EXPLORING HOSPICE CARE IN THE NETHERLANDS

Current practices and patients' symptom burden and well-being

Exploring hospice care in the Netherlands
Current practices and patients' symptom burden and well-being
Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht
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Current practices and patients' symptom burden and well-being

Verkenning van hospicezorg in Nederland
De huidige praktijk en door patiënten ervaren symptoomlijden en welbevinden
(met een samenvatting in het Nederlands)

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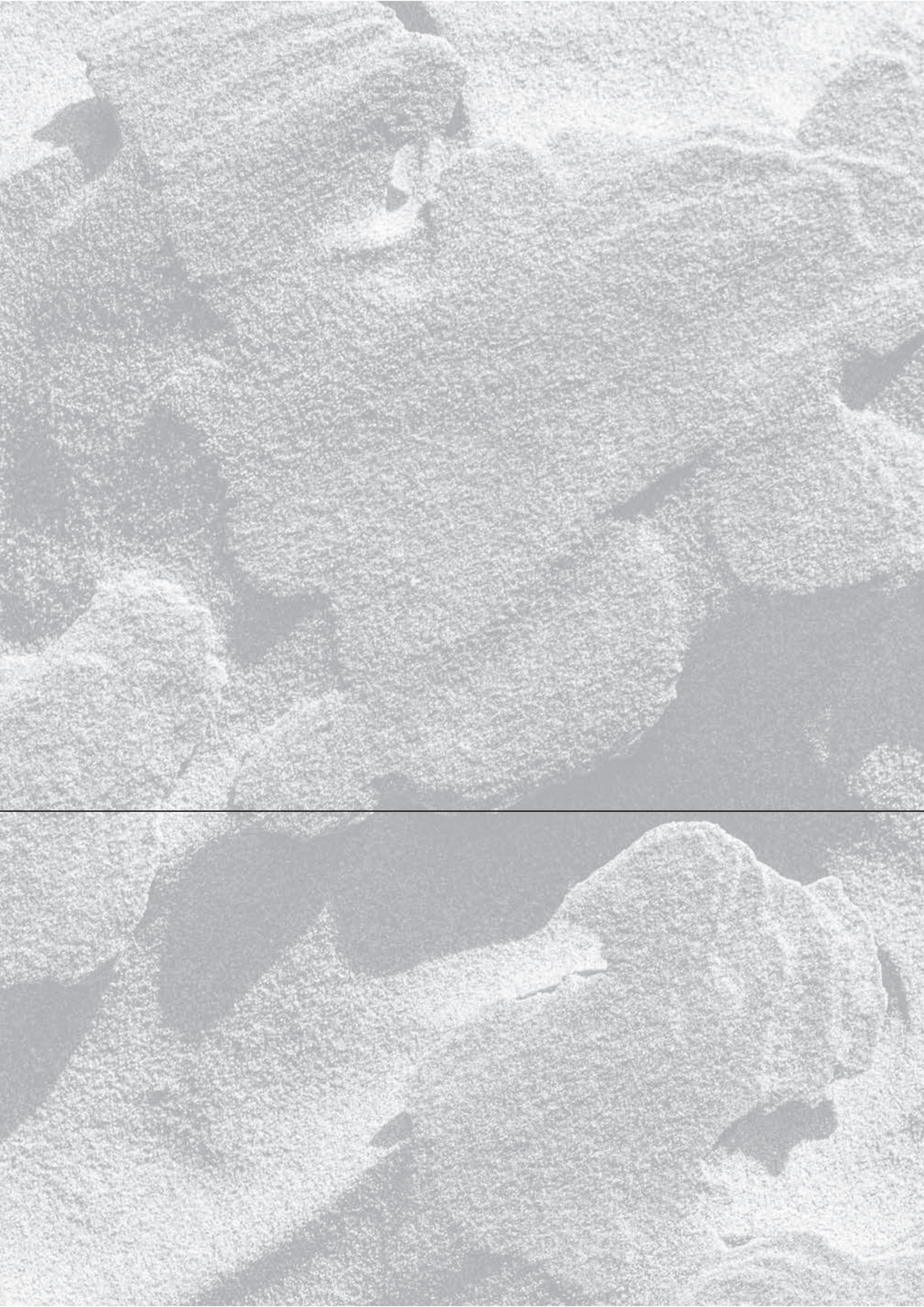

1

GENERAL INTRODUCTION

Everyone is confronted with death and dying during his or her life. In our society, however, death and dying are usually invisible. We tend to deal with serious illness by invoking the concept of a battle: battling against cancer, conquering illness; surrender is not an option. Discussions on death and dying and care for the dying have been increasing in recent years. Appropriate care and decisions to treat an individual or not are professionally and publicly discussed, and interviews with and programs focused on people living with incurable diseases are seen on television more and more often. The fact that not all patients survive serious illness and that survival is more a matter of luck than the outcome of a struggle is openly discussed. It is increasingly recognized that appropriate care is based on the patients' individual perceptions, needs, and preferences.

This thesis is on hospice care: specialized palliative care for patients in the last months of life in a hospice, focusing on their needs and preferences.

In the next 50 years the Dutch population will increase to over 20 million people. The number of patients living with life-threatening illnesses, organ failure, and frailty will increase. Those suffering from comorbidity or the consequences of past treatment will increase as well. These changes will result in more variance in illness trajectories and pose new challenges for healthcare systems worldwide. The number of people dying in the Netherlands will increase from over 143,000 in 2016 to over 200,000 in 2050.(1) Estimating that 80% of these deaths will be expected(2), the number of patients who require palliative care will increase from 114,000 to 160,000 per year.

PALLIATIVE CARE

During the palliative phase of a life-threatening disease, improvement of the quality of life and sometimes the prolongation of life as well may be achieved (if possible) by treating the underlying disease (illness directed palliation, such as palliative systemic therapy for cancer patients). During

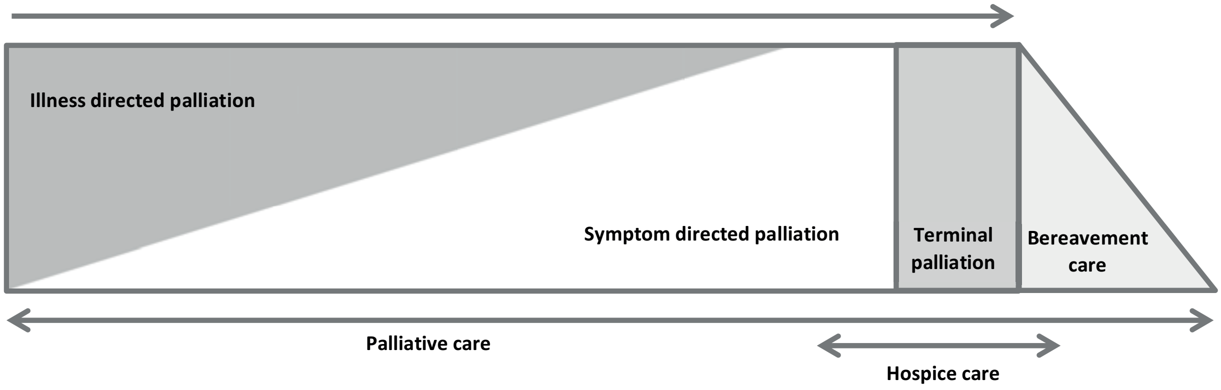

Figure 1. The palliative care continuum(4)

the palliative phase increasing attention is paid to the symptoms and problems caused by the advanced illness and its treatment (symptom directed palliation). During the course of the disease, the possibilities and effect of illness directed treatment diminish and ultimately this treatment is discontinued because it has no effect and/or because of its side effects. When death is imminent (the terminal phase, the last days or 1-2 weeks of life) palliation aims to preserve, comfort, and optimize the quality of dying.(3) After death bereavement care is provided to the family. This 'continuum of palliative care' is depicted in figure 1.

