiated. In all project teams most participants often perceived the ownership of the initiative as unclear. Healthcare professionals participating in the project often felt insufficiently supported by their management. Before the start of the project, all networks had identified transmural collaboration as an important challenge in palliative care. They voluntarily opted to participate in the project and to develop a transmural consultation service in their region. After the start of the project, however, project teams experienced a lack of ‘best practices’ or other guidance in how to organize the service. They further felt that establishing a transmural consultation service is by definition complex, because of the involvement of different care organizations. The management of the care organizations involved in the project sometimes turned out to be reluctant when confronted with the efforts that were required for the actual development or implementation of the service.

> *In network D, the manager of a transmural care organization attended a meeting of the project team. During this meeting, the project team coordinator asked the manager about her expectations of the transmural palliative care consultation service. The manager replied that the board of the transmural care network agreed with the project on the condition that concrete results would be achieved. She added that the project team was free to determine themselves how the transmural palliative care consultation service would be organized.*

> *In network A, a project plan for the transmural palliative care consultation service was submitted to the board of the palliative care network. In the project plan, the project team explained that a transmural palliative care consultation service may facilitate continuity of palliative care, but that there is limited evidence on benefits and costs. The board responded that the project plan was not sufficiently scientifically substantiated.*

They sometimes felt that there was insufficient evidence to demonstrate its benefits and cost-effectiveness. Overall, project team members reported that they received insufficient manifest positive response or rewards for their efforts and their time investments in the project from the management of the care organization they represented, despite explicit support of the management prior to the start of the project.

A practical barrier was that registration of transmural consultations in patients' medical files can be complex, e.g. because electronic registration systems within and outside the hospital are different and not matching.

Outer setting

National quality frameworks for palliative care were considered very supportive by project team members. These frameworks include the 'Netherlands Quality Framework for Palliative Care' and quality frameworks for oncology care, such as the Multidisciplinary Standards for Oncological Care, that both promote transmural collaboration between palliative care experts from hospital and primary care.

> *In network C, the network coordinator stated: "Then the Multidisciplinary standards for oncological care (SONCOS standards) came, which state that establishment of a palliative care expert team within the hospital is a requirement. Which has now been done, and what is nice in terms of initiating new developments is that, in collaboration with [name hospital] and general practitioners, we now organize palliative care consultation meetings every Wednesday, for nurses, general practitioners, but also other disciplines."*

Healthcare professionals and other participants expressed a need for national guidance, but also wanted to adapt the intervention to the local situation. Financial reimbursement of the efforts of the transmural consultation service was mostly considered as a substantial barrier. In the Netherlands, all registered consultations outside the hospital provided by healthcare professionals from regional PCTs are financially supported from an earmarked government grant. For their coordination and other organizational issues these regional PCTs are supported by the Netherlands Comprehensive Cancer Organization (IKNL)[1]. In contrast, hospital PCTs get no extra reimbursement per registered consultation. Reimbursement for the registered consultations, coordination and other activities of the hospital PCT is part of a total budget for all specialist medical care activities, with some hospitals being more generous towards activities regarding palliative care than others. Most, but not all hospitals participating in the project were willing to continue their financial support for the PCT after its transition into a transmural consultation service. Several physicians and nurses involved in palliative care consultation nevertheless indicated that reimbursement for their working hours for the existing hospital or regional PCT was already insufficient, with the efforts for the transmural service coming on top of this. Further, project team members indicated that besides financial support, training, physical space and time are needed to be able to start and continue a palliative care consultation service.

Characteristics of individuals involved in the implementation

Involvement of different disciplines in project teams made the process sometimes more complex. We observed e.g. differences in professional jargon, views on palliative care, meeting habits and experience with policy making processes. In all four project teams, processes were sometimes also complicated because opinions differed about who was in control over the development and implementation of the service and about which steps needed to be taken when and by whom. Most project team members tended to identify mainly with their own care organization. Several project team members found it difficult to collaborate with physicians or nurses from other care organizations whom they did not know. Tasks and responsibilities of the project team and project team members were often not well defined. Project team members expected that the project team coordinator would initiate the development of transmural procedures, whereas the coordinators expected initiatives from project team members, based on their clinical expertise and experience. Physicians and nurses working for the transmural palliative care consultation service were mostly very dedicated and enthusiastic, but they also felt that being a member of the project team and/or the transmural consultation service involved

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[1] Nowadays, the regional PCTs are supported by Fibula, an organization that focuses on the organization of palliative care and stimulates partnerships.

extra efforts: meetings of the project team and the transmural consultation service were e.g. scheduled during their regular work time, without diminishing their regular tasks. Further, working in an unfamiliar environment may be strenuous, for example for community care nurses who had to attend meetings of the service within the hospital. Healthcare professionals from different care organizations often had varying views on palliative care, working procedures and on what activities may be expected from the service. For some, the emphasis was on providing advice on care for individual patients with complex problems. Others felt that they should also organize other activities in the area of palliative care, such as education and activities to advocate palliative care. In some cases, hospital-based healthcare providers and healthcare providers working outside the hospital did not manage to develop a shared view on the activities of the transmural palliative care consultation service.

> *In network B, general practitioners and hospital physicians participating in transmural meetings experienced the mutual exchange of their expertise as important. General practitioners indicated that they felt they relatively often contributed by providing information on important psychosocial and spiritual aspects of patients' care, with hospital physicians focusing more on medical aspects and quick solutions for patients' problems. Hospital physicians indicated that they had difficulties with time-consuming discussions of individual patients. Community care nurse consultants experienced a barrier to actively participate in transmural meetings in the hospital, due to hierarchal relationships and time pressure.*

In addition, different participants asked for different motivators for the actions needed. Physicians and nurses needed inspiring examples from other regions, and time and recognition for extra efforts for the transmural consultation service. On the other hand, coordinators and managers often felt a need for scientific evidence.

Implementation process

In all four networks, agreeing about the steps in the implementation process was more time consuming than expected. Project team meetings were often focused at sharing experiences of problems in transmural collaboration and it turned out to be difficult to arrive at a concrete problem definition, a concrete goal and appropriate actions for the project. Project plans for implementation of the transmural consultation service varied from global to elaborated in detail.

> *In network C, the service was started after the establishment of one common telephone number in one of the two hospitals, for all palliative care consultations in the network, despite the lack of a formal implementation plan. This was*

mainly because this hospital strongly supported the development of a transmural consultation service. However, during the project, the two hospital PCTs and the regional PCT gradually returned to working more separately again, despite this shared telephone number.

During the project, three out of four networks managed to develop and implement some level of a transmural palliative care consultation service (table 3). Organization models for the transmural consultation service varied, but a common characteristic was that a nurse has the role of front guard for consultations from both hospital and non-hospital healthcare professionals. The nurse performs an initial exploration of the problem underlying the request for an advice, and, if possible, immediately provides the advice. In case advice from a physician is needed, depending on the problem, the nurse asks a hospital or non-hospital physician consultant to discuss the case with the applicant and to provide an advice.

Table 3 | Characteristics of the transmural palliative care consultation services

Network characteristics	**A**	**B**	**C**	**D**
Outcome in 2019	The existing hospital PCT collaborates at some level with the newly established primary care PCT.	The hospital PCT and the regional PCT collaborate in providing a transmural palliative care consultation service.	The hospital PCTs and the regional PCT collaborate in providing a transmural palliative care consultation service.	No transmural palliative care consultation service was developed.
Composition of the (transmural) PCT that provides the transmural palliative care consultation service				
Physicians				NA
- General practitioner	3	2	4	
- Hospice physician	1	1	-	
- Hospital physician	4	6	3	
- Nursing home	4	2	2	
- Intellectual disability physician	1	-	-	
Nurses				
- Home care nurse	-	-	2	
- Hospice nurse	-	2	1	
- Hospital nurse	2	2	7	
- Nursing home nurse	-	1	-	
Transmural palliative care consultation service				
· Number of consultations in **2019**	173	78	72	NA

In two networks, the service, besides providing advice for patients who present with complex problems, also organizes transmural multidisciplinary meetings to discuss patient cases and training in palliative care for physicians and nurses from various healthcare settings. In the third network, the hospital PCT and the regional PCT jointly provide palliative care training sessions for non-specialized healthcare professionals. Future aim of this service is that both teams increase their collaboration to form a really integrated transmural palliative care consultation service.

DISCUSSION

Summary of findings

Healthcare professionals are motivated to collaborate in a transmural palliative care consultation service but the development of such a service is a time consuming and complex process. Several facilitators and barriers play a role. The representation of multiple care organizations in the project teams made the development and implementation of a transmural palliative care consultation service complex. Healthcare professionals from different care organizations differed in perspectives on palliative care and working procedures. When developing the transmural consultation service, they mostly found ways to deal with these differences. Support of the management of several care organizations, which is needed to involve sufficient palliative care experts, was sometimes lacking. Those involved in the development of the transmural consultation service felt that they were insufficiently supported for their efforts and time investments.

Healthcare professionals’ perspectives on palliative care and transmural collaboration

Healthcare professionals working for the consultation service considered national quality frameworks for palliative care[29,30] as facilitating and supportive to substantiate the importance of the initiative. However, it turned out to be difficult to find a shared view on concrete goals and activities of the service, whereas having shared goals and visions is considered to be an important dimension of transmural collaboration.[31,32]

One of the barriers was that healthcare professionals from hospital and primary care working for the consultation service experienced difficulties in transmural collaboration, due to differences in their respective input in meetings, differences in focus and in time spent per case, and differences in professional language use. Also healthcare professionals sometimes felt uncomfortable due to differences between the hierarchical structure in the hospital environment and primary care. These findings are in line with other studies.[33,34] In a review on advance care planning (ACP) for patients with cancer, Kuusisto et al. found differences between hospital physicians and general practitioners in their opinion on the appropriate timing of the start of the palliative phase, and in how to continue conversations about preferences for care throughout the illness process.[33] In a descriptive qualitative study on healthcare providers' views on the transition between hospital and primary care for patients in the palliative phase, Flierman et al. found similar differences in views on when and how patients should be informed about their limited life expectancy between hospital and primary care professionals.[34] Therefore, whereas transmural collaboration is essential, it also brings challenges. It took relatively much effort to make healthcare professionals involved agree about the bottlenecks in palliative care in their network and about the added value of transmural collaboration. Views on palliative care differed between healthcare professionals from different organizations and also between healthcare professionals within organizations. It is known from other studies that especially nurses find it difficult to describe their role and responsibilities in palliative care.[35] Our findings show that actually all healthcare professionals find it difficult to describe their role and responsibilities in transmural collaboration in palliative care. For a transmural consultation service, more shared views on palliative care and the roles and responsibilities of involved healthcare professionals from hospital and regional PCTs are needed.

Our findings show that in the one network in which participants perceived the project as top-down initiated no transmural consultation service was developed. The baseline situation in the networks thus seemed a predictor of success and may be an indicator for how to coordinate or manage innovations in this area.

Organization of a transmural palliative care consultation service

Support of the management of healthcare organizations was found to be a facilitator for the initiative, especially support of the local hospital(s) involved. However, throughout the project, care organizations sometimes expressed doubts about the intended effects of a transmural consultation service. The lack of evidence regarding the effectiveness of transmural consultation services contributed to these doubts. In addition, the care organizations that were involved in the project are participants of a network that has been set up to promote transmural collaboration in palliative care, but in which collaboration and responsibilities are not always formalized.[31] Our findings show that the unclear ownership of the initiative was a barrier for transmural collaboration. We found that the management of different healthcare organizations sometimes had different ideas about the organization of palliative care and about their own role in transmural collaboration. With unclear ownership of the initiative it turned out to be difficult to get everyone on the same page.

A difference in focus between professionals and managers was also identified as a barrier for the organization of a transmural consultation service. Healthcare professionals who were already working for either a hospital or a regional PCT focused on the best palliative care for the individual patient whereas the management of healthcare organizations focused on evidence-based benefits and costs. We found that different stakeholders asked for different motivators, which slowed down the process. Other studies also showed that, although perceived as important, transmural collaboration between healthcare professionals from different care organizations is complex.[36] In a systematic review on values of integrated care, it was found that healthcare professionals and the management of healthcare organizations associate different values with transmural collaboration. The management attached more importance to general values such as ‘cost-effectiveness’ and ‘evidence-based practice’, whereas healthcare professionals attached more importance to values that are specifically relevant for collaboration, such as ‘collaborative attitude’, ‘co-ordination’ and ‘co-production’.[37]

Although healthcare professionals perceived the national quality frameworks as supportive, because they emphasize the importance of transmural collaboration for good-quality palliative care, these frameworks offer no practical guidance regarding the best way to organize transmural collaboration. Further, reimbursement systems for hospital and non-hospital consultations and other activities from the hospital and regional PCT vary greatly in the Netherlands.[38] In addition, hospital and other care organizations often have different registration systems, and privacy legislation makes it difficult to exchange information between healthcare professionals from different care organisations.[39]

Another barrier was that several healthcare professionals felt that activities for the transmural palliative care consultation service were not perceived, by others or by themselves, as a serious part of their regular work. Healthcare professionals were especially reluctant towards taking responsibility for organizational tasks for the transmural consultation service. Reasons for this, as was also found in other studies, were time pressure in their daily activities due to increased efficiency requirements,[40-42] but also that healthcare professionals tend to focus on what they consider medical or nursing aspects, and distance themselves from what is considered care coordination or organizational tasks not directly related to an individual patient.[41,43,44] Based on our findings, it can be questioned to what extent it can be expected from healthcare professionals to carry out organizational tasks in the development and implementation of a transmural consultation service, where it is unclear if these tasks are part of their regular work and where their efforts are hardly acknowledged. Following the results of our study, healthcare professionals need more guidance on and support in organizational issues regarding transmural collaboration in palliative care. Measuring the impact of transmural palliative care at several levels has been shown to be complex.[32,45] However, more scientific evidence of what a transmural consultation service contributes to continuity of palliative care in terms of benefits and 'cost-effectiveness' would be helpful in getting more management support.