Palliative care is 'care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment and treatment of problems of a physical, psychological, social, and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.'(5)

Hospice care is positioned in the last phase of palliative care and focuses on symptom directed palliation, palliation in the terminal phase and bereavement care.

HOSPICE CARE

A historical perspective

The term hospice originates from medieval times. Hospices were shelters and resting places for pilgrims on a long journey. Jean Garnier in France and Sister Aikenhood in Ireland reintroduced the term hospice during the 19th century. Inspired by their religious background and feeling a need to care for the dying, they initiated homes to care for sick people at the end of their lives. Contemporary hospices can be traced back to the initiatives of Dame Cicely Saunders, founder of the first contemporary hospice in 1967, St. Christopher's in London.

Saunders referred in 1959 to hospice care as compassionate care that integrated working with the heart and working with the mind to optimize care for the dying. Hospice care was considered a concept rather than a place where care was provided. Dame Cicely Saunders described the essentials of hospice care in terms of service, population, care, aim, staff, communication, and education and research.(6) Based on this vision, the definition of palliative care was developed in 1990 and adapted in 2002 by the World Health Organization (WHO).(7)

Over the years, all over the world, hospices arose from small-scale initiatives based on local beliefs and opportunities and influenced by legislation and financial possibilities. As a result, a variety of hospice care models and initiatives exist at this time.

A 2013 review of the international literature concluded that there was no consistent definition of hospice care.(8) There were, however, six common elements of hospice care that were mentioned in 75% or more of the papers:

1. Availability for patients with advanced incurable disease (100%);
2. Care aiming to control symptoms and optimize the quality of life (100%);
3. An inter-professional approach to care provided by nurses, physicians, chaplains, psychologists, etc. (92%);
4. Attention to care for caregivers (92%);
5. Bereavement care (75%);
6. The context of hospice care in community-based programs (75%).

The Dutch Association of Hospice Care (DAHC) describes hospice care as 'multidimensional care for patients in the palliative terminal phase and for their loved ones, provided by a multidisciplinary team of formal and informal caregivers, aiming to optimize the quality of life, bereavement and dying. Hospice care is specialized palliative care provided in a hospice facility or at home, provided or supported by a multidisciplinary hospice team.'(9)

Hospice care development in the Netherlands

The first hospice in the Netherlands was the 'bijna-thuis-huis' in Nieuwkoop, founded by Pieter Sluis, a general practitioner. Hospices were initially mostly citizens' initiatives, predominantly influenced by the founder's personal experiences and originating from the belief that end of life care should be improved by de-medicalization and enabling patients unable to die at home to be in home-like surroundings. Hospices were mainly funded by charity. So far hospice care in the Netherlands has been predominantly inpatient care. Patients with an estimated life expectancy of <3 months have access to hospice care. Two mainstream organizational structures were developed: 1) volunteer-driven hospices and 2) professional-driven hospices (figure 2). The latters may be stand-alone hospices or hospice-units in nursing homes.

Hospices are mostly small units providing care and services within the local surroundings of the hospice facility. Three umbrella organizations are involved in hospice care. Volunteers in Palliative Terminal Care in the Netherlands (Vrijwilligers Palliatief Terminale Zorg Nederland, VPTZ Nederland) covers volunteer-driven hospices. Professional-driven hospices (having or wishing to obtain the Perspekt Quality Mark Hospice Care) are part of the Dutch Association of Hospice Care (Associatie Hospicezorg Nederland, AHzN), and hospice-units in nursing homes are members of Actiz, the association of organizations operating in the field of care and services for the elderly, the (chronically) ill and the young.

Organizational structure	**Volunteer-driven hospice**	**Professional-driven hospice**	
		Stand-alone	**Hospice-unit nursing home**
Association / umbrella organization	**Volunteers Palliative Terminal Care the Netherlands (VPTZ)**	**Dutch Association of Hospice Care the Netherlands (AHzN)**	**Actiz** Association of organizations operating in the field of care and services for the elderly, (chronically) ill and the young
National and regional collaboration	Fibula, umbrella organization of Networks Palliative Care		
Access	Patients with an estimated life expectancy < 3 months		
Finance	Healthcare Insurance act	Healthcare Insurance Act (PTZ) or Long-Term Care Act	Long Term Care Act
	Palliative Terminal Care Regulation Ministry of Health, Welfare and Sport		
	Voluntary contribution		
	Donations from charity and foundations		
Characteristics	Local context Religious / Non-religious		
Staff	Trained volunteers 24/7 Patients' general practitioners District nurses	Specialized nurses 24/7 in multidisciplinary team collaboration with physicians (GP's, medical specialists), chaplain, paramedics, music and art therapists, and trained volunteers	

Figure 2. Overview of the organizational structures of hospice care in the Netherlands

In volunteer-driven hospices trained volunteers offer 24/7 availability and basic care.(10,11) Medical care is provided by the patients' own general practitioners and nursing care by district nurses.(11) Almost half (47%) of the volunteer-driven hospices are part of a larger community-based volunteers' initiative to support patients and families at home.(11) In professional-driven hospices care is provided by a hospice-based multidisciplinary team of professionals and trained volunteers. The core team consists of nurses, physicians, and a chaplain or psychologist. Professional-driven hospices are situated in stand-alone hospices or hospice-units in nursing homes.

Most patients stay in the hospice until death (last resort care). Sometimes patients are admitted for a period of a few weeks for crisis management or to optimize symptom treatment and/or to unburden the relatives (respite care). Respite care, outpatient hospice care, and hospice based consultation are not yet covered by insurance.(9)

According to the organizations mentioned above, there are over 250 hospices and hospice care units in the Netherlands. Since hospice is not a protected title, there is no control on hospice initiation: anyone can establish a hospice facility and there are no predefined quality criteria, rules or regulations.

The number of hospices not attached to a hospice organization is unknown. As a result, we do not know the exact number of hospices in the Netherlands.

The quality of palliative care and hospice care

The Dutch Ministry of Health, Welfare and Sport initiated a National Palliative Care Program (2015-2020) to ameliorate the quality of palliative care aimed at supporting patients in the last phase of life and their families so that they can receive the physical, psychological, social, and spiritual care and support that fits their needs and preferences, at the right moment and in the appropriate setting.(12) Several initiatives have been undertaken to provide a standard to assess the quality of hospice care. The Dutch Association of Hospice Care initiated the Performance Care Quality Mark Hospice Care (PREstatieZOrg Hospicezorg, PREZO) in collaboration with the institute for quality assessment in care, the Perspekt Foundation.(13) Furthermore, a Quality Framework for Palliative Care in the Netherlands was developed in 2017 by the Dutch Association for Professionals in Palliative Care (Palliactief) and the Netherlands Comprehensive Cancer Organization (Integraal Kankercentrum Nederland, IKNL).(5)

The PREZO Quality Mark is a performance-oriented quality system describing performances provided to the patient. The patient perspective includes seven areas of quality of life: 1) living, 2) spiritual, 3) social, 4) physical, 5) psychological, 6) dying and 7) aftercare. The foundation of the areas is comprised of four pillars: autonomy, an individual care-plan, information, and communication / safety. In addition, seven requirements have been formulated to facilitate formal and informal caregiving and support responsible entrepreneurship: 1) competences and 2) attitude of formal caregivers and volunteers, 3) integral care and support, 4) safety, 5) strategy and policy, 6) results, and 7) management.(14)

The Quality Framework for Palliative Care in the Netherlands describes the quality of care for the whole palliative phase. The Quality Framework was built upon the following question: What do patients and their families, care providers, and insurers think that the quality of palliative care in the Netherlands should be? The ten domains included in the Quality Framework are: 1) core values and principles, 2) structure and process, 3) the physical dimension, 4) the psychological dimension, 5) the social dimension, 6) the spiritual dimension, 7) the dying phase, 8) bereavement, 9) culture, and 10) ethical and legal aspects.(5)

Society, the government, and insurance companies expect insight into the quality of hospice care provided. In his letter to the House of Representatives the Dutch State Secretary of Public Health, Welfare and Sport wrote that 'organizations that are involved in hospice care themselves invest in better quality and are more willing to demonstrate what care they provide.'(15) Although the satisfaction scores of bereaved family members is high,(16) insight into the quality of hospice care is lacking.

This thesis was constructed in collaboration with the Dutch Association of Hospice Care, which felt that an in-depth exploration of specialized hospice care is needed to better assess the hospice population, symptom burden, (un)well-being, needs, preferences, and the multidimensional approach.

The hospice population

Death certificates do not include hospices as a location where death occurred and all deaths in palliative care units are registered as nursing home deaths. Based on the death certificate the number of patients who died in a hospice can be estimated only by the percentage of the category 'other sites' on the death certificate (6% in 2014). According to an estimation of the Netherlands Comprehensive Cancer Organization approximately 10% of all expected deaths, approximately 11,400 per year, occurred in a hospice facility.(4) This is probably an underestimation of the true number of patients receiving hospice care.

Patients have access to hospice care if their estimated life expectancy is <3 months. There are no additional preconditions. Hospital nurses (38%) or GPs (30%) usually initiate the referral to a hospice. Sometimes patients and their family take the initiative (11%).(17) Hospice patients and their families stated that, while the choice not to die at home was deliberate, the choice for a specific hospice setting was based on the option provided by a healthcare professional, close to the patients' residence.(18) Koekoek et al. also found that patients admitted to a hospice specified that their choice was based on location and the experiences of friends and family instead of the care organization.(19) West et al. found no differences between professional- and volunteer-driven hospices with respect to patient characteristics of age, gender, and primary diagnosis. There were significant differences, however, in the care provided. Technical procedures were performed more often in professional-driven hospices (82% versus 70%) and paramedical care was provided more often in the hospice-units of nursing homes.(20)

SYMPTOMS AND WELL-BEING

A symptom is defined as a problem expressed by a patient in the physical, psychological, social or spiritual area as the expression or consequence of an underlying illness or its treatment.(21) For optimal palliative care, insight into the patients' symptoms, needs, well-being, and influencing factors and associations is vital.

The expression of a symptom involves three steps: 1) production (the cause of the symptom), 2) the perception of the symptom in the central nervous system, and 3) the expression, the observable effect of the symptom.(22)

Each symptom has four dimensions. The first is the *physical* dimension, which includes the pathophysiology, sensory, and functional dimensions. Second, there is the *psychological* dimension, which entail the affective and cognitive aspects of the symptom experienced by the patient. The third dimension is the *social*, which concerns the patients' behavior and interactions and the consequences for fulfilling social roles. Finally, the fourth dimension is the *existential* or *spiritual* dimension: the thoughts, feelings and questions that the symptom gives rise to about the sense and meaning of life associated with the illness trajectory and death and dying.(21,23,24)

Symptom management starts with an adequate assessment of symptoms. If a patient expresses a symptom, a multidimensional assessment provides insight into the severity and experience of the symptom. Assessment tools can be used to support this assessment. In addition, a physical examination should always be performed. Appropriate additional tests or diagnostics should be performed, if necessary for adequate treatment.(23)

Studies of the Dutch hospice population (i.e. patients with an estimated life expectancy <3 months, predominantly inpatients) are scarce. Overall, studies show that during the last year of life both cancer patients and non-cancer patients suffer concurrently from multiple symptoms.(3,25-28) The symptom burden in a cancer patient population is associated with age, gender, diagnosis, performance status, and multi-morbidity.(29-31) The intensity of symptoms increases as death approaches, in particular in the last two months of life, and the quality of life decreases with a risk of a low quality of dying and risk of disturbed bereavement.(3,28,32,33) The tools used to study symptom prevalence, intensity, and well-being differ greatly.(3) As a result, the symptoms of palliative care and hospice care patients differ, and the results are not comparable.

As indicated by the definition a symptom is a subjective patient experience.(21,22,34) Therefore, the gold standard for assessing the symptom burden is patient self-assessment. Patient reported outcome measures (PROMs) can be used to gain insight into the patients' symptom prevalence and intensity to support communication and to evaluate the effect of interventions.(35-37) The Edmonton Symptom Assessment System (ESAS) has proven to be a valid and reliable clinical tool for monitoring symptom severity and for use in research.(38-42) In the Netherlands, an adapted Dutch translation of the ESAS, the Utrecht Symptom Diary, has been developed to monitor symptom prevalence and intensity. It measures eleven frequently occurring symptoms: pain, sleeping disturbance, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnoea, fatigue, anxiety, and depressed mood, and one item on well-being. All symptoms are assessed using an 11-point numerical scale (0=no symptom, best possible to 10=worst intensity, worst possible). Patients can add items if necessary. Finally, patients are asked to indicate their own priority, i.e. which symptom(s) ha(s)(ve) to be addressed first. The recall period of the USD is now/at this moment. In hospice care the USD is usually filled in at least twice a week, and more often if indicated. Patients usually fill in the USD in the late afternoon. The USD is primarily implemented in standard hospice care to support clinical decision making and may also be used for research purposes.

Hospice care aims to optimize the quality of life and death and to provide bereavement care. Care and treatment should fit the patients' needs and preferences. Hospice patients suffer from multiple symptoms concurrently in all four areas. Insight into hospice care provided, and into the symptoms, well-being and preferences of hospice patients has been lacking to date.

MULTIDIMENSIONAL CARE

Hospice care is multidimensional care that focuses on the complex system of physical, psychological, social, and spiritual suffering.(5,7) Problems experienced in one dimension can be caused and influenced by other problems in other dimensions and vice versa. This was first described by Cicely Saunders in the concept of 'total pain', which describes the expression of physical symptoms as a starting point for exploring other dimensions and their influence on these symptoms.(43)

To optimize the patients' quality of life, all dimensions of suffering should be assessed systematically. Interdisciplinary collaboration in a multi-professional team is needed to ensure that continuous attention is paid to all dimensions.(44)

A multidimensional assessment of the patient entails four dimensions:

1. the physical dimension: physical and functional aspects;
2. the psychological dimension: emotional and cognitive status;
3. the social dimension: the patients' social roles and the availability of a social network;
4. the spiritual dimension: beliefs, meaning and major life questions.

Palliative reasoning is an adapted method of clinical reasoning, supporting the multidimensional analysis and treatment of symptoms and improving communication, in a methodological and structural way and is to be used by either individual caregivers or by a multi-professional team.