Strengths and limitations

A strength of this multiple case study is that it provides valuable insight into the development and implementation of a transmural palliative care consultation service in four palliative care networks. Two researchers, each in other networks, followed the process in project teams during 2-3 years and were able to collect in-depth information about the process in the four networks. A limitation is that the CFIR may not be entirely appropriate for research on transmural collaboration in palliative care. However, the CFIR is based on relevant implementation theories in various disciplines[26] and offered a clear structure for data collection and analysis. Because of the similarities and differences between the networks found during the study, it is expected that the findings are applicable to similar contexts in other parts of the Netherlands and Europe.

Conclusion

In conclusion, healthcare professionals were motivated to collaborate in a transmural palliative care consultation service, because they believe it can contribute to high-quality palliative care. Facilitators for developing the service were support of the management of several healthcare organizations, and national quality frameworks for palliative care. However, more shared views on goals and activities of a transmural palliative care consultation service are needed, as well as more guidance on how to organize such a service in the complex area of palliative care. A clear and comprehensive financing system is another prerequisite. Healthcare organizations should provide healthcare professionals involved with consistent and explicit support and reward them for their efforts in such an initiative. Finally, more research is needed on benefits and 'cost-effectiveness' of different models of integrated transmural palliative care consultation services.

Acknowledgements

The authors wish to thank the coordinators of the palliative care networks in which the study was conducted and the participating care organizations and healthcare professionals for their cooperation.

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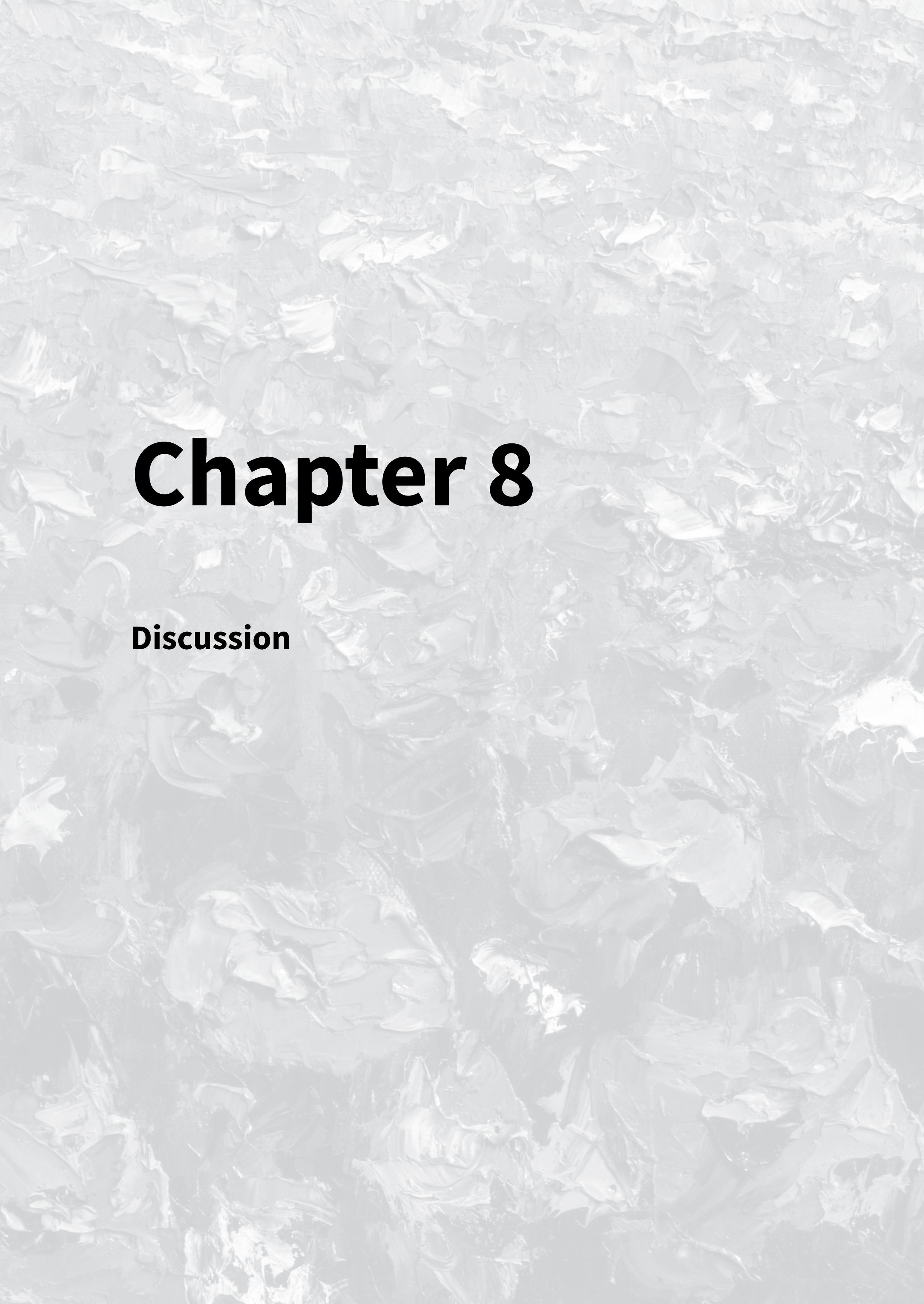

Chapter 8

Discussion

The studies described in this thesis give insight in the perspectives and experiences of nurses and physicians working in different care settings on transmural collaboration in palliative care and give clues to improve the organization of transmural collaboration in palliative care. This chapter presents an overview of the main findings, some methodological considerations and a discussion of selected topics. These topics relate to the concept ‘continuity of care’ and to professional attitudes of nurses and physicians towards transmural collaboration. Finally some recommendations for clinical practice and future research will be discussed.

8.1 MAIN FINDINGS

Satisfaction with hospital care

The COMPASS study was a multicenter study on the effe**c**ts and c**o**sts of consultation of expert tea**m**s for **pa**lliative care in ho**s**pital**s** in the Netherlands, in which patients with advanced cancer filled out questionnaires about their satisfaction with hospital care. In this study, satisfaction with care was measured with the EORTC INPATSAT-32, a questionnaire that was developed to assess satisfaction with hospital care of cancer patients. In a secondary analysis of these data, ‘satisfaction with nurses and exchange of information’ and ‘satisfaction with physicians’ were found to represent the most relevant dimensions of satisfaction with hospital care (chapter 2). The study showed the complex association between the role of nurses and physicians and patients’ satisfaction with care, with various interrelated elements contributing to patients’ satisfaction: technical skills, interpersonal skills, information provision and availability.

Survey studies

Most studies presented in this thesis were part of a regional learning and improvement program “Transmural collaboration in palliative care” in seven palliative care networks in the southwest region of the Netherlands. This program included four survey studies on experiences with transmural collaboration in palliative care of patients, bereaved relatives, nurses and physicians. The results of the surveys among nurses and physicians are partly described in this thesis (chapter 3 and 5, respectively). A summary of all survey studies is presented in Appendix 3. In the survey among 93 patients, we found that they were rather satisfied with palliative care and transmural collaboration in palliative care. Patients gave a mean score of 8,1 for satisfaction with care (on a scale from 1 to 10 with a higher score representing a higher quality). The 340 bereaved relatives who filled out the survey gave a lower mean score 7.2 for satisfaction with care. About half of the bereaved relatives were (completely) satisfied with the collaboration of care providers, a quarter were (completely) not satisfied and a quarter were neutral or did not answer the question.

The findings from the survey studies among nurses and physicians showed that both nurses and physicians indicated that transmural collaboration in palliative care can be improved. Nurses' mean score for the quality of transmural collaboration, on a scale from 1 to 10, was 6.8, with nurses in care homes or nursing homes giving the lowest mean score and nurses in home care giving the highest mean score. With regard to information exchange, we found that one third of all nurses missed information they needed for the last deceased patient they had cared for. In the survey among physicians, we found quite large differences between hospital and non-hospital physicians in experiences with transmural collaboration and information exchange. In cases where patients with a poor prognosis are discharged after hospital admission, more than four in five hospital physicians indicated that they inform general practitioners about these patients' preferences. However, only one in three general practitioners and only one in five nursing home physicians indicated that they are usually adequately informed about these patients' preferences. Almost one third of all physicians indicated that poor collaboration with physicians from other care settings 'always' or 'often' hinders them in providing adequate palliative care.

Action research

The region-wide research program on transmural collaboration also included seven improvement projects with an action research approach. In these projects, palliative care networks developed and implemented a self-chosen intervention to improve transmural collaboration in palliative care. Each network constituted a project team and two researchers followed the process in all project teams during 2-3 years. They collected mostly qualitative data during their observations and also conducted an interview study with palliative care champions in hospital and home care, and a medical record review. The interview study showed that hospital and home care nurses both felt little responsibility for transmural collaboration in palliative care with home care and hospital staff, respectively (chapter 4). The medical record review showed that, for patients with a limited life expectancy going home after a hospitalization, one out of two hospital discharge letters lacked information on their limited life expectancy (chapter 6).

The action research data collected in the improvement projects were analyzed using the Consolidated Framework for Implementation Research (CFIR)[1] (chapter 7). The CFIR distinguishes five domains: intervention characteristics, inner setting, outer setting, characteristics of individuals involved in the implementation, and the implementation process. For this analysis, the project teams were considered as 'inner setting', i.e. as the implementing organization. We found that the improvement projects fitted well with the objectives of the Netherlands Quality Framework for palliative care, that emphasizes the importance of transmural collaboration for good-quality palliative care.[2] In all improvement projects the findings showed that healthcare professionals were motivated to work on more adequate transmural collaboration, because they believe it can contribute to high-quality palliative care. However, they need more guidance in defining shared views on and jointly engaging in goals, activities and working procedures and on organizational issues.

8.2 METHODOLOGICAL CONSIDERATIONS

The study on patient satisfaction with hospital care among patients with advanced cancer had several strengths: it was conducted in nine hospitals in the Netherlands, both university and general hospitals. All patients had advanced cancer with a limited prognosis of less than a year, but there was a variation in types of cancer, number of comorbidities and treatment status. A limitation is the total number of 105 patients, which is quite modest.

Our survey studies on experiences with transmural collaboration and information handovers in palliative care among nurses and physicians working in various settings provide valuable insight in the experiences of a large number of nurses and physicians working in different care settings. A limitation of the study among nurses is that nurses were openly invited to participate via several networks and media. Therefore we could not calculate a response rate and there is a possibility that selection bias occurred. A strength of the survey study among physicians is that it provides insight in how physicians self-assess their performance in estimating and communicating prognosis, and in differences in perspectives between hospital and non-hospital physicians regarding estimating and communicating a poor prognosis in palliative care. A limitation of the survey study among physicians is that the questions about estimating and communicating prognosis were somewhat general, which may have resulted in the physicians' responses representing their views on the subject rather than their actual behavior.

In general, the cross-sectional nature of these survey studies limits the possibility of making robust causal inferences, i.e. we cannot draw conclusions about causality in the relationship between findings within each survey study. However, the findings of the survey studies can be used to generate hypotheses about such causality.

A strength of our qualitative interview study among palliative care nurse champions is that the findings provide new insights into the views of palliative care nurse champions on their role and responsibilities. The fact that our questions were somewhat general and that especially in the hospitals the time available for the interviews was often limited, leaving little time for asking in-depth questions, can be considered a limitation.

Our medical record review is one of the few studies in which the hospital discharge letter and the medical record were studied from randomly chosen patients with cancer or other diseases who died within one year after hospital admission. Limitations are that this is a single-site study and that we did not study nursing information handovers for these patients.

The multiple case action research study provides in-depth insight into the development and implementation of a transmural palliative care consultation service in four palliative care networks. A limitation is that the CFIR may not be entirely appropriate for research on transmural collaboration in palliative care. Although the CFIR offers a conceptual framework that identifies factors that influence an intervention's implementation across multiple types of care setting, 'the inner setting', i.e. the implementing organization, consisted of several independent organizations, which is rather uncommon when using this framework. However, the CFIR is based on implementation theories in various domains[1] and offered a clear structure for data collection and analysis.

It applies to all studies that we expect that the findings are applicable to similar contexts in other parts of the Netherlands and Europe. However, caution is advised due to differences between countries in healthcare systems and the organization of palliative care, and in the training of nurses and physicians in the field of palliative care.

8.3 INTERPRETATION OF THE FINDINGS

8.3.1 The patient's perspective

A key finding from the secondary analysis of the data from the COMPASS study was that patients with advanced cancer were reasonably satisfied with hospital care. The study showed that satisfaction with nurses and satisfaction with physicians were the main underlying dimensions of satisfaction with hospital care. This finding confirmed findings from other studies[3,4] in which nursing care and physician care were also found to represent the most relevant dimensions of satisfaction. Plotti et al.,[3] for example, found that expert care for patients with gynecological cancer was associated with significantly higher scores on satisfaction with physicians' information provision, nurses' technical skills, nurses' information provision and general satisfaction than standard care.

Research into patients' satisfaction with transmural collaboration between different care settings is scarce. In this paragraph we will provide a reflection on the meaning of the concepts continuity of care, integrated care and transmural collaboration for patients in the palliative phase.

Integrated care and transmural collaboration both aim to promote continuity of care. Haggerty et al.[5] identified three types of continuity in health care that might be relevant for patients: informational, management and relational continuity. Informational continuity of care refers to the exchange of information on the medical condition of the patient, but also of information about the patient's preferences for treatment and care, values and context. Management continuity refers to the delivery of services in a complementary and timely manner. Relational continuity relates to a consistent core group of healthcare providers who provide patients with a sense of coherence.[5] To achieve continuity of care for patients with an advanced illness, integrated palliative care has been promoted.[6] Integrated palliative care focuses on coordinating care around the needs of patients and on transmural collaboration between healthcare professionals from different care organizations. It should optimize informational, management as well as relational continuity of care.[6]

Research on perspectives of patients and/or their relatives on continuity of care is scarce.[6,7] Probably this is partly due to complexity of the concept. In interviews on patients' perspectives on quality of palliative care, patients often are asked general questions with regard to continuity of care. Vedel et al.,[8] for example, did a study on patients', family caregivers', and professionals' perspectives on quality of palliative care. They asked patients 'Is continuity of care important to you? What is important to you in terms of how your care is coordinated?' and found that patients highly valued the quality of their relationship with healthcare professionals (attention received, availability of the healthcare professional, individualization of care, anticipation of needs), but no themes related to transmural collaboration were reported in this study.[8] Maybe as a result of the way questions were formulated, patients related continuity of care to care provided within a specific care setting.[8]

Only a few studies focused more specifically on the meaning of continuity of palliative care from the perspectives of patients and their caregivers. In a qualitative study with patients and family caregivers in five European countries, Den Herder-van der Eerden et al.[6] explored how patients receiving palliative care and their caregivers experience continuity of care. This study demonstrated the importance of informational and relational continuity for patients with a life-limiting illness. Morey et al.[7] built on the results of this study by conducting a longitudinal study that aimed to understand the aspects of continuity of care that are important for patients and their caregivers while transitioning from an in-hospital to a home-based palliative care team. It was found that in hospital, continuity of care was mainly experienced as consistency of information exchange between care providers (informational continuity), during their transition from hospital to home patients considered consistency of treatments, e.g. care plans and medication schedules, as most important (management continuity), and when receiving palliative care at home, continuity of care was experienced as a consistent group of care providers (relational continuity). In this study,[7] it was also found that patients and their caregivers value continuity of care as important, but that they had difficulty defining continuity of care themselves. This study suggests that researchers and healthcare professionals are more familiar with the concept continuity of care than patients and their caregivers, and that researchers more often relate the concept continuity of care to transmural collaboration between care providers from different care settings than patients and families do. For patients and their caregivers, different elements of continuity of care have different importance, depending on where a patient is in their transition,[7] which underlines the complexity of the concept.

Den Herder-van der Eerden et al.[6] also found that, in the perception of patients and their family caregivers, transmural collaboration between healthcare professionals often takes place behind the scenes. Patients and their caregivers indicated in this study that they appreciate healthcare professionals having a collaborative attitude and a small number of healthcare professionals being involved, without needing to know details about their collaboration. In this study,[6] as well as in other studies,[7,9] it was also found that informational and management continuity of care within and across care settings tends to be suboptimal in palliative care and that, according to patients and their relatives, healthcare professionals often lack a collaborative attitude.

Although the perceptions of patients and relatives on continuity of care were not explicitly explored, the findings from several studies in this thesis suggest that patients and relatives sometimes may suffer from sub-optimal transmural collaboration between healthcare professionals in different care settings. We found for example that information exchange in palliative care was often sub-optimal (chapter 3-6). Healthcare professionals receiving a nursing information handover (chapter 3) or a medical discharge letter (chapter 5) for patients who are transferred from one care setting to another in the last phase of life, often missed information they need to ensure continuity of care. This may be less of a problem for patients who are well-informed and capable of giving information and expressing their care needs themselves. However, other studies found that patients and relatives feel burdened when they have to take care of information handovers or informational continuity within or across care settings themselves.[6,7,9]

Little is known on how patients and relatives perceive the roles and responsibilities of care professionals across care settings (management continuity), and on their experiences with regard to relational continuity when receiving care from healthcare professionals from different care settings.

8.3.2. Professional attitude of nurses and physicians

In the survey studies among nurses and physicians (chapter 3 and 5, respectively) and in the multiple case study (chapter 7), we found that most healthcare professionals attach much importance to transmural collaboration and continuity of palliative care for patients and their relatives. They also indicated, however, that in clinical practice transmural collaboration and information exchange are often suboptimal. Our survey study among physicians showed that almost one third of all physicians indicated that poor collaboration with other care settings often hinders them in providing adequate palliative care (chapter 5). In the multiple case study (chapter 7) we found that, in daily practice, healthcare professionals providing palliative care tend to consider transmural collaboration only to a limited extent as their responsibility. The findings from the interview study among palliative care nurse champions on their views and on their role and impact also showed that both hospital and home care nurses in general felt little responsibility towards transmural collaboration with home care and hospital staff, respectively (chapter 4). The findings from the medical record study showed that one out of two hospital discharge letters lacked information related to the patient's limited life expectancy (chapter 6). Most studies in this thesis thus demonstrate that healthcare professionals are motivated to collaborate with healthcare professionals in other care settings, but that they are struggling to fulfill this part of their role.

One possible explanation for the gap between good intentions and clinical practice is the professional attitude of nurses and physicians towards transmural collaboration in palliative care. Professionalization is described as a process that serves to secure and protect exclusive areas of knowledge, skills and expertise of professionals in the healthcare system.[10] The findings from several studies in this thesis showed that healthcare professionals in different care settings have different views on palliative care (chapter 4 and 7), have a different professional language (chapter 7) and do not automatically have a shared view on goals and activities of transmural collaboration in palliative care (chapter 7). Auschra[11] has suggested that different professions may have divergent cultural assumptions and professional values, and may follow different procedures which can make collaboration difficult. In addition, palliative care is a relatively complex area with many unresolved issues, such as the identification of patients who need palliative care, the assessment of care needs in different domains, and the responsibilities of generalist versus specialist palliative care.[12,13] These findings indicate that healthcare professionals need more shared professionalization and professional attitudes towards transmural collaboration in palliative care.

An additional explanation for the discrepancy between healthcare professionals' views and practices may be that both nurses and physicians find it difficult to describe their role and responsibilities in transmural collaboration. In their qualitative systematic review of studies on nurses' role in palliative care, Sekse et al.[14] found that due to many activities it was difficult for nurses to describe their role and responsibilities in palliative care. Main aspects of nurses' role in palliative care found were: 'being available' as well as being 'being a coordinator of care', 'doing what's needed', 'being attentively present and dedicated', 'standing in demanding situations'. Sekse et al.[14] included several studies in which nurses had an important role as coordinator and liaison point in the complex field of palliative care, but these were also often only referring to coordinating activities *within* a specific care setting. Taking up their role in the nurse-patient relationship as well as their role in the coordination of care, with both roles being not clearly described and visible, may bring tension for nurses[14] and a focus on the nurse-patient relationship and coordinating activities within the own care setting.

For physicians in the Netherlands, the base of the medical profession is the physician-patient relationship by virtue of the Medical Treatment Contracts Act (Wet op de geneeskundige behandelingsovereenkomst, Wgbo).[15] A widely adopted framework that specifies seven professional roles of physicians is the Canadian Medical Education Directives for Specialists (CanMEDS) framework.[16] The CanMEDS roles or competencies are: medical expert and decision maker; communicator; collaborator; leader; health advocate; scholar; professional. The Medical Training Framework 2020 of the Netherlands Federation of University Medical Centers (NFU)[17] is based on the CanMEDS roles in which 'medical expert' is the core role. The NFU mentions under the role of 'collaborator' intraprofessional collaboration, interprofessional collaboration and multidisciplinary collaboration. Adequate information transfer to other healthcare professionals could also be considered to be a task within this role. Transmural collaboration is, however, not explicitly mentioned.

8.4 RECOMMENDATIONS

The findings of the research presented in this thesis involve several recommendations for clinical practice and further research.

8.4.1 For clinical practice

Healthcare professionals and professional organizations

Healthcare professionals need to develop shared views on the importance and organization of transmural collaboration in palliative care, and on the roles and responsibilities of professionals involved. To achieve this, professional associations should, in mutual consultation, give direction to the coordination of roles and responsibilities related to transmural collaboration in palliative care. Further, transmural collaboration should be addressed in education programs at all levels and for all relevant disciplines. In both nursing and medical guidelines specific information should be added about information exchange addressing end-of-life care for patients with a limited life-expectancy.

Healthcare organizations and networks

Healthcare organizations should support healthcare professionals in transmural collaboration in palliative care. Nurse champions could be better supported in taking up a more active role in transmural collaboration and in the use of specialist palliative care. Efforts to improve the documentation of information related to patients' limited life expectancy and information exchange between healthcare professionals working in different care organizations, or the development of a transmural palliative care consultation service, should be adequately rewarded. Palliative care networks should establish quality indicators for transmural collaboration, for example regarding transmural palliative care consultation and information exchange.

Government

On the national level, the government should pay more attention to compliance with quality indicators for transmural collaboration in palliative care and give direction for appropriate financing of activities that aim to promote transmural collaboration. Further, more attention should be paid to possibilities for exchanging information securely between care organizations and, if needed and on condition that the patient agrees, agreements regarding access to electronic record systems for healthcare professionals from other care organizations.

8.4.2 For research

Research on perspectives of patients and/or their relatives on continuity of care is still scarce. Continuity of care and transmural collaboration as elaborated in this thesis mainly refer to processes between healthcare professionals that are not always visible for patients and relatives. Future research should focus on patients' and relatives' experiences regarding continuity of care and transmural collaboration.

Further, more research is needed to clarify the role and responsibilities of nurses and physicians in transmural collaboration in palliative care and on how to embed this role in their daily clinical practice.

The findings of the studies in this thesis also show that more research is needed on benefits and 'cost-effectiveness' of different models of integrated transmural palliative care interventions, for example an integrated transmural palliative care consultation service or structured discharge procedure.

As research method for studying the effectiveness of complex interventions aimed to improve transmural collaboration in palliative care, a randomized clinical trial may be the ideal but it seems less suitable. Often many organizations and healthcare professionals participate in such an intervention and, in practice, the intervention may be adapted by participants and change over time. Action research, case studies and narratives may be more suitable, because they can provide important insights into facilitators and barriers for complex intervention development and implementation in palliative care.

Aggregated data from health insurance companies (in the Netherlands VEKTIS has all data from healthcare claims in the Netherlands) can also provide important information: the number of hospital admissions in the last months before dying in a specific region, before and after implementing an intervention, could for example be used to get insight in the (cost)effectiveness of the intervention.

Finally, evidence of effectiveness is an important facilitator of implementation of innovations in palliative care. Palliative care organizations and palliative care networks should therefore be encouraged to engage with research. A critical self-reflective attitude is important, both at the individual and at the organizational and network level. An example of a tool that can be used for a critical self-assessment is the Self-evaluation tool from Fibula[18] which is based on the Netherlands Quality Framework for palliative care. The purpose of this Self-evaluation tool is to provide insight into where the palliative care network as a whole or a care organization within the network stands in relation to the values, wishes and needs of patients with palliative care needs and their relatives.

In conclusion, this thesis shows that healthcare professionals generally have a positive attitude and great willingness to be engaged in transmural collaboration in palliative care, but that translating this attitude and willingness into clinical practice is not easy. Efforts at the level of policy making, organization of care, education and training, and research are needed to achieve the final goal of seamless transmural collaboration and high-quality palliative care for all patients in all settings.

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Chapter 9

Summary / Samenvatting
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SUMMARY

In **chapter 1** the background and aim of this thesis were described. Most of the studies described in this thesis were part of a consortium-inspired research program 'Transmural collaboration in palliative care', funded by the Netherlands Organization for Health Research and Development (ZonMw), in which the Consortium for Palliative Care in the southwest Netherlands aimed to improve transmural collaboration in the consortium region. Transmural collaboration in healthcare refers to collaboration between healthcare professionals from different care organizations.

Palliative care focuses on the prevention and relief of suffering of patients and their families facing the problems associated with life-threatening diseases. Nowadays, in the Netherlands, palliative care is mostly offered in non-specialized care settings, both intra- and extramural, by healthcare professionals for whom palliative care is not their main expertise. For complex problems, healthcare professionals can consult palliative care specialists from several disciplines who are organized in palliative care teams (PCTs).

In all these care settings, high-quality palliative care is supposed to be in line with patients' preferences for treatment and care. Besides communication between healthcare professionals and patients, an increasingly important factor in palliative care is collaboration between healthcare professionals from different care organizations. Transmural collaboration between health care professionals involved is important to ensure patient's safety and continuity of care, especially in the last phase of life where treatment goals and patient's preferences for care may change. Some studies have shown that transmural collaboration in palliative care is often not optimal.

The aim of this thesis was to gain insight into the perspectives and experiences of nurses and physicians working in different care settings on transmural collaboration in palliative care, and to gain insight into how transmural collaboration in palliative care can be efficiently organized.