Palliative reasoning consists of four steps in a structural and iterative process:

Step 1. Assess the individual situation
Medical history
Multidimensional assessment of the patients' current status
Prognosis
Medication
Symptom analysis
Meaning of the symptom for the patient
Priorities and wishes of the patient

Step 2. Summarize the problem and formulate a proactive care plan

Name the problems and formulate a working hypothesis

Policy considerations

Consider consultation of an expert and/or perform additional diagnostics

Formulate aims of treatment

Formulate a proactive care plan:

- treatment of the cause of the problem (if possible)
- symptomatic treatment (non-pharmacological and/or pharmacological)
- support by other disciplines

Step 3 Evaluate

Plan how the effect of the care plan is measured, by whom and when.

Measure the effect by symptom severity and experience and patient functioning and well-being

Step 4. Adapt the care plan as needed and constant evaluation

If the effect is positive: continue to evaluate

If the effect is limited or absent:

- adapt the care plan (go back to phase 2)
- re-analyze the problem (go back to phase 1)
- accept the situation(23,45,46)

Palliative reasoning has been increasingly adopted and implemented in Dutch hospices in recent years. Insight into the symptom burden of hospice patients, the practice and effect of multidimensional hospice care, and the effect of palliative reasoning is largely lacking.

OBJECTIVES

The aims of this thesis are: 1) to gain insight into Dutch hospice care and 2) to explore the symptoms, well-being and needs of hospice patients.

The following research questions were formulated:

Part I Exploration of hospice care in the Netherlands

1 What are the main characteristics of hospice care in the Netherlands, and how are these characteristics operationalized in daily practice?

2 How is multidimensional care provided for hospice inpatients by the multidisciplinary hospice team?

- How are the physical, psychological, social, and spiritual dimensions described in the patient notes by nurses, physicians and other caregivers and in the minutes of the multi-professional team meeting?

  - How do multidisciplinary team members reflect on the multidimensional hospice care described and provided?

3 Does hospice assistance at home enable patients in the last year of their life to die in their preferred location? Second, what are the symptom burden and (in)stability of these patients and how can they be identified?

Part II Symptoms and well-being of hospice patient

4 What is the symptom burden of hospice patients and how does age influence symptom prevalence and intensity?
5 Which symptoms predict the state of well-being of cancer patients admitted to a hospice?
6 What is the concordance between patients' and nurses' assessments of symptom intensity and does it improve over time after admission?

METHODS

Part I Exploration of hospice care in the Netherlands

To explore hospice care in the Netherlands from a provider perspective, a cross-sectional hospice survey study was first performed. Next, multidimensional care was studied, using an explorative two-phased mixed method design: a quantitative retrospective study analyzing patient records, followed by a discussion of the results of the quantitative study in focus groups. To answer the third question, a retrospective observational design was used.

Part II Symptoms and well-being of hospice patient

To gain insight into the symptoms, well-being, and needs of patients admitted to a hospice retrospective quantitative studies were performed, using prospectively collected data during standard care, in Academic Hospice Demeter in De Bilt, a seven-bed professional-driven hospice in the center of the Netherlands. Patient data were gathered during daily care for clinical practice and research purposes, using the Utrecht Symptom Diary, an adapted Dutch translation of the Edmonton Symptom Assessment System.

A cross-sectional design was used to describe the influence of age on symptom burden. Next, a combined cross-sectional and longitudinal study was performed to provide insight into the symptom burden and well-being of patients at admission as well as during their stay, as death approached. Finally, to study the concordance between patients' and nurses' assessments of symptom intensity, a longitudinal descriptive study was performed using dyads of patients' and nurses' symptom intensity scores.

SAMPLES

Part I Exploration of hospice care in the Netherlands
The population of the hospice care studies consisted of professional-driven hospices in the Netherlands. These hospices are organized under the Dutch Association of Hospice Care (DAHC). A total of 36/42 members of the DAHC were included in the first study. The second study, on multidimensional care, consisted of a subsample of 12 hospices. These 12 hospices were enrolled in the quantitative phase of the study. For the qualitative part, five hospices were selected. For the third study, an outpatient hospice service from Academic Hospice Demeter was studied.

Part II Symptoms and well-being of hospice patient
Data on symptom burden and well-being were gathered from academic hospice Demeter, where systematic symptom assessment and symptom monitoring by the Utrecht Symptom Diary was implemented from its foundation in 2007. For the first and third study, data from all patients were used, regardless of the primary diagnosis. To study which symptoms predict well-being (the second study) only patients with a primary cancer diagnosis were selected.

OUTLINE OF THIS THESIS

This thesis reports on six studies.

First, **chapter 2** describes an exploration of hospice care in the Netherlands. **Chapter 3** explores multidimensional hospice care. In **chapter 4** an innovative integrated hospice at home service is evaluated

Patients' symptoms and needs are central in the second part of this thesis. First, **chapter 5** looks at the differences in the symptom burden between age groups. Then, in **chapter 6**, a study on symptoms predicting the well-being of hospice cancer patients suffering at admission as well as during their hospice stay is described. The last chapter of this thesis, **chapter 7**, discusses the concordance between patients' and hospice nurses' reports of symptom intensity and its changes in the first three weeks after admission.

Finally, in **chapter 8**, we discuss our results, the strengths and weaknesses of the studies in this thesis and the implications of these results for hospice care.

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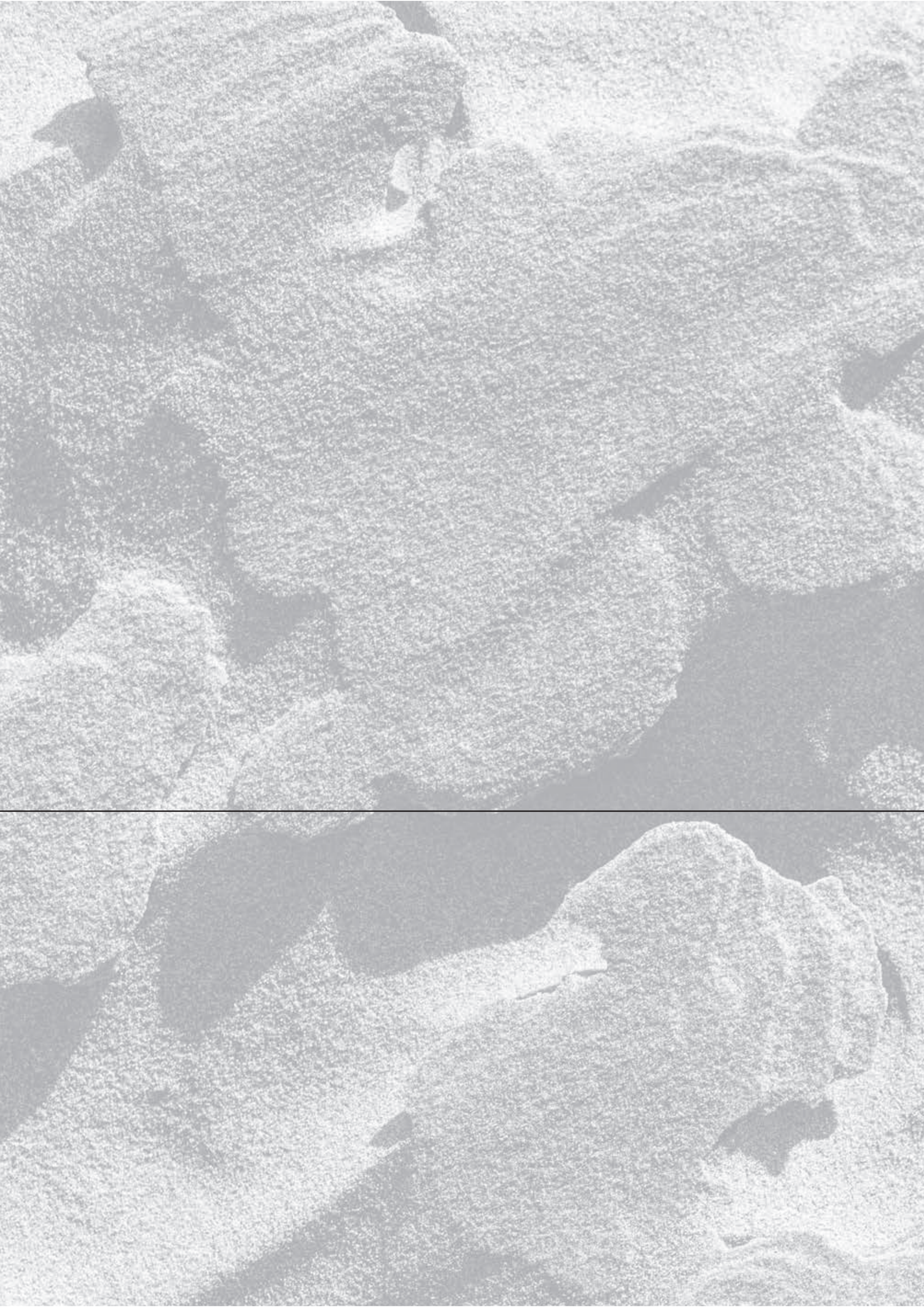
Part 1