Acknowledging the importance of the patient's perspective, **Chapter 2** describes the results of a sub study on data of the COMPASS study, a multicenter study on the effe***c***ts and c***o***sts of consultation tea***m***s for ***pa***lliative care in ho***s***pital***s*** in the Netherlands. The aim of the sub study was to assess the level of satisfaction with hospital care of patients with advanced cancer. In the period January 2013 to February 2015, in nine hospitals in the Netherlands, eligible patients were asked to fill out the EORTC INPATSAT-32 questionnaire, measuring patient satisfaction, and the EORTC QLQ-C15-PAL, measuring quality of life. One hundred and five patients participated in the study. We found that the mean general satisfaction score, on a scale from 0 to 100 where a higher score indicates a higher level of satisfaction, was 72 (sd 21). This means that these patients were reasonably satisfied with hospital care. The dimensions we found as explaining a large part of the variance in satisfaction scores, 'satisfaction with nurses and exchange of information' (explaining 62.1% of the total variance) and 'satisfaction with physicians' (7.7%), were also found in other studies to represent the most relevant dimensions of satisfaction. Further, we found that these underlying dimensions 'satisfaction with nurses and exchange of information' and 'satisfaction with physicians' represent aspects of quality of care distinct from dimensions of quality of life in patients with advanced cancer. Therefore, this study suggests, that especially nursing interventions aimed at improving patient satisfaction and other outcomes may improve cancer patients' satisfaction with end-of-life care.

Chapter 3 describes the results of a survey study among nurses. Aim of this study was to get insight in the quality of collaboration and information exchange in palliative care from the perspectives of nurses. In the period May - December 2017, we performed a cross-sectional regional survey study among nurses working in different care settings in the southwest of the Netherlands. Nurses were approached via professional networks for palliative care, professional newsletters and social media. Respondents answered to questions about collaboration in palliative care in general and about their last deceased patient. A total of 933 nurses filled in the questionnaire. Of all respondents, 39% were working in home care, 18% in a hospice, 14% in a care home or nursing home, 13% in hospital, and 16% in another or more than one setting. We found that nurses working in care homes or nursing homes were least positive about inter-organizational collaboration. Of all nurses, 46% had actively searched for such collaboration in the last year. With regard to information exchange, we found that, for their last deceased patient, 10% of all nurses had not received the information handover in time and 33% missed information they needed. An adequate information handover was positively associated with timeliness and completeness of the information and the patient being well-informed, not with procedural characteristics. This study suggests that health care organizations should give more attention to shared professionalization towards inter-organizational collaboration among nurses in order to facilitate high-quality palliative care.

In **Chapter 4**, the results are described of an interview study among palliative care nurse champions, working in hospital and home care. Aim of the study was to describe palliative care nurse champions' views on their role, responsibilities and added value. In 2018, a qualitative interview study was conducted with 16 palliative care nurse champions in two hospitals and four home care organizations in the southwest of the Netherlands. We used a deductive approach, using an initial framework drawing on existing literature about the role of palliative care nurse champions. This initial framework consisted of the following elements: role in clinical practice, role in relation to the palliative care expert team, role in inter-organizational collaboration. We found, that most palliative care nurse champions described their role by explaining concrete tasks or activities. Most nurse champions perceive their main task in patient care as disseminating information about palliative care to colleagues, whereas some home care nurses also mentioned activities aimed at raising awareness of palliative care among colleagues. With regard to their role in relation to the palliative care expert team, most nurses were to a limited extent involved in collaboration with this team, whereas several studies emphasize the important role of the expert team for nurses champions. Further, both hospital and home care nurses felt little responsibility towards collaboration with home care or hospital staff, respectively. Especially hospital nurses found it difficult to describe their role. Our study suggests, that careful selection, training, support and task descriptions for nurse champions are needed to make the concept of nurse champions work in palliative care.

Chapter 5 describes the results of a survey study among physicians on estimating patients' poor prognosis and communicating about this. The aim of this study was to determine how physicians in different care settings self-assess their performance in estimating and communicating prognosis to patients in palliative care, and how they perceive their communication with other physicians about patients' poor prognosis. A cross-sectional survey study was performed among a random sample of general practitioners (GPs), hospital physicians (HPs) and nursing home physicians (NHPs) in the southwest of the Netherlands. A questionnaire was developed that had three versions: for GPs, HPs and NHPs. A total of 547 physicians participated: 259 GPs, 205 HPs, 83 NHPs. In total, 61% of physicians indicated being able to adequately estimate whether a patient will die within a year, which was statistically significantly associated with use of the Surprise Question. In the case of a prognosis of less than a year, 75% of physicians indicated that they communicate with patients about preferences regarding treatment and care, which was statistically significantly associated with physicians' being trained in palliative care. In cases where patients with poor prognosis are discharged after hospital admission, 83% of HPs indicated that they inform GPs about these patients' preferences compared with 29% of GPs and 22% of NHPs indicating that they are usually adequately informed about this. Differences in experiences between hospital and non-hospital physicians may be the result of different professional values and different procedures regarding advance care planning (ACP) between physicians working in different care settings. A more shared professionalization towards estimating and communicating prognosis in palliative care may facilitate transmural collaboration between physicians. Further, more physicians should be trained in communicating about patients' poor prognosis and care preferences.

In **chapter 6**, the results are described of a retrospective medical record review on the quality of hospital discharge letters for patients at the end of life. This study was performed in the Maasstad Hospital in Rotterdam, and was part of an improvement trajectory regarding the exchange of information for patients with a limited life expectancy in the palliative care network area surrounding this hospital. The aim of this study was to examine the timeliness and quality of the hospital discharge letter for patients with a limited life expectancy who were discharged after a hospitalization. Patients were included if they had been admitted to the hospital during the period January 1 to July 1, 2017 and had died within a year after discharge. Data were collected from the records of 108 patients with cancer or other diseases. For 6% of all patients the discharge letter was sent within two days after discharge. For 57 patients (53%), we found that the discharge letter included information that related to their limited life expectancy (e.g. agreements about treatment limitations), whereas the patient's limited life expectancy was addressed in the medical record in 76 cases (70%). We found statistically significant more often related information in discharge letters for patients who died within three months than for patients who died between three and twelve months after hospitalization. This study suggests, that, to improve the quality of the discharge letter for patients in the last phase of life, training of hospital physicians and development of specific guidelines for medical information exchange between care settings are needed.

Chapter 7 describes the results of a multiple case study in four palliative care networks in the research region. The aim of the study was to determine facilitators and barriers in the process of developing and implementing an integrated transmural palliative care consultation service. In the period early 2017 to December 2019, this multiple case study was performed in four palliative care networks who aimed to develop a transmural palliative care consultation service. We found, that, in each region, project team members thought that the core goal of a transmural consultation service is improvement of continuity of palliative care for patients throughout their illness trajectory. Healthcare professionals are motivated to collaborate in a transmural palliative care consultation service but the development of such a service is a time consuming and complex process. Several facilitators and barriers play a role. The representation of multiple care organizations in the project teams made the process complex. Healthcare professionals from different care organizations differed in perspectives on palliative care and working procedures. Most project teams found ways to deal with these differences. Support of the management of several care organizations that is needed to involve sufficient palliative care experts was sometimes lacking. Three networks managed to develop and implement a transmural palliative care consultation service at some level, one network did not manage to do so. Our study suggests, that healthcare professionals need more shared views on goals and activities of a transmural consultation service, more guidance on organizational issues and appropriate financing. Further, more research is needed to provide evidence on benefits and costs of different models of integrated transmural palliative care consultation services.

Finally, **chapter 8** (General discussion) summarizes the key findings of the studies conducted, provides some methodological considerations, and gives a broad reflection on some overarching topics. The meaning of the concepts continuity of care, integrated care and transmural collaboration for patients in the palliative phase are first discussed. Other studies found that patients and their relatives value continuity of care and appreciate healthcare professionals having a collaborative attitude. Although the perceptions of patients and relatives of continuity of care were not explicitly explored, the findings from several studies in this thesis suggest that patients and relatives sometimes suffer from sub-optimal transmural collaboration between healthcare professionals in different care settings. The gap between good intentions towards transmural collaboration of healthcare professionals and clinical practice where transmural collaboration is often perceived as sub-optimal is explored. Our findings indicate that healthcare professionals need more shared professionalization and professional attitudes towards transmural collaboration in palliative care. The chapter concludes with a number of recommendations for clinical practice and for future research to achieve the final goal of seamless transmural collaboration and high-quality palliative care for all patients in all settings.

SAMENVATTING

In **hoofdstuk 1** worden de achtergrond en het doel van dit proefschrift beschreven. De meeste van de in dit proefschrift beschreven studies maakten deel uit van een consortium-breed onderzoeksprogramma ‘Transmurale samenwerking in de palliatieve zorg’, gefinancierd door de Nederlandse Organisatie voor Gezondheidsonderzoek en Ontwikkeling (ZonMw), waarmee het Consortium Palliatieve Zorg in Zuidwest-Nederland beoogde de transmurale samenwerking in de consortiumregio te verbeteren. Transmurale samenwerking in de zorg verwijst naar samenwerking tussen zorgprofessionals van verschillende zorgorganisaties.

Palliatieve zorg richt zich op het voorkomen en verlichten van lijden van patiënten en hun families die worden geconfronteerd met de problemen die samenhangen met levensbedreigende ziekten. Palliatieve zorg wordt in Nederland vooral verleend in niet-gespecialiseerde zorgsettings, zowel intra- als extramuraal, door zorgprofessionals voor wie palliatieve zorg niet hun belangrijkste expertise is. Voor complexe problemen kunnen zorgprofessionals terecht bij palliatieve consultatieteams met daarin zorgverleners met expertise op het gebied van palliatieve zorg vanuit meerdere disciplines.

In al deze zorgsettings dient palliatieve zorg aan te sluiten bij de behoeften, wensen en voorkeuren van patiënten voor behandeling en zorg. Naast communicatie tussen zorgprofessionals en patiënten is samenwerking tussen zorgprofessionals van verschillende zorgorganisaties een steeds belangrijker aspect van palliatieve zorg. Goede transmurale samenwerking is belangrijk om de veiligheid en continuïteit van zorg van de patiënt te waarborgen, vooral in de laatste levensfase waarin behandeldoelen en zorgvoorkeuren van de patiënt kunnen veranderen. Studies hebben aangetoond dat transmurale samenwerking in de palliatieve zorg vaak niet optimaal is.

Het doel van het onderzoek dat wordt beschreven in dit proefschrift was om inzicht te krijgen in de perspectieven en ervaringen van verpleegkundigen, verzorgenden en artsen in verschillende zorgsettings met betrekking tot transmurale samenwerking in de palliatieve zorg, en in hoe transmurale samenwerking in de palliatieve zorg efficiënt kan worden georganiseerd.

Als voorstudie worden in **Hoofdstuk 2** de resultaten beschreven van een secundaire analyse van gegevens van de COMPASS-studie, een multicenter onderzoek naar de effecten en kosten van consultatieteams voor palliatieve zorg in ziekenhuizen in Nederland. Het doel van deze analyse was om de mate van tevredenheid met de ziekenhuiszorg van patiënten met gevorderde kanker vast te stellen. In de periode januari 2013 tot februari 2015 werd in negen ziekenhuizen in Nederland aan daarvoor in aanmerking komende patiënten gevraagd om de EORTC INPATSAT-32 vragenlijst in te vullen, die patiënttevredenheid meet, en de EORTC QLQ-C15-PAL, die kwaliteit van leven meet. Honderdvijf patiënten namen deel aan het onderzoek. We vonden dat de gemiddelde algemene tevredenheidsscore, op een schaal van 0 tot 100 waarbij een hogere score een hoger niveau van tevredenheid aangeeft, 72 was (sd 21). Dit betekent dat deze patiënten redelijk tevreden waren over de ziekenhuiszorg. De dimensies die we vonden als verklaring voor een groot deel van de variantie in tevredenheidsscores, ‘tevredenheid met verpleegkundigen en uitwisseling van informatie’ (verklaarde 62,1% van de totale variantie) en ‘tevredenheid met artsen’ (7,7%), werden ook in andere studies gevonden als de meest relevante dimensies van tevredenheid. Verder vonden we dat de onderliggende dimensies ‘tevredenheid met verpleegkundigen en uitwisseling van informatie’ en ‘tevredenheid met artsen’ niet altijd samenlopen met de kwaliteit van leven bij patiënten met gevorderde kanker. Wij concludeerden dat met name verpleegkundige interventies de tevredenheid van patiënten met kanker met de zorg aan het levenseinde kunnen verbeteren.

Hoofdstuk 3 beschrijft de resultaten van een vragenlijstonderzoek onder verpleegkundigen en verzorgenden (in het vervolg van deze samenvatting aangeduid als verpleegkundigen). Doel van dit onderzoek was om inzicht te krijgen in de kwaliteit van samenwerking en informatie-uitwisseling in de palliatieve zorg vanuit het perspectief van verpleegkundigen. In de periode mei - december 2017 hebben we een cross-sectioneel regionaal vragenlijstonderzoek uitgevoerd onder verpleegkundigen werkzaam in verschillende zorgsettings in het zuidwesten van Nederland. Verpleegkundigen zijn benaderd via professionele netwerken voor palliatieve zorg, professionele nieuwsbrieven en sociale media. Respondenten beantwoordden vragen over samenwerking in de palliatieve zorg in het algemeen en over hun laatst overleden patiënt. In totaal hebben 933 verpleegkundigen de vragenlijst ingevuld. Van alle respondenten werkte 39% in de thuiszorg, 18% in een hospice, 14% in een verzorgings- of verpleeghuis, 13% in het ziekenhuis en 16% in een andere of meer dan één setting. We vonden dat verpleegkundigen werkzaam in verzorgings- of verpleeghuizen het minst positief waren over de samenwerking tussen organisaties. Van alle verpleegkundigen had 46% het afgelopen jaar actief gezocht naar een dergelijke samenwerking. Met betrekking tot informatie-uitwisseling vonden we dat voor hun laatst overleden patiënt 10% van alle verpleegkundigen de informatieoverdracht niet op tijd had ontvangen en 33% had belangrijke informatie gemist. Informatieoverdracht werd vaker als adequaat gekwalificeerd als de informatie tijdig en volledig werd aangeleverd, en als de patiënt zelf ook goed geïnformeerd was, maar er was geen verband met procedurele kenmerken. Dit onderzoek suggereert dat zorgorganisaties meer aandacht zouden moeten besteden aan gedeelde professionalisering met betrekking tot inter-organisatorische samenwerking tussen verpleegkundigen om palliatieve zorg van hoge kwaliteit te faciliteren.

In **hoofdstuk 4** worden de resultaten beschreven van een interviewstudie onder verpleegkundige aandachtsvelders palliatieve zorg, werkzaam in het ziekenhuis en in de thuiszorg. Het doel van het onderzoek was om de visie van aandachtsvelders palliatieve zorg op hun rol, verantwoordelijkheden en toegevoegde waarde te beschrijven. In 2018 is een kwalitatief interviewonderzoek uitgevoerd met 16 aandachtsvelders palliatieve zorg in twee ziekenhuizen en vier thuiszorgorganisaties in Zuidwest-Nederland. We gebruikten een deductieve benadering, gebruikmakend van een eerste raamwerk op basis van bestaande literatuur over de rol van aandachtsvelders palliatieve zorg. Dit initiële raamwerk bestond uit de volgende elementen: rol in de patiëntenzorg, rol in relatie tot het palliatieve consultatieteam, rol in inter-organisatorische samenwerking. We vonden dat de meeste aandachtsvelders hun rol beschreven aan de hand van concrete taken of activiteiten. De meeste aandachtsvelders zien als hun belangrijkste taak in de patiëntenzorg het verspreiden van informatie over palliatieve zorg onder collega's, terwijl sommige thuiszorgverpleegkundigen ook activiteiten noemden die gericht waren op het vergroten van het bewustzijn van palliatieve zorg bij collega's. Met betrekking tot hun rol in relatie tot het palliatieve consultatieteam waren de meeste verpleegkundigen in beperkte mate betrokken bij samenwerking met dit team, terwijl verschillende studies de belangrijke rol van het consultatieteam voor verpleegkundige aandachtsvelders palliatieve zorg benadrukken. Verder voelden zowel ziekenhuis- als thuiszorgverpleegkundigen weinig verantwoordelijkheid ten aanzien van de samenwerking met respectievelijk de thuiszorg of ziekenhuispersoneel. Vooral ziekenhuisverpleegkundigen vonden het moeilijk om hun rol te beschrijven. Onze studie suggereert dat zorgvuldige selectie, training, ondersteuning en taakbeschrijvingen nodig zijn om het concept van aandachtsvelders in de palliatieve zorg te laten werken.

Hoofdstuk 5 beschrijft de resultaten van een vragenlijstonderzoek onder artsen over het inschatten van een beperkte levensverwachting van patiënten en het communiceren hierover. Doel van dit onderzoek was om te bepalen hoe artsen in verschillende zorgsettings de kwaliteit van hun eigen inschatting van en communicatie bij een beperkte levensverwachting van patiënten in de palliatieve zorg beoordelen, en hoe zij hun communicatie met andere artsen over een beperkte levensverwachting van patiënten ervaren. Dit cross-sectionele vragenlijstonderzoek werd uitgevoerd onder een aselecte steekproef van huisartsen, ziekenhuisartsen en specialisten ouderengeneeskunde in Zuidwest-Nederland. Er werd een vragenlijst ontwikkeld met drie versies: voor huisartsen, ziekenhuisartsen en specialisten ouderengeneeskunde. In totaal namen 547 artsen deel: 259 huisartsen, 205 ziekenhuisartsen, 83 specialisten ouderengeneeskunde.

In totaal gaf 61% van de artsen aan goed te kunnen inschatten of een patiënt binnen een jaar zal overlijden, wat statistisch significant samenhing met het gebruik van de Surprise Question. Bij een levensverwachting van minder dan een jaar gaf 75% van de artsen aan met patiënten te communiceren over voorkeuren ten aanzien van behandeling en zorg, wat statistisch significant samenhing met getraind zijn in palliatieve zorg van artsen. In gevallen waarin patiënten met een beperkte levensverwachting na een ziekenhuisopname worden ontslagen, gaf 83% van de ziekenhuisartsen aan de huisartsen te informeren over de voorkeuren van deze patiënten, vergeleken met 29% van de huisartsen en 22% van de specialisten ouderengeneeskunde die aangaven hierover meestal voldoende geïnformeerd te worden door de ziekenhuisarts. Verschillen in ervaringen tussen ziekenhuis- en niet-ziekenhuisartsen kunnen het gevolg zijn van verschillende professionele waarden en verschillende procedures met betrekking tot pro-actieve zorgplanning (ACP) tussen artsen die in verschillende zorgsettings werken. Een meer gedeelde professionalisering met betrekking tot informatie-uitwisseling over het inschatten en communiceren van de levensverwachting in de palliatieve zorg kan transmurale samenwerking tussen artsen vergemakkelijken. Verder zouden meer artsen moeten worden getraind in het communiceren over een beperkte levensverwachting en zorgvoorkeuren van patiënten.

In **hoofdstuk 6** worden de resultaten beschreven van een retrospectief medisch dossieronderzoek naar de kwaliteit van ontslagbrieven voor patiënten in de laatste levensfase. Dit onderzoek is uitgevoerd in het Maasstad Ziekenhuis in Rotterdam en was onderdeel van een verbetertraject met betrekking tot informatie-uitwisseling voor patiënten met een beperkte levensverwachting in het palliatieve zorg netwerkgebied rondom dit ziekenhuis. Het doel van deze studie was het onderzoeken van de tijdigheid en kwaliteit van de ontslagbrief vanuit het ziekenhuis voor patiënten met een beperkte levensverwachting die werden ontslagen na een ziekenhuisopname. Patiënten werden geïncludeerd als zij in de periode 1 januari tot 1 juli 2017 in het ziekenhuis waren opgenomen en binnen een jaar na ontslag waren overleden. Gegevens werden verzameld uit de dossiers van 108 patiënten met kanker of andere ziekten. Bij 6% van alle patiënten werd de ontslagbrief binnen twee dagen na ontslag verzonden. Voor 57 patiënten (53%) vonden we dat de ontslagbrief informatie bevatte die betrekking had op hun beperkte levensverwachting (bijv. afspraken over behandelbeperkingen), terwijl de beperkte levensverwachting van de patiënt in 76 gevallen (70%) wel in het medisch dossier werd vermeld. We vonden statistisch significant vaker gerelateerde informatie in ontslagbrieven voor patiënten die binnen drie maanden overleden dan voor patiënten die tussen drie en twaalf maanden na ziekenhuisopname overleden. Deze studie suggereert dat, om de kwaliteit van de ontslagbrief voor patiënten in de laatste levensfase te verbeteren, training van ziekenhuisartsen en de ontwikkeling van specifieke richtlijnen voor de uitwisseling van medische informatie tussen zorgsettings nodig zijn.

Hoofdstuk 7 beschrijft de resultaten van een meervoudige case studie in vier netwerken palliatieve zorg in de regio Zuidwest-Nederland. Het doel van het onderzoek was om bevorderende en belemmerende factoren in het proces van het ontwikkelen en implementeren van een geïntegreerde transmurale palliatieve consultatiedienst vast te stellen. In de periode begin 2017 tot december 2019 is deze meervoudige case studie uitgevoerd in vier netwerken palliatieve zorg. We vonden dat in elke regio projectteamleden aangaven dat het belangrijkste doel van een transmurale consultatiedienst het verbeteren van de continuïteit van palliatieve zorg voor patiënten tijdens hun ziektetraject is. Zorgprofessionals zijn gemotiveerd om samen te werken in een transmurale consultatiedienst voor palliatieve zorg, maar de ontwikkeling van een dergelijke dienst is een tijdrovend en complex proces. Verschillende bevorderende en belemmerende factoren spelen een rol. De vertegenwoordiging van meerdere zorgorganisaties in de projectteams is een van die factoren. Zorgprofessionals van verschillende zorgorganisaties verschilden in perspectieven op palliatieve zorg en werkwijzen. De meeste projectteams vonden manieren om met deze verschillen om te gaan. Ondersteuning van het management van meerdere zorgorganisaties om voldoende deskundigen op het gebied van palliatieve zorg te kunnen betrekken bij de consultatiedienst, ontbrak soms. Drie netwerken slaagden erin om op zeker niveau een transmurale consultatiedienst voor palliatieve zorg te ontwikkelen en te implementeren, één netwerk slaagde daar niet in. Onze studie suggereert dat zorgprofessionals behoefte hebben aan meer gedeelde visies op doelen en activiteiten van een transmurale consultatiedienst, meer begeleiding bij organisatorische vraagstukken en passende financiering. Verder is beter inzicht nodig in de voordelen en kosten van verschillende modellen van geïntegreerde transmurale consultatiediensten voor palliatieve zorg.

Ten slotte vat **hoofdstuk 8** de belangrijkste bevindingen van de uitgevoerde onderzoeken samen, wordt er stil gestaan bij enkele methodologische overwegingen en wordt een brede reflectie gegeven op enkele overkoepelende onderwerpen. Eerst wordt ingegaan op de betekenis van de begrippen continuïteit van zorg, integrale zorg en transmurale samenwerking voor patiënten in de palliatieve fase. Uit eerdere studies bleek dat patiënten en hun naasten waarde hechten aan continuïteit van zorg en een samenwerkingsgerichte houding van zorgprofessionals waarderen. Hoewel de percepties van patiënten en naasten van continuïteit van zorg in dit proefschrift niet expliciet zijn onderzocht, suggereren de bevindingen in verschillende hoofdstukken dat patiënten en familieleden soms last hebben van suboptimale transmurale samenwerking tussen zorgprofessionals in verschillende zorgsettings. De kloof tussen goede bedoelingen ten aanzien van transmurale samenwerking van zorgprofessionals en de klinische praktijk, wordt in dit hoofdstuk nader verkend. Het hoofdstuk wordt afgesloten met een aantal aanbevelingen voor de klinische praktijk en voor toekomstig onderzoek, met als uiteindelijke doel te komen tot naadloze transmurale samenwerking en hoogwaardige palliatieve zorg voor alle patiënten in alle settings.

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ERASMUS UNIVERSITY ROTTERDAM

PHD PORTFOLIO

Marijanne Engel

Description	Organizer	Workload ECTS
Required		
Erasmus MC - ESP11 Methods of Public Health Research (2016)	NIHES	0.70
Erasmus MC - CC02 Biostatistical Methods I: Basic Principles (2016)	NIHES	5.70
Consortiumdag Zuidwest-Nederland 31 okt. 2017 (2017)	Consortium palliatieve zorg Zuidwest-Nederland	0.50
Ned. Vlaamse Wetenschapsdagen 2017 (2017) (1 poster presentation)		1.00
EAPC 2018 (2018) (3 poster presentations)	EAPC	1.00
Post-EAPC 2018 (2018) (1 oral presentation)	PalliActief i.s.m. Expertisecentra Palliatieve Zorg	1.00
Erasmus MC - Scientific Integrity (2018)	Department Medical Ethics	0.30
Erasmus MC - CPO-course: Patient Oriented Research (2018)	Erasmus MC - The Congress Bureau	0.30
Erasmus MC - ESP01 Principles of Research in Medicine and Epidemiology (2018)	NIHES	0.70
Congress Public Health Research in Pall Care (2018) (2 poster presentations)	End-of-Life Care Research Group VUB & UGent	1.00
Nationaal Congres Palliatieve Zorg 2018 (2018) (1 oral and 2 poster presentations)	PalliActief	1.00
TSPZ Projectleidersbijeenkomst verbetertrajecten (2019) (organizer and presentation)	Marijanne Engel	0.50
NVivo 12 Introduction Course (2019) (organizer and attended)	Marijanne Engel	1.30
ACP-I Congress 2019 (2019) (1 oral presentation)	ACP-i (Advance Care Planning international) Society	1.00
Vertegenwoordiger MBL sectie in JVO (2017-2019)		5.00
Erasmus MC - Biomedical English Writing and Communication (2019)	Sally Hill, course lecturer	3.00
Ned. Vlaamse Wetenschapsdagen 2019 (2019) (1 oral and 1 poster presentation)	PalliActief en Federatie Palliatieve Zorg Vlaanderen	1.00
Aansturen onderzoeksassistent (2020)		0.50
Netwerk palliatieve zorg Rotterdam e.o. presentaties divers (2020)		0.50
Optional		

Community Project Onderwijs 2016-2017 (2017)	Alice Griffioen, stafmedewerker onderwijs MGZ	1.00
Community Project Onderwijs 2017-2018 (2018)	Alice Griffioen, stafmedewerker onderwijs MGZ	1.00
Community Project Onderwijs 2018-2019 (2019)	Alice Griffioen, stafmedewerker onderwijs MGZ	1.00
Beoordeling bachelor essays 2020 (2020)	Alice Griffioen, stafmedewerker onderwijs MGZ	1.00
		------ +
Total EC		**30.00**

Appendix 1

TSPZ - Samenvatting Ideaalmodel transmurale overdracht

Transmurale Samenwerking in de Palliatieve Zorg
een regionaal leer- en verbeterprogramma

Marijanne Engel
Andrée van der Ark
Agnes van der Heide (Projectleider)

Januari 2017

Inhoudsopgave

Transmurale Samenwerking in de Palliatieve Zorg
een regionaal leer- en verbeterprogramma
Inleiding ideaalmodellen

De ideaalmodellen

Uit de eerste gesprekken met de netwerkcoördinatoren is duidelijk geworden dat er gezamenlijk gedragen wensen zijn, maar dat er ook grote verschillen bestaan tussen de netwerken. Dit benadrukt het belang om sterk bij de praktijk aan te sluiten. De conclusie is dat een interventie opleggen dus niet zal werken. Daarom is er voor gekozen om ideaalmodellen te ontwikkelen op elk van de vier thema's binnen dit project:

1. Transmurale overdracht
2. Transmuraal zorgpad
3. Transmuraal consultatieteam
4. Casemanagement

De ideaalmodellen zijn ontwikkeld op basis van wetenschappelijk bewijs, richtlijnen, bestaande modellen en ervaringen in de praktijk – gekaderd in de visie op palliatieve zorg uit de zorgmodule (later wordt dit het kwaliteitskader). Dit schetst een beeld van hoe we op basis van de huidige kennis denken dat een ideale overdracht/zorgpad/consultatieteam/ casemanager er uit zou moeten zien. In dit document vindt u samenvattingen van deze ideaalmodellen.