EXPLORATION OF HOSPICE CARE IN THE NETHERLANDS



2

EXPLORING HOSPICE CARE, A NATIONAL SURVEY OF PROFESSIONAL-DRIVEN HOSPICES

Everlien de Graaf, Daniëlle Zweers, Saskia CCM Teunissen

Submitted

ABSTRACT

Background

Worldwide, hospice care developed in a variety of care initiatives and programs. In the Netherlands hospices are either volunteer-driven or professional-driven. The aim of this study is to explore hospice care provided by professional-driven hospices.

Design

An exploratory mixed-method survey was performed from June 2014-December 2015. The convenience sample consisted of 42 professional-driven hospices. Qualitative data were obtained through mission and vision statements and provided the main characteristics of hospice care. The quantitative items, based on national guidelines and quality statements, were used to gain insight into current practices and organizational structures. Data were analyzed using a qualitative content analysis, and descriptive statistics.

The results from the qualitative phase were used as a framework for describing results.

Results

Patients <3 months prognosis had access to hospice care. Multidimensional care was provided by a multiprofessional team supported by trained volunteers. The core team consisted of nurses, physicians and chaplains. Besides last resort admissions, respite-(68%), crises-(42%), day-(8%) and homecare (30%) was provided. Multidimensional assessments were based on expert opinion predominantly, 50% supported by tools.

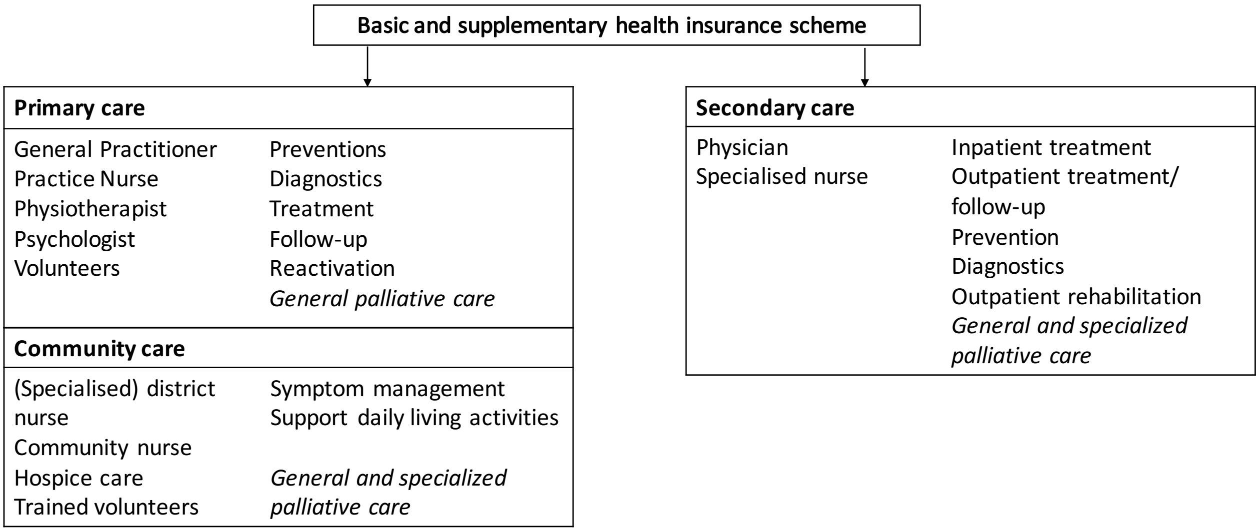
Conclusion

Professional-driven hospices strive to provide a combination of last resort, respite and crisis care in hospice and home locations by multi professional teams and trained volunteers. Support of these functions by the implementation of tools for systematic multidimensional assessment, monitoring and evaluation is limited. Research requires patient outcomes as the key to ameliorate the quality of hospice care. Dutch results can support other countries with short histories in hospice care to further develop specialized palliative care.

INTRODUCTION

Worldwide, hospice care developed over the last decades in a wide variety of initiatives; from newly developed solitary initiatives to complete integration of the hospice care concept within national healthcare systems or products of care.(1) In Europe a lot of differences in developmental trajectories of hospice care are found.(1)

Hospice care is multidimensional care, aiming to optimize the quality of life of patients and their families in the last months of life by diminishing physical, psychological, social and spiritual suffering.(2) Care in hospices is provided by a multidisciplinary team of professionals and trained volunteers, to address the wide dispersion of multidimensional symptoms, problems and needs of hospice patients.(3) Hospices could play a role in the amelioration of the quality of palliative care provided by generalist palliative care providers, and develop and disseminate knowledge through research and education.(4) In the Netherlands palliative care is not a medical specialty yet, palliative care is part of general health care. An overview of the Dutch healthcare system is provided in Figure 1.(5)



Basic and supplementary health insurance scheme

Primary care	
General Practitioner Practice Nurse Physiotherapist Psychologist Volunteers	Preventions Diagnostics Treatment Follow-up Reactivation *General palliative care*
Community care	
(Specialised) district nurse Community nurse Hospice care Trained volunteers	Symptom management Support daily living activities *General and specialized palliative care*

Secondary care	
Physician Specialised nurse	Inpatient treatment Outpatient treatment/ follow-up Prevention Diagnostics Outpatient rehabilitation *General and specialized palliative care*

Figure 1. Palliative- and hospice care in the Dutch healthcare system, De Graaf et al, 2016

Palliative care is mostly provided by generalist palliative care providers, for instance general practitioners and district nurses at home and medical specialists and nurses in hospitals. Besides generalist palliative care, specialist palliative care is provided in hospices or by hospice caregivers in primary care. Hospices in the Netherlands are either volunteer- or professional-driven hospices (figure 2). Volunteer driven hospices provide home-like, generalist palliative care. Daily support is provided by trained volunteers and the patient’s own general practitioner. If necessary, district nurses will be involved, asked by a general hospice coordinator. Professional-driven hospices are hospices providing specialized palliative care by a multi professional team of professional caregivers supported by trained volunteers. The nursing staff is available 24/7. Medical care is provided by one or more hospice GP's or other physicians with additional palliative care training and/or the patient's own GP. Professional-driven hospice care is provided in stand-alone hospices, and hospice units of elderly care facilities. Professional-driven hospices collaborate in the Dutch Association of Hospice care (DAHC).

<table>
<tr><td>Access</td><td colspan="3">Patients with an estimated life expectancy < 3 months</td></tr>
<tr><td rowspan="2">Finance</td><td colspan="2">Healthcare Insurance Act
Own contribution</td><td>Longterm Care Act</td></tr>
<tr><td colspan="3">Complementaed with donations from charity and foundations</td></tr>
<tr><td>Characteristics</td><td colspan="3">Fit local context
Religious / Non-religious</td></tr>
<tr><td>Association</td><td>Volunteers Palliative Terminal Care</td><td>Dutch Association of Hospice Care</td><td>Actiz</td></tr>
<tr><td>Organizational structure</td><td>Volunteer-driven hospice</td><td>Professional-driven
stand- alone hospice</td><td>Professional-driven
nursing home hospice</td></tr>
<tr><td>Staff</td><td>Trained volunteers 24/7
and
Patients' general practitioner
District nurses</td><td colspan="2">Specialized nurses 24/7
Physicians (GP, medical specialist, elderly care specialist), Chaplain, Paramedical and supportive specialists
Supported by trained volunteers</td></tr>
</table>

Figure 2 Palliative- and hospice care in the Dutch healthcare system, De Graaf et al. 2016

Hospice care can be considered a complex intervention, being multidimensional care and support, provided by a multidisciplinary team and targeting the multiple interacting symptoms, problems, and needs of patients in the last months of life, and their family.(6) The Medical Research Council developed a model to support the development, piloting and feasibility, evaluation, and implementation of evidence based complex interventions, the MRC framework.(6) The first step in the MRC development phase is problem identification and definition.(7) It is hypothesized that Dutch hospice care has developed over the years, from caring for inpatients in the last phase of life to multiprofessional, multidimensional care for patients and their families and additional services in the community. However, insight into the organization of care and the care and treatment provided in hospices in the Netherlands is lacking.

This study aimed to provide a first exploration of hospice care in the Netherlands from a hospice provider perspective, by giving insight into the operationalization of the original Cicely Saunders essential elements of the hospice care concept. The results will provide opportunities for benchmarking and identify opportunities for improvement of specialized palliative care.

METHODS

An explorative, descriptive mixed method study was performed from June 2014 to June 2015 using a survey entailing qualitative and quantitative items. The first items were qualitative, enabling participants to upload or paste their mission- and vision statements documents, and provided the core characteristics of hospice care. The quantitative data provided an overview of the operationalization of these characteristics and the dispersion between participating hospices was exposed. The core characteristics, described in the mission and vision statements, were used as a structure to describe the results.(8,9)
The STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) statement(10) and COnsolidated criteria for REporting Qualitative studies (COREQ)(11) were used to support the quality of this report.

Setting and population

A convenience sample of professional-driven hospices was drawn by inviting all members of the DAHC to participate. Members were 1) independent facilities, providing hospice care driven by professionals, assisted in daily care by a team of trained volunteers, 2) specialized palliative care units in nursing homes and 3) specialized palliative care teams of home care organizations. This survey was executed in three tranches during a one-year-period. All surveys returned, were included in this study.

Ethics approval and consent to participate

All members of the DAHC were invited for an informative presentation of the study explaining the background, rationale and study procedures. After the presentation all members consented to participate in the study. Participants received an email with a short invitation, a link to the online survey, written information and instructions. Reminders were sent after 2, 4 and 6 weeks. Data were anonymized by the principal investigator (EG) prior to the data analysis. This study was performed according to the declaration of Helsinki (12) and the principles of good clinical practice. (13)

Outcomes and measurement

The survey was based on the definition of palliative care(14) and operationalized using national guidelines(15,16) and quality indicators.(17) It was structured in 14 main themes: 1) strategic management (mission- and vision statements), 2) hospice characteristics, 3) collaboration, 4) organization, 5) registration, 6) facilities, 7) geographic context, 8) care process, 9) patient assessment, 10) patient needs, 11) multiprofessional team meeting, 12) quality of care, 13) knowledge and expertise, and 14) staff. The survey entailed 91 items, with a minimum of 2 items per subthemes, for data triangulation. Face- and content validity were tested by a group of experts: six hospice managers with different backgrounds, and three researchers (EG, DZ, ST). As a result, four items were adapted in concordance with the advice from the experts to improve the readability of the items and two items were added. After each subject an open question provided participants the possibility to add information on the subject. The final survey entailed 93 items and took 90 minutes to complete.

Data analysis

First, the qualitative data derived from the by participants provided mission and vision statement documents, were analyzed using content analysis by two researchers (EG, DZ). The documents were studied in four steps, first the documents were read and coded, subsequently the codes were described in subcategories and thereafter in generic categories.(18) This categorization was discussed within the research team (EG, DZ, ST). After consensus was reached the two researchers (EG, DZ) categorized the generic categories into main categories, the core characteristics of hospice care.(18,19) To ensure trustworthiness, these core characteristics were checked with the original data in the mission statements (EG, DZ, ST).(20,21)

Then the quantitative data were analyzed using descriptive statistics including proportions for categorical data and mean, range and standard deviation on continuous data. In addition, the core characteristics were dichotomized in present, yes or no, to provide insight into the distribution of these characteristics between hospices and the heterogeneity of exposed hospice care.

To ensure trustworthiness of the study researchers used peer debriefing (EG, DZ, ST) during the entire process of data collection and analysis to enhance the quality of the results and reduce bias. In addition, an audit trial was logged to collect all decisions made during the research process. A member check was performed, presenting the results to the participants, to check if the results reflected the reality of the participants and to assess the understanding and interpretation of the data. No adaptions were made.(20)

RESULTS

A total of 42 hospices were invited to participate in the survey of which 36 completed the questionnaire. Five declined participation and one hospice returned the survey without answering any questions and was excluded. See figure 3 for the flowchart of participation.

Three hospices did not complete the full survey (one after Q36 and two after Q38), one hospice started the survey after Q39. In appendix 1 all items of the survey are presented including the analysis of missing items. No differences in number of beds, and years of experience were found between hospices that did and did not complete the survey. In addition, two home care services were not able to fill out all items, since the items related to admission and setting, were not applicable.

The 36 participating hospices have 7.5 beds on average (4-12; SD 2.177) and 11.77 years of experience (1-24; SD 6.074). All hospices use several strategies and combinations of strategies to inform patients, mostly face to face, flyers or folders, by telephone and internet.