Verder verloop van het project

Een netwerk kan zelf een keuze maken voor één ideaalmodel waarmee het aan de slag wil. Hiermee gaan we met elkaar om de tafel. Waar staat het netwerk nu? Op welke manier kunnen we het beste meer richting dat ideaalbeeld gaan bewegen? Eerst wordt er een startpunt gekozen: een klein concreet begin, afhankelijk van waar de beste kansen en mogelijkheden liggen in dat netwerk. Bijvoorbeeld op een bepaalde locatie, of bij een bepaalde doelgroep. Het kan zijn dat dit een nieuw project wordt, maar een netwerk mag er ook voor kiezen bij een bestaand project aan te sluiten. Vervolgens wordt er een plan voor doorontwikkeling opgesteld om meer richting het ideaalmodel te bewegen. Van het begin af aan worden alle partijen betrokken en krijgen zij de kans mee te denken. Door het netwerk wordt een projectgroep gevormd en een projectleider aangesteld.

Na deze voorbereidingsfase start de implementatie. De projectgroep gaat het project uitvoeren, de onderzoeker loopt mee en doet actie-onderzoek. Dit betekent dat de onderzoeker steeds informatie verzamelt over het proces en uitkomsten - met name via interviews met betrokkenen (zorgverleners, patiënten en naasten). De opbrengst daarvan wordt tussentijds teruggekoppeld naar de projectgroep. Het gaat vooral om inzichten in knelpunten en in nieuwe mogelijkheden. Dit helpt de implementatie van het project te ondersteunen en bevordert de doorontwikkeling. Er is dus een cyclus van interactie tussen onderzoeker en projectgroep, waarin men elkaar versterkt. Meer informatie over actie-onderzoek vindt u in het laatste onderdeel van dit document.

De planning is dat de netwerken voor 12 december een definitieve keuze maken. Dan wordt elk verbetertraject per netwerk verder uitgedacht en worden in dec/jan de plannen ingediend bij ZonMw.

Transmurale Samenwerking in de Palliatieve Zorg
een regionaal leer- en verbeterprogramma

1. SAMENVATTING IDEAALMODEL:

Transmurale Overdracht (voorbeeld: van ziekenhuis naar VVT)

Inleiding

Samenhangende zorg eist samenwerking tussen professionals en instellingen. Juist op overdrachts-momenten bestaat het risico, dat er niet genoeg informatie wordt overgedragen waardoor de continuïteit van zorg in gevaar komt. Een onvolledige, onjuiste of te laat ontvangen overdracht kan ertoe leiden dat zorgverleners die de zorg overnemen hun verantwoordelijkheid voor kwaliteit en veiligheid van de zorg niet goed kunnen nemen. Patiënten lopen dan risico op gezondheidsschade en verlies van kwaliteit van leven [1,2].

Er zijn in de praktijk meer overgangssituaties, maar voor deze samenvatting is gekozen voor de transmurale overdracht van ziekenhuis naar verpleeg- of, verzorgingshuis, of de thuissituatie (VVT). Uit een landelijk onderzoek van de Inspectie voor de Gezondheidszorg (IGZ) naar de overdracht van zorg voor kwetsbare ouderen in de periode oktober 2013 – januari 2015 bleek dat de overdracht van ziekenhuis naar VVT in geen van de onderzochte regio's zo betrouwbaar was georganiseerd dat een goede overdracht gewaarborgd was en er gesproken kon worden van continuïteit in zorg [3]. De IGZ toetste de veldnormen, zoals met veldpartijen opgesteld in 2013, onderverdeeld in drie thema's:

- De procedure rond de overdracht;
- De medische overdracht (inclusief medicatie-overdracht);
- De verpleegkundige overdracht.

Zorgverleners lijken zich onvoldoende bewust van hun verantwoordelijkheid voor de continuïteit van zorg. Overdrachten worden niet altijd tijdig gestuurd naar de opvolgende zorgverlener en zijn niet altijd compleet.

Knelpunten in overdracht van zorg bij palliatieve patiënten

Uit diverse publicaties komt het beeld naar voren van enerzijds een door alle betrokkenen gewenste continuïteit van zorg en anderzijds ontwikkelingen die dat tegenwerken.

Zo is de continuïteit van de zorgverlening in de eerste lijn afgenomen door een toename van het aantal betrokken partijen bij de palliatieve zorg. Door de komst van huisartsenposten is er een extra schakel bij gekomen in de huisartsengeneeskunde [4]. Met name voor palliatieve patiënten bestaat het risico dat de zorg in de ANW-uren wordt overgenomen door een arts van de huisartsenpost die minder goed op de hoogte is van de situatie van de patiënt. Het risico daarvan is dat de zorgverlening niet optimaal is en dat patiënten onnodig worden doorverwezen naar de Spoedeisende hulp (SEH) van een ziekenhuis. Het systeem van overdracht van huisarts naar huisartsenpost blijkt niet waterdicht [2,4]. Ook de continuïteit van de wijkverpleegkundige zorg is afgenomen. Door de marktwerking is een veel groter aantal thuiszorgorganisaties actief. Het is daardoor voor huisartsen moeilijker om goede afspraken met wijkverpleegkundigen te maken [4].

Naast genoemde ontwikkelingen in de zorg zouden de opgelegde veldnormen voor de overdracht van kwetsbare ouderen onvoldoende worden nageleefd [3].

Ook voor palliatieve patiënten geldt voor zowel de medische (inclusief medicatie) als de verpleegkundige overdracht dat de feitelijke informatieoverdracht van de tweede naar de eerste lijn kan worden verbeterd. Zo richt de transferverpleegkundige zich bij ontslag uit het ziekenhuis vooral op informatieoverdracht richting thuiszorgorganisaties [4,5]. Specifiek voor palliatieve zorg is veel onderzoek gedaan naar de samenwerking tussen medisch specialist en huisarts [4]. Bij palliatieve patiënten verloopt de overdracht van de medisch specialist naar de huisarts niet altijd goed. In de periode waarin de patiënt behandeld wordt door de medisch specialist staat de huisarts vaak op afstand en ontvangt hij weinig tot geen informatie over het verloop van het ziekteproces en de ingezette behandelingen. Ook komt het voor dat de huisarts niet direct op de hoogte wordt gebracht wanneer een patiënt uitbehandeld is in het ziekenhuis. Het gevolg is dat de huisarts niet altijd weet welke patiënten in zijn praktijk palliatief zijn, waardoor pro-actief handelen wordt bemoeilijkt.

In een recent onderzoek naar de verpleegkundige overdracht bij kwetsbare ouderen [6] wordt verder genoemd dat door verpleegkundigen in de overdracht veel aandacht zou worden besteed aan fysieke behoeften van patiënten en aan taken van verpleegkundigen, en dat er minder aandacht is voor wensen en bevindingen van patiënten. Ook wordt in dit onderzoek als knelpunt genoemd dat de drie onderdelen van de overdracht (medisch, verpleegkundig, medicatie) vaak geen geheel vormen omdat ze afzonderlijk worden opgesteld. Divers onderzoek naar ‘Palliatieve spoedzorg’ (zorg in Avond, Nacht, Weekend) bevestigt het beeld van een niet optimale overdracht van palliatieve patiënten [2,7].

Normen voor een goede overdracht van zorg bij palliatieve patiënten

De Zorgmodule Palliatieve Zorg 1.0 [8] en andere visiedocumenten beogen een bijdrage te leveren aan het optimaliseren van de zorgverlening in de palliatieve fase van een chronisch ziekteproces door de minimale eisen te beschrijven waaraan in deze fase de zorg aan patiënten en hun naasten moet voldoen. In de Zorgmodule Palliatieve Zorg wordt gesteld dat palliatieve zorg met aandacht voor continuïteit, deskundigheid en samenwerking moet worden geleverd.

Er is groeiende aandacht voor informatieoverdracht tussen zorgverleners, maar toch lijkt het overgrote deel van de veldnormen die in de zorgsector worden uitgebracht nog puur medisch-inhoudelijk gericht te zijn [5].

Voor de medische en de verpleegkundige overdracht gelden de betreffende richtlijnen van de gezamenlijke veldpartijen [9,10] als uitgangspunt. De Blok et al. [5] hebben in 2012 alle veldnormen voor de overdracht van patiëntinformatie tussen ziekenhuis en VVT in kaart gebracht. Veldnormen moeten door verschillende partijen gedragen worden en onderschreven zijn door ten minste één type evidentie. In totaal werden 24 veldnormen geïdentificeerd die voldeden aan de volgende definitie: een onderbouwd en breed gedragen inzicht of aanbeveling, zoals een richtlijn, standaard, kernboodschap, norm of handreiking, waaraan zorgverleners en zorgorganisaties geacht worden te voldoen om kwalitatief goede zorg te verlenen.

Veel van deze veldnormen waren gericht op regio’s of specifieke doelgroepen (op basis van aandoening). De gevonden normen konden worden ingedeeld in drie categorieën:
- normen betreffende informatieoverdracht in zijn algemeenheid;
- normen betreffende informatieoverdracht bij bepaalde aandoeningen;
- normen betreffende informatieoverdracht over medicatie.

Er werden drie veldnormen gevonden die specifiek gaan over informatie-uitwisseling met betrekking tot de kwetsbare oudere patiënt/cliënt. Dit zijn de praktijkgids Kwetsbare Ouderen (VMS, 2009), de Nota Medische Verslaglegging (Verenso, 2009) en het Standpunt Sterke medische zorg voor kwetsbare ouderen (KNMG, 2010).

De Blok et al. deden ook onderzoek naar good practices ten aanzien van de overdracht van patiënt-informatie tussen ziekenhuizen en VVT. Er bleken geen good practices in Nederland voorhanden welke voldeden aan alle gedefinieerde criteria en de criteria 'wetenschappelijk onderbouwd' en 'gebaseerd op de veldnormen'.

Organisatie van de zorg, inclusief de wijze waarop informatieoverdracht dient plaats te vinden, krijgt wel langzaamaan meer aandacht [1]. Dit geldt ook voor normen die worden opgesteld met als doel transmurale zorgverlening of zorgverlening in de keten in goede banen te leiden. Een voorbeeld daarvan is de uitwerking van de overdracht in het SONCOS Normeringsrapport 2016 [11]. Naast de algemeen geldende richtlijnen voor de overdracht wordt in dit rapport t.a.v. de overdracht van palliatieve oncologische patiënten gesteld:

- Er dient gestructureerd en tijdig transmuraal overleg en overdracht te zijn ten behoeve van optimale palliatieve zorg in de thuissituatie.
- Het multidisciplinair team dient tevens beschikbaar te zijn voor overleg over patiënten die ontslagen zijn en thuis palliatieve zorg ontvangen onder leiding van de huisarts.

In reactie op het rapport van de IGZ over de overdracht [3] wordt door veel veldpartijen momenteel gewerkt aan aanpassingen van de richtlijnen en normen voor de overdracht van ziekenhuis naar VVT. Zo is de beroepsvereniging Verpleegkundigen & Verzorgenden Nederland (V&VN) bezig met de herziening van de richtlijn Verpleegkundige en Verzorgende Verslaglegging uit 2011. De herziening vindt plaats in overleg met alle V&VN afdelingen (waaronder V&VN Palliatieve Zorg) en naar verwachting zal de herziene richtlijn medio 2018 worden opgeleverd (bezoek website V&VN 28 oktober 2016).

Interventies die bijdragen bij aan een betere overdracht van zorg

Gezien de genoemde knelpunten is er opvallend weinig onderzoek gedaan naar interventies om de overdracht bij palliatieve patiënten te verbeteren [12]. Een internationale review over transfers van ziekenhuis naar huis van chronisch zieke patiënten suggereert dat bepaalde interventies heropnames kunnen voorkomen [13]: zorgcoördinatie door een verpleegkundige, communicatie tussen de primaire zorgverlener en het ziekenhuis, en een huisbezoek binnen drie dagen na ontslag. Specifiek voor palliatieve zorg zijn er nog weinig interventies ten behoeve van goede overdracht onderzocht. In een pilot in Groningen leidde het gebruik van een gestandaardiseerd Advanced Care Planning (ACP) document daadwerkelijk tot een hogere documentatiegraad [14].

Ook wordt er positief gesproken over elektronische overdrachtsdocumentatie. Elektronisch gegenereerde ontslagbrieven zouden meer kans hebben om alle relevante patiëntinformatie te bevatten [5]. Aan het digitale overdrachtsysteem POINT (Punt voor Overdracht, Informatie, Naslag en Transfer) van ziekenhuis naar VVT wordt bij de overdracht van palliatieve patiënten steeds vaker een speciaal formulier voor aanvullende informatie toegevoegd.