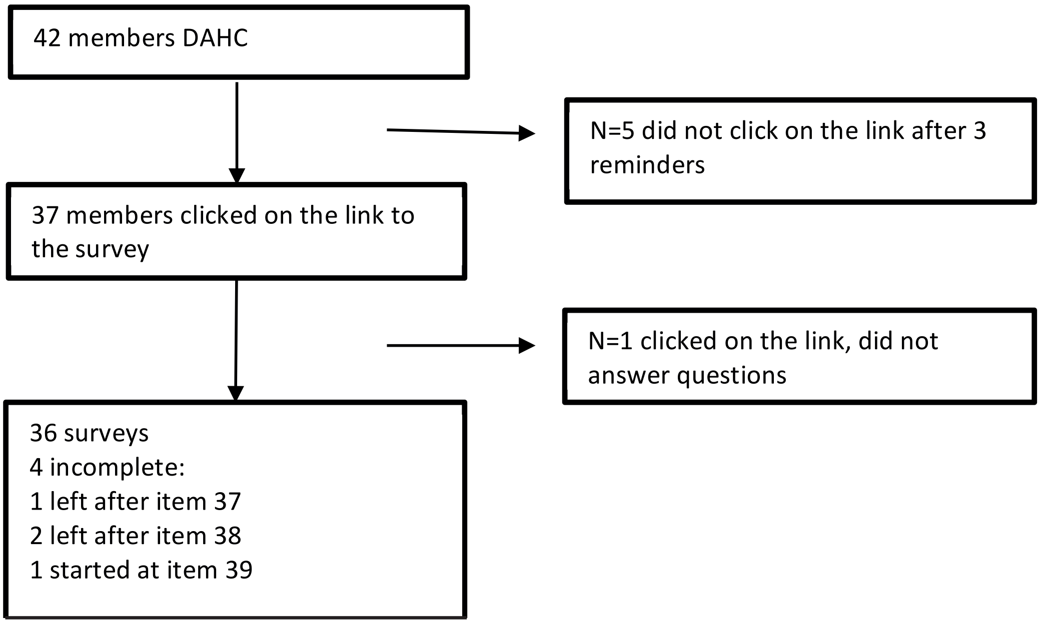


Figure 3. Flowchart participation

The reported core characteristics (main categories) are: population, aim of hospice care, described care, atmosphere and attitude, hospice staff, and community services, education and research. provided. Overview of these core characteristics is depicted in table 1.

Population of care

The population care for are patients, and their families. All hospices describe to care for patients with a life limiting illness, of whom 11 (30%) explicitly states that patients should have a life expectancy of less than three months to be eligible for care. Other hospices use descriptive terms for admission eg. palliative terminal phase. Some hospices describe that patients suffering from psychiatric disorders, or patients suffering from dementia, who need continuous 24/7 supervision cannot be cared for, due to limitations in type of care, staff or facilities. Eight (22%) hospices work with a conscious case mix, based on illness-, age, or the complexity of patients and/or care needs. Patients can be signed up for admission themselves in 87% of hospices, and can be referred to a hospice by their general practitioner (92%), medical specialist (90%), district nurse (92%) and the patient or family (87%)
Besides patients, families are described as the population of care by 32/36 participants, providing care, guidance and education.

Aim of hospice care

Hospice care aims to optimize the quality of life, death, and bereavement. However, only the quality of life is described in all mission statements.
The aims of hospice admissions are last resort (100%), respite-care (68%), unplanned admissions

Table 1. Overview of core characteristics

Research	Participation	x	x		x	x		x	x	x	x	x	x	x	x		x	x	x	x
	Initiate	x				x	x			x										
Quality	Active improvements	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x		
Education	Collaboration	x	x	x	x	x	x	x	x	x	x	x			x		x	x	x	x
	Stand alone	x	x	x	x	x		x	x	x		x		x	x		x	x	x	
	Population													x				x		
	Volunteer	x	x	x	x	x		x		x		x			x			x	x	
	Hospital	5	x	x			2	3	x	2		x						1	1	
Consultation	National	2	x			x		4	x	2	1				1	1	1	3		1
	Local	x	x			x	x	x	x	x			x		x		x	x	x	x
	Primary care	x		x		x	x	x		x				x	x		x	x	x	
	Hospice/PC phycisian	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Interdisciplinary consultation	GP	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Nurse	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Chaplain	x	x	x	x	x	x	x	p	x	x	x	x	x	s	x	x	x	p	x
	Method	x	x		x	x	x	x	x	x	x	x	x	x	x	x	c	c	x	c
	Planned	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Instrument*	3	1	1	3	1	2	5	3	5	2	3		2	1	2	1	2	1	2
Assessment	Overall imression	2	5	4	2	4	3	1	4	2	3	3	5	4	5	4	3	3	5	4
	Referrer			x					x	x										
Priority	GP				x							x							x	x
	Hospice team		x	x	x			x			x					x	x		x	x
	Family/carer	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x
	Patient	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Spiritual	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Dimensions	Social	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Professional	x	x	x	x	x	x	x		x		x		x	x		x	x	x	
	Psychological	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Physical	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Aim	Home	x		x				x		x				x			x		x	
	Respite	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x		x	x
	Crisis	x	x	x	x	x		x		x		x	x		x				x	
	Daycare	x																		
Population	Family/carer	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x
	Patient	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	Hospice	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19

20	x			x	x		x	x	x	x	x						1	2	x		x	x	x	x	x	x	3		x		x	x			x
21	x	x		x			x	x		x	x	x	x				1	3	x	x	x	x	x	x	x	x						x	x		x
22	x	x				x	x	x	x	x	x	x	x		x	x	3	2	x	x	x	x	x	x	x	x			x				x		x
23	x	x			x		x	x	x	x	x	x		x			4	2	x	x	p	x	x	x	x	x			x		x	x	x		
24	x	x	x		x		x	x		x	x	x	x		x		5																		
25	x	x			x	x	x	x	x	x	x						3	2	x		x	x	x	x	x	x		x							
26	x	x		x			x	x	x	x	x						4	5	x	x	x	x		x		1	5				x	x	x	x	x
27[1]	x	x	?	?	?	?	x	x	x	?	?	x					?	?	x	x	x	x	x	x			x		x		x		?		
28	x	x					x	x	x	x	x								x	x	x	x	x	x			1		x		x				
29	x					x						x			x	x	4	2																	
30	x				x		x	x		x	x	x					3	3	i		s	x	x		x	x	x					x	x	x	
31	x	x		x	x		x	x	x	x	x	x	x	x		x	1	5	x	c	x	x	x	x	x	x			x		x		x		x
32	x	x			x		x	x		x	x	x	x				3	2	x	x	x	x	x	x			2	1				x			x
33	x	x					x	x	x	x	x	x	x	x		x	4	2	x	c	x	x		x	x	x		1	x		x		x		x
34	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	3	2	x	o	x	x	x	x	x	x	1	1	x		x	x	x		x
35	x					x	x	x	x	x		x	x				1	1	i			x	x		x	x	x	6			x		x		
36	x	x			x		x	x	x	x	x	x	x	x	x		4	1	x	c	x	x	x	x	x	x	x		x			x	x		x

Q=quality, 1=incomplete; I= incidental; c= care plan; O=own method care facility; S=social work; P=psychologist; *=maximum value 5 due to crises (42%) and day-care (8%). Only four hospices ensure a free bed for unplanned acute admissions, the other hospices specified that respite- and acute care are only provided when beds are available. Home hospice care is provided by 11 (30%) hospices.

Described care

The patients' progressive disease is assessed based on the primary diagnosis (89%), metastasis (84%), comorbidity (81%) and illness trajectory (84%). Prognosis of the remaining lifetime is based on physicians' estimation (84%), the 'surprise question' (14%), and/or a non-specified prognostic model (8%). The assessment of the patients' functional status is based on professional estimation (54%) predominantly. Standardized performance scores used are the Karnofsky Performance Status (14%), the ECOG performance status (3%), and/or a patient self-report score (14%).

Symptom burden is predominantly estimated by caregivers (49%) or assessed using measurement tools: the distress thermometer (24%), a self-developed problem-checklist (35%), standardized symptom diary (16%), self-developed symptom diary (3%) and/or other consisting of a variety of tools e.g. delirium observation scale, hospital anxiety and depression scale, and not specified self-adapted measurement tools (30%). The burden of family caregivers is estimated by 57% of the hospices, 30% used an assessment tool. A multidimensional family burden assessment is predominantly based on professional estimation (57%), a self-designed assessment tool (32%), and various combinations of tools and/or methods (21%).

Hospices describe that teams prioritized the integral care based on priorities of patients (N=32; 87%), family (N=24; 87%) and the multiprofessional hospice team (N=13; 35%). An assessment of the patients' needs at admission is based on the patients' (in)dependence (87%), diagnosis (84%), cognitive status (84%), social status (84%) and symptoms (81%). Furthermore, the patients' priorities (78%), emotional status (78%), functional status (78%), prognosis (76%), and spiritual status (76%) are taken into account. Educational level and priorities of referrers are considered least important in estimating the patients' needs, mentioned by 16% and 27% of respondents respectively.

The quality of care provided is evaluated with patients during care by all hospices. In 32/36 hospices evaluations with bereaved family members are performed, a questionnaire is used by 87% of hospices and interviews by 73% of hospices, indicating double strategies in multiple hospices. In total, 28/36 hospices actively motivate family members to complete an evaluation for quality purposes.

Atmosphere and attitude

Atmosphere and attitude are major themes in all mission- and vision statements. The atmosphere is described in terms of home-like, welcoming, and comfortable. All hospices described the importance of respect for all patients, regardless their social, cultural or spiritual background. Patients are treated as equals and the staff's respect for the patients' privacy was mentioned by all hospices.

Hospice staff

Hospice care is provided by a multiprofessional team of professionals and trained volunteers. Hospices have a median of 70 volunteers (8-165) (table 2.). The core of the multiprofessional team consists of 1) nurses: registered nurses (mean 12; range 3-18) and nursing aids (mean 3.56; range 1-8), 2) physicians: general practitioners (median 4 ; range 1-30), hospice physician (mean 1.68; range 1-5), elderly care physician (mean 2.08; range 1-6), and/or medical specialist (mean 1.75; range 1-3). Chaplains (mean 1.11; range 1-3) are part of the core team in 28/36 hospices; three hospices have psychologists and two hospices a social worker instead of a chaplain in the core team. Multiprofessional Team Meetings (MTM) are structurally organized in 32 (87%) hospices and methods of clinical reasoning are being used in 31 (84%) hospices.

Being there", support and personal care was described as the main responsibilities of the trained volunteers. Overall, "being there" was documented as the added value of volunteers in comprehensive hospice care. Care for caregivers

Hospices describe to care for caregivers, by structured emotional and spiritual support to the hospice staff, professionals 26/36 as well as trained volunteers 20/36.

Community services, education and research

Hospices describe their responsibility towards the local community and society in sharing skills and knowledge. Consultation in the local community is provided by 23 (62%) hospices. Caregivers of 15 (41%) hospices participate in consultation services in local hospitals and 18 hospices (49%) participate in national consultation services. Education is provided by 25 hospices (67%), in addition education is provided in collaboration with other institutes by 23 hospices (62%). Education is directed to professional caregivers 26/36 and trained volunteers 25/36, including hospice staff as well as primary care providers in the local community. Education is provided by nurses, physicians and chaplains.

Research is initiated by 12 hospices (32%), although only two hospices performed studies on an academic level. Furthermore, 25 hospices (68%) indicate to participate in studies, initiated by other hospices, hospitals, nursing schools/universities of applied sciences, or universities.

DISCUSSION

Hospice care in the Netherlands, as part of the European tradition of hospice care, developed from small scaled inpatient care initiatives, to a large variety of facilities providing inpatient, home care and consultation in the local community. All hospices describe their care as personalized and multidimensional, provided by a multiprofessional team of professionals and trained volunteers. However, the distribution of the characteristics between hospices and their operationalization in daily hospice care differ largely. From hospices with basic organizational structures providing inpatient care by a multiprofessional team, to hospice providing multiprofessional inpatient and outpatient multidimensional care, community services, education and research which could be considered as integrated models of hospice care. Moreover, care is predominantly based on professional estimations instead of a systematic and methodological approach. As a result, the care provided is more likely to depend on individual caregivers than on standards or a quality framework.

The hospice care concept

The essentials of hospice care 'multidimensional care for patients with a life limiting illness and their families, provided by a multiprofessional team' described by Dame Cicely Saunders (4), are clearly recognized in the core characteristics (main characteristics) of hospice care identified in this study, and seem to be adopted in Dutch hospices. However, the operationalization and integration of these core characteristics differs largely between hospices.

West et al, analyzed the care provided to 7966 patients admitted to Dutch volunteer-driven and professional-driven hospices between 2007 and 2012, and found that differences in care provided could only be linked to the differences in organization.(22) The differences found in our study support their finding that hospice care is more provider-driven than patient-needs driven, although this seems to be in contrast to the reported focus on patient and family needs in the mission statements. The Dutch healthcare system, prescribes a life expectancy of less than 3 months to access hospice care. As a result, hospice care is provided to cancer patients predominantly, since the life expectancy of chronic patients is harder to predict.(23) Ruijs et al found that 25% of palliative care patients in the community experience unbearable suffering.(24) This could indicate a need for earlier hospice care at home or short admissions for symptom analysis and treatment and/or respite care.

Education and research are least developed in Dutch hospice care. Although twelve hospices indicate to initiate research studies, only two hospices initiate and perform research studies on an academic level resulting in peer reviewed publications.

Regarding Dutch policy of palliative care as general care, professional-driven hospices are the only specialized palliative care services providing multiprofessional multidimensional care to patients and their families in the Netherlands.

Evidence Based Practice

Worldwide, patient self-assessment is the Gold Standard to assess patients' needs and symptom burden.(25) However, only half of the hospices in our survey use assessment tools. A previous study showed that hospice patients experience seven symptoms concurrently on average at admission.(26) Besides, assessment tools support communication between patients and staff, but also between staff members.(27) These opportunities are left behind. This could indicate a lack of evidence based practice. Based on the factors of the PRECEDE-PROCEED model, predisposing factors, enabling factors and reinforcing factors can explain the lack of evidence based practice in hospice care.(28): 1) education, 2) attitude, 3) structures and 4) resources. First, nurses are leading in professional-driven hospices. The mean age of hospice nurses is over 50. Evidence based practice was not part of their initial training and education. Second, some Dutch GP's and hospice physicians feel that hospice care should focus on communication and support. In their opinion, the use of tools would not improve or even hinder the quality of patient care. Third, the development of hospice care is mainly solitary, within the hospice itself. This internal focus could hinder innovation. Finally, 4) most hospices have limited resources, as a result professional development depends on the motivation and resources of individual caregivers.

The use of assessment tools should never displace observation and compassionate communication but should be used to support communication and provide patients the opportunity to express their needs and preferences.

Overall, the lack of systematic use of tools to support the assessment, monitoring and evaluation of symptom severity could indicate that the current level of symptom management and needs-driven care in Dutch hospices is suboptimal, although good examples and implemented best practices do exist.

Development of hospice care

The MRC framework, used to develop future proof hospice care, starts with problem identification and problem definition in the development phase.(7) This results from this exploration of hospice care, provided by specific hospices, suggests room for the amelioration of hospice care in the broad range of multiprofessional, multidimensional care provided. However, the differences in the operationalization of hospice characteristics could be appropriate in relation to a local community of a hospice or a specific patient population. Besides, these differences could implicate different levels of hospice development. This hypothesis is supported by the results of a previous study on multidimensional care provided in hospices, which also showed large differences between hospices. Multidimensional care was considered important by all members of the multiprofessional teams of the participating hospices. However, integrated multidimensional care, performed by all members of the multiprofessional team, during all phases of clinical reasoning was only found in few hospices, supported by interdisciplinary collaboration, and implemented methods of clinical reasoning and supportive structures.(29)

Strengths and limitations

For this explorative study a convenience sample was used including a variety of hospice facilities in the Netherlands. Because volunteer-driven hospices