Hudson et al. [15] stellen dat de patiëntenoverdracht deel uitmaakt van transmurale zorg welke een complexe natuur heeft. Om de overdracht van patiënteninformatie te verbeteren, zal daarom verder gekeken moeten worden dan de overdracht zelf. Het opstellen van goede veldnormen, richtlijnen en een effectief format voor de overdracht is een goed begin, maar hiervoor is wel meer wetenschappelijke onderbouwing vereist. Naast het ontwikkelen, uitdragen en handhaven van een goede veldnorm zal tijdens de implementatie ook aandacht besteed moeten worden aan een breed scala van factoren, variërend van persoonlijke tot en met context-gerelateerde items [5].

Onderzoek naar uitkomsten

Bij een verbetertraject gericht op verbetering van de overdracht kan worden gedacht aan onderzoek naar de volgende kenmerken op het gebied van de inhoudelijke overdracht en organisatie en samenwerking:

- Kenmerken van de medische en verpleegkundige overdracht zelf:
    - Volledigheid
    - Nauwkeurigheid
    - Tijdigheid
- Kenmerken van de ontslagprocedure / gemaakte afspraken;

Daarnaast kan worden gekeken naar het effect van een verbetertraject op:

- Aantal ziekenhuis(her)opnames.

Verder kan worden gedacht aan onderzoek naar ervaringen van palliatieve patiënt en naasten op het gebied van :

- Kwaliteit van leven;
- Symptoomlast;
- Belasting van de mantelzorger.

De ideale medische overdracht (inclusief de medicatie-overdracht) bevat in elk geval de volgende elementen:

- Het is een overdracht van volledige en juiste informatie naar de juiste zorgverlener. De overdracht bevat concreet minimaal een aantal onderdelen;

- Het is een tijdige overdracht;
- De overdracht gaat samen met prettige communicatie en doorverwijzing.

Andere elementen die zouden bijdragen aan een goede overdracht zijn:

- Er is een gestructureerd en gestandaardiseerd overdrachtsformat, bijvoorbeeld in de vorm van een ontslagpad.
- De arts neemt, zodra de ontslagdatum bekend is, vóór ontslag van de patiënt contact op met de huisarts of met de specialist ouderengeneeskunde (afhankelijk van locatie waar patiënt naartoe gaat).
- De arts maakt adequaat gebruik van elektronische overdracht mogelijkheden (dit verkleint de kans op fouten).

[6, 9, richtlijnen diverse beroepsverenigingen van specialisten].

De ideale verpleegkundige overdracht kent de volgende elementen:

- Het is een overdracht van volledige en juiste informatie naar de juiste zorgverlener.

De overdracht bevat minimaal een aantal onderdelen;

- Het is een tijdige overdracht;
- De overdracht gaat samen met prettige communicatie en doorverwijzing.

Andere elementen die zouden bijdragen aan een goede overdracht zijn:

- Er is een gestructureerd en gestandaardiseerd overdrachtsformat, bijvoorbeeld in de vorm van een ontslagpad.
- Het is duidelijk wie de overdracht moet maken/doen, bijvoorbeeld indien een eerstverantwoordelijke verpleegkundige niet aanwezig is: wie neemt haar rol in de overdracht over.
- Aanwezigheid van ‘interactief forum’ gericht op de patiëntenoverdracht: het biedt mogelijkheid interacties met elkaar aan te gaan, te overleggen, informatie uit te wisselen, elkaars rollen te bespreken, elkaars standpunten te bespreken.
- Multiprofessionele communicatiepaden tussen ziekenhuizen en thuiszorginstellingen met daarin aandacht voor communicatierollen, multi-professionele teams en IT-systemen hebben positieve uitkomsten voor patiënten en zorgverleners m.b.t. tevredenheid over de overdracht van patiënteninformatie.

[6, 10]

Andere projecten binnen Palliantie

In het kader van het ZonMw programma Palliantie lopen naast het project Transmurale Samenwerking in de Palliatieve Zorg (TSPZ) drie grote projecten speciaal gericht op overdracht:

- Toward a seamless palliative care trajectory (penvoerder: AMC): moet leiden tot minder ongewenste ziekenhuisopnames, betere kwaliteit van leven, vermindering van symptoomlast en een lagere belasting van de mantelzorger.
- Bijdragen aan welbevinden van patiënten en naasten door markering van de palliatieve fase en proactieve zorgplanning (penvoerder Expertisecentrum Palliatieve Zorg NoordOost): Het doel van dit project is dat de organisaties die participeren in het Consortium Ligare markering van de palliatieve fase en het gebruik van proactieve zorgplanning gaan implementeren.
- Palliatieve spoedzorg: IQ healthcare doet momenteel landelijk onderzoek naar de kwaliteit van de palliatieve zorg buiten kantoortijden door huisartsen geleverd.

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Appendix 2

TSPZ - Samenvatting Ideaalmodel transmurale consultatie

Transmurale Samenwerking in de Palliatieve Zorg een regionaal leer- en verbeterprogramma

Andrée van der Ark
Marijanne Engel
Agnes van der Heide (Projectleider)

Januari 2017

Transmurale Samenwerking in de Palliatieve Zorg
een regionaal leer- en verbeterprogramma
Samenvatting ideaalmodel: Transmurale Consultatie

Consulenten werken transmuraal samen

Idealiter heeft een transmuraal team beschikking over een goede diversiteit aan consulenten die hecht samenwerken. Denk aan **1^e^, 2^e^ en 3^e^ lijns consulenten**, verpleegkundigen en artsen, met beschikking over een **rijke tweede schil** waarin diverse disciplines vertegenwoordigd zijn. **Ook niet-medische disciplines** horen hierbij vanwege de psychosociale en spirituele aspecten die onderdeel zijn van palliatieve zorg. De SONCOS normen stellen dat diverse disciplines samenkomen in een **minimaal maandelijks MDO**. Een diverse samenstelling bevordert de bekendheid met palliatief redeneren en met de multidisciplinaire aanpak die hier onlosmakelijk mee verbonden is (aanname). Het bevordert de kwaliteit van symptoomanalyse, omdat consulenten met verschillende ervaring en expertise vaak verschillende symptomen signaleren [1-3]. Een indirect voordeel van deze transmurale samenwerking is dat men beter bekend raakt met elkaars expertise en behoeften. Consulenten ervaren dat dit deuren kan openen naar betere transmurale samenwerking op andere vlakken (bron: interviews). Idealiter hebben alle consulenten goede **scholing in de palliatieve zorg** (minimale eisen in SONCOS normen). Transmurale samenwerking betreft ook zorgverleners buiten het team: goede **samenwerking met de hoofdbehandelaar** inclusief tijdige en goede **overdracht van het uitgebrachte advies** (SONCOS).

Het team blijft bij de patiënt

Het ideaal is: **één patiënt, één team**. Een knelpunt uit de praktijk is dat er problemen kunnen ontstaan door de verschillende werkwijzen van teams wanneer een patiënt bijvoorbeeld van het ziekenhuis naar huis gaat. Dit kan voorkomen worden door transmuraal te werken. Bovendien maakt dit het mogelijk een vertrouwensrelatie op te bouwen tussen de patiënt en het team [4]. Idealiter volgt een consultatieteam dus de patiënt, ongeacht waar deze zich bevindt. Dit betekent dat het **team consulten verleent in de 1^e^, 2^e^ en 3^e^ lijn (inclusief bed-side indien nodig).** Indien dit niet mogelijk is, is onderlinge afstemming met omliggende teams en zorgvuldige overdracht naar het volgende team cruciaal.

Intensieve betrokkenheid?

Consultatieteams in Nederland brengen advies uit, maar leveren zelf geen zorg. Over de effectiviteit van dit model is weinig wetenschappelijke kennis beschikbaar. Nederlandse consultvragers ervaren wel een verbetering in kwaliteit van zorg door het consult [2].

In het buitenland zijn palliatieve teams vaak meer betrokken bij de zorg. Sommige buitenlandse studies vinden een effect: de inzet van een palliatief team verbetert de kwaliteit van leven en stemming van de patiënt [5-7], de patiënt overlijdt vaker thuis [8], naasten zijn meer tevreden met de zorg [6, 9] en hebben meer vertrouwen in hun zelfredzaamheid [9]. In enkele studies lijken patiënten waarbij een palliatief team is ingezet ook langer te leven [5, 10]. Gunstige effecten op het welzijn van de patiënt, symptoomlast en ziekenhuiskosten zijn sterker bij vroegtijdige, proactieve inzet van palliatieve teams dan bij late, reactieve inzet [5, 6, 11]. Deze vroegtijdige inzet houdt in dat aan begin van de palliatieve fase een **symptoom assessment** gedaan wordt en het team een **proactief behandelplan** (helpt) opstellen. Gedurende het ziekteverloop blijft het team **vast aanspreekpunt** voor de patiënt en kan het ondersteuning bieden op het gebied van **zorgcoördinatie** en **behandelbeleid**.

Consulenten uit IKNL-teams sluiten in sommige gevallen aan bij PaTz-groepen en andere MDO’s. Sommige netwerken palliatieve zorg combineren het consulentschap van verpleegkundigen met een functie als AIV-verpleegkundige of casemanager.

Randvoorwaarden

De praktijkervaring van een langlopend transmuraal team leert dat het belangrijk is dat **voorwachten vrijgepland** worden om consulten tijdig en met voldoende aandacht te kunnen afhandelen (interview). Ook de **dienstdoende arts** zou **consulturen vrijgepland** moeten hebben op één of meer momenten van de dag om consulten en bijkomende taken af te handelen. Palliatieve zorgvragen kunnen complex van aard zijn, waardoor er meer tijd nodig is om tot zorgvuldige anamnese, psychosociale analyse en besluitvorming te komen. Arts-consulenten geven aan dat een gehaaste afhandeling een negatief effect kan hebben op de kwaliteit van het consult (interview). Analyses van consultregistraties ondersteunen dit: intensiever contact tijdens het consult leidt tot betere inventarisatie van behoeften [12, 13].

Waar passend kunnen **meetinstrumenten** ingezet worden bij een consult (SONCOS). Voordelen hiervan, zoals het inzichtelijk maken van problemen en registratie van kennis over de doelgroep, moeten hierbij afgewogen worden tegen de kosten in tijd en energie van zorgverlener en patiënt.

In Nederland vinden consultaties vaak laat in het ziekteproces plaats, bij consultaties door huisartsen bijvoorbeeld voornamelijk in de laatste maand van het leven [14]. Sommige consulenten geven aan dat artsen soms te lang wachten met een consultvraag (interviews). Idealiter wordt het consultatieteam **tijdig ingeroepen**. Om dit te bereiken is het belangrijk dat een team investeert in **Public Relations (PR)**. Bekendheid met het consultatieteamteam en met palliatief redeneren kan leiden tot betere en snellere probleemherkenning en meer consultvragen (interviews).

Idealiter bestaat er **passende en werkbare financiering**. Palliactief en het IKNL ontwikkelen momenteel een landelijk kwaliteitskader palliatieve zorg, waarbij passende financiering een streven is. Buitenlandse kosteneffectiviteitsstudies laten zien dat inzet van palliatieve teams daar de ziekenhuiskosten verlaagt (9-25%) door kortere opnameduur, minder intensieve behandeling en minder opnames op de Intensive Care [15; kosten buiten het ziekenhuis niet meegenomen]. Over kosteneffectiviteit in Nederland is weinig bekend, al loopt hier een studie naar (COMPASS, resultaten komend jaar verwacht). In het kader van kostenbesparing en substitutie naar de eerste lijn zou een transmuraal team steeds goed moeten kijken hoe met zo min mogelijk inzet van middelen goede zorg kan worden geleverd. Duidelijke rolverdeling en prioritering van activiteiten wordt geadviseerd [model beschikbaar: 16].

Verder is een **passende ICT voorziening** een randvoorwaarde. Idealiter is dit geen losstaand systeem, zoals het huidige PRADO, maar een geïntegreerde consultatiemodule in een bestaand, transmuraal systeem.

Overige aspecten ideaalmodel

- Het transmuraal team is **actief in het vergroten van expertise** door middel van scholing, voorlichting en via casuïstiek besprekingen.
- Het **adherentiegebied is passend**: voldoende klein om indien nodig bedside consulten te kunnen verrichten en de regio te kennen, en voldoende groot om ervaringsexpertise op te doen (interviews).
- Zoals eerder genoemd zijn **werkafspraken met omliggende consultatieteams** belangrijk. Mede-doel van het kwaliteitskader is het toewerken naar synchronisatie van consultatieteams en meer standaardiseren van kwaliteit. Daarbij hoort ook een goede afstemming met de **pijnteams** van ziekenhuizen (ervaring van transmuraal team), **specialistische teams** van thuiszorginstellingen (ervaring consulent) en de **PaTz-groepen** in de regio. Statische afspraken zijn niet voldoende: zorg is constant in ontwikkeling, dus er dient steeds gezocht te worden naar mogelijkheden voor meer efficiënte afstemming of samenwerking.
- **Casuïstiekbesprekingen met omliggende teams** helpen om het eigen functioneren aan derden te toetsen (ervaringen arts en consultent).
- **Heldere, volledige en tijdige consultregistratie** is van belang om het functioneren te monitoren en toetsen en geeft inzicht in de bereikte doelgroepen en aard en omvang van consulten. Dergelijk inzicht is een belangrijke voorwaarde voor tussen-

tijdse evaluatie, bijsturing en doorontwikkeling. Idealiter worden hierbij ook kosten en baten goed geregistreerd om kosteneffectiviteit te monitoren.

- Kostenbesparing in de zorg is een belangrijk thema. In het kader hiervan kan het gebruik van **teleconsultatie** nader verkend worden. Dit kan kosten beperken terwijl het bereik qua tijd en ruimte te vergroten en daarmee transmuraal werken versterken. Een specialist uit het ziekenhuis kan bijvoorbeeld zelf de patiëntsituatie thuis in de gaten houden [4, 17, 18].

Transmuraal team	**Randvoorwaarden**	
- 1^e, 2^e en 3^e lijns consulenten - Substantiële palliatieve opleiding - Rijke tweede schil - Niet-medische disciplines zijn betrokken - Minimaal maandelijks MDO - Overdracht naar hoofdbehandelaar - Team blijft bij patiënt waar nodig - Team consulteert in de 1^e, 2^e en 3^e lijn (bed-side indien nodig) - Consultvraag wordt tijdig gesteld	- Voorwachten vrijgepland - Dienstdoende arts consulturen vrijgepland - Meetinstrumenten worden ingezet waar passend - Aandacht voor PR - Passende en werkbare financiering - Passende ICT voorziening **Overige aspecten** - Actief in het vergroten van expertise - Passend adherentiegebied - Werkafspraken met omliggende consultatieteams	- Werkafspraken met pijnteams ziekenhuizen, specialistische teams thuiszorg, PaTz - Casuïstiekbesprekingen met omliggende consultatieteams - Heldere, volledige en tijdige consultregistratie - Eventueel: teleconsultatie - Vroegtijdige inzet - Symptoom assessment - Proactief behandelplan (steunen) - Aanspreekpunt blijven - Zorgcoördinatie steunen - Behandelbeleid steunen

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Appendix 3

Publiekssamenvatting resultaten vragenlijstonderzoek TSPZ onder vier doelgroepen

Samenvatting resultaten TSPZ vragenlijstonderzoek,
update mei 2020

ALGEMEEN

In het kader van het project ’Transmurale samenwerking in de palliatieve zorg’ is in de periode januari – december 2017 een vragenlijstonderzoek gedaan onder patiënten, nabestaanden, verpleegkundigen & verzorgenden en artsen in Zuidwest-Nederland. Hieronder volgt een samenvatting van de resultaten.

Deelnemers:

Patiënten	Nabestaanden	Verpleegkundigen & verzorgenden	Artsen
90	**340**	**1000**	**550**

Patiënten

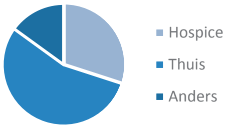
Drieënnegentig patiënten hebben een vragenlijst ingevuld, waarvan 30% op het moment van invullen van de vragenlijst in een hospice verbleef, de rest merendeels (55%) thuis. De gemiddelde tevredenheid over de kwaliteit van zorg was hoog met een rapportcijfer van 8,1. 54% van de patiënten was in de zes maanden voorafgaand aan het invullen van de vragenlijst minimaal éénmaal opgenomen geweest in het ziekenhuis (d.w.z. minimaal één nacht in het ziekenhuis gebleven). 56 patiënten beantwoordden vragen over het aantal zorgverleners dat zij hadden gezien in de laatste drie maanden, gemiddeld hadden zij contact gehad met 4,2 verschillende soorten zorgverleners. Het meest positief waren patiënten over de aandacht van zorgverleners, het vertrouwen in de zorgverleners en de begrijpelijkheid van gegeven informatie. Iets minder positief waren zij over belevingsaspecten, zoals het gevoel dat zorgverleners samen met hen vooruit keken hoe het beste verder te gaan, de aandacht die er was voor naasten, en de voorbereiding op ontslag uit het ziekenhuis. Zorg in de avond, nacht en weekenden (ANW) en ongeplande, acute zorg kwamen veel voor: ruim een op de drie patiënten (37%) had in de laatste 3 maanden contact gehad met een vervangend huisarts of de huisartsenpost en de meest recente ziekenhuisopname was meestal (bij 83% van de opnames) onverwacht geweest.

4,2 zorgverleners

Figuur 1 Aantal verschillende soorten zorgverleners.

8,1

Kwaliteit van de zorg

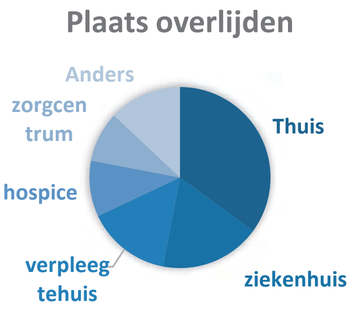


Figuur 2 Plaats van verblijf patiënt

Patiënten over zorgverleners:

+ Aandacht
+ Vertrouwen
+ Begrijpelijkheid
- Belevingsaspect
- Aandacht voor naasten
- Voorbereiding ontslag ziekenhuis

Nabestaanden



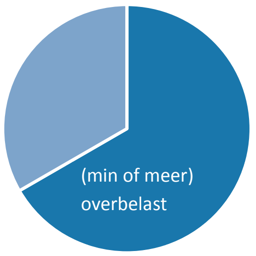
Figuur 1 Plaats van overlijden volgens naaste

340 nabestaanden hebben een vragenlijst ingevuld, van wie 81% vrouwen. 35% van de nabestaanden vulde de vragenlijst in op basis van ervaringen met de zorg voor een naaste die thuis was overleden, 18% op basis van ervaringen met een naaste die in het ziekenhuis was overleden, 15% met een naaste overleden in het verpleeghuis, 10% met een naaste overleden in het hospice en 9% met een naaste overleden in een zorgcentrum. De gemiddelde tevredenheid over zorg was lager dan bij patiënten met een rapportcijfer van 7,2. Opvallend was dat bijna een op de vijf nabestaanden de kwaliteit van zorg onvoldoende vond (zij gaven een rapportcijfer 5 of lager), en veel nabestaanden aangaven dat er sterke kwaliteitsverschillen waren tussen zorgaanbieders. Ongeveer de helft was (helemaal) tevreden over de samenwerking van zorgverleners, een kwart (helemaal) niet tevreden en een kwart was neutraal of had de vraag niet beantwoord. Het naderende levenseinde werd in 78% van de gevallen door een arts met de patiënt en/of naaste besproken: vaak was dit een medisch specialist (56%), iets minder vaak een huisarts (30%) of een specialist ouderengeneeskunde (13%). Nabestaanden rapporteerden, net als patiënten, veel onverwachte opnames in de laatste levensfase. Ongeveer de helft van de patiënten overleed uiteindelijk op de plaats van voorkeur.

Mantelzorgbelasting

De ervaren mantelzorgbelasting was hoog, met een gemiddeld rapportcijfer van 7,9 (waarbij 0=’helemaal niet zwaar’ en 10=‘heel zwaar’). Bijna een derde van de nabestaanden gaf aan overbelast te zijn geraakt en nog bijna een derde min of meer overbelast. Verder gaf 33% aan niet voldoende steun te hebben ontvangen tijdens de mantelzorg voor hun naaste. Ondersteuning na overlijden werd ook vaak als onvoldoende ervaren. Zorgverleners namen in 39% van de gevallen na overlijden contact op.

Figuur 4 Mantelzorg belasting op een schaal van 1 tot 10

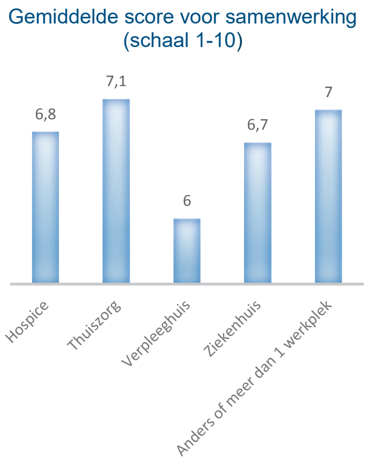


Figuur 5 Percentage mantelzorgers dat (min of meer) overbelast is geraakt.

Figuur 6 Percentage mantelzorgers dat onvoldoende steun ervaarde.

Verpleegkundigen en verzorgenden

Negenhonderddrieëndertig verpleegkundigen en verzorgenden hebben de vragenlijst ingevuld, onder wie 33% verpleegkundigen niveau 5 of 6, 36% verpleegkundigen niveau 4 en 32% verzorgenden (niveau 3). De meeste deelnemers waren werkzaam in de thuiszorg (39%) of in het hospice (18%). De tevredenheid over samenwerking met zorgverleners buiten de eigen organisatie kreeg gemiddeld een rapportcijfer 6,8. Zorgverleners in verpleeghuizen gaven gemiddeld het laagste rapportcijfer voor de samenwerking met zorgverleners buiten de eigen instelling: een 6,0. Bij de - indien ontvangen - overdracht over ‘de laatst overleden patiënt aan wie zorg was verleend’ gaf 34% van de respondenten aan dat de overdracht niet alle informatie bevatte die nodig was. Een voldoende/goede beoordeling van de overdracht hing vooral samen met een tijdige en complete overdracht en met het (goed) geïnformeerd zijn van deze ‘overgedragen’ (laatste) patiënt over zijn of haar ziekte en vooruitzichten. Bijna alle verpleegkundigen en verzorgenden vinden transmurale samenwerking belangrijk, maar bijna de helft zoekt niet zelf de samenwerking op met zorgverleners buiten de organisatie.



Figuur 2 Gemiddeld cijfer voor samenwerking per werkplek.

6,8
Tevredenheid samenwerking

6,0
Gemiddeld cijfer voor samenwerking door zorgverleners in verpleegtehuis

Artsen

In totaal hadden 547 artsen een vragenlijst ingevuld, waarvan 259 huisartsen, 205 medisch specialisten en 83 verpleeghuisartsen. Huisartsen gaven als gemiddeld rapportcijfer voor samenwerking met het ziekenhuis een 7,3. Bij specialisten ouderengeneeskunde was dit een 6,2. Medisch specialisten gaven voor samenwerking met huisartsen gemiddeld een 7,5. Veel artsen gaven over zichzelf aan dat zij goed in staat zijn om een beperkte levensverwachting in te schatten en te communiceren met de patiënt en met andere artsen, maar artsen hebben minder goede ervaringen met artsen buiten hun eigen organisatie wat betreft de communicatie over patiënten met een beperkte levensverwachting. Bij ontslag van patiënten met een beperkte levensverwachting na een opname in het ziekenhuis ontvangen huisartsen en specialisten ouderengeneeskunde vaak wel informatie over medische situatie en medicatie, maar (veel) minder vaak informatie over de psychosociale situatie, de prognose en wensen van de patiënt t.a.v. behandeling en zorg.

Overdracht bevat:
\+ Medische situatie
\+ Medicatie
\- Psychosociale situatie
\- Prognose
\- Wensen t.a.v. behandeling/zorg

7,3
Tevredenheid huisarts over samenwerking ziekenhuis

6,2
Tevredenheid SO over samenwerking ziekenhuis

7,5
Tevredenheid MS over samenwerking met huisarts

Wat betreft consultatie zijn de meeste artsen (83%) bekend met een consultatieteam palliatieve zorg in de regio, 75% van de huisartsen maakt wel eens gebruik van zo'n team. Zij geven het advies een gemiddeld rapportcijfer van 8,2. Van de medisch specialisten vraagt 32% wel eens advies aan een consultatieteam; zij waarderen het advies gemiddeld met een 7,9. Van de specialisten ouderengeneeskunde vraagt 35% wel eens advies aan een consultatieteam; het gemiddelde rapportcijfer voor deze consulten is een 8,4. Bij verdere analyses is ook gekeken naar mogelijke verklaringen waarom artsen weinig consult vragen. Onder oudere artsen is het aandeel artsen dat aangeeft te consulteren groter dan onder jongere artsen. Verder is het belang dat artsen hechten aan het krijgen van deskundig advies een belangrijke voorspeller of ze een consult vragen.

Conclusie

Definitieve conclusies over de ervaringen van patiënten en nabestaanden met samenwerking in de palliatieve zorg kunnen we op basis van deze resultaten nog niet trekken. Wel zien we bijvoorbeeld dat nabestaanden kritischer zijn over de kwaliteit van zorg voor hun overleden naaste dan patiënten.

Wat betreft zorgverleners kunnen we het volgende zeggen: verpleegkundigen & verzorgenden gaven aan dat de samenwerking tussen verschillende zorgorganisaties en de overdracht van informatie voor patiënten in de palliatieve fase kan worden verbeterd. Ook uit het vragenlijstonderzoek onder artsen kwam naar voren dat de communicatie en informatieoverdracht tussen ziekenhuisartsen en niet-ziekenhuisartsen over patiënten met een beperkte levensverwachting kan worden verbeterd. De vragenlijsten bevatten meer informatie dan hier is samengevat.

Hoe zijn de bevindingen meegenomen in de verbetertrajecten?

De bevindingen hebben inhoudelijke aandachtspunten voor de verbetertrajecten opgeleverd: hoe kan een traject het beste worden vormgegeven, wat zijn aandachtspunten voor het traject in dit netwerk? Ook hebben ‘harde’ cijfers geholpen om draagvlak voor het verbetertraject te verkrijgen bij besturen en op de werkvloer. Het inzetten van resultaten van de vragenlijsten in de verbetertrajecten is daarbij een doorlopend proces geweest waarbij ervaringen en reflecties vanuit de projectgroep en betrokken zorgverleners, gedurende het verbetertraject steeds werden afgezet en vergeleken met wat er in de vragenlijsten gevonden werd. Daarnaast hebben de onderzoekers samen met de projectgroepen in kaart gebracht welke aanvullende informatie nodig of gewenst was en hebben zij deze aanvullende informatie met daarvoor geschikte methoden verzameld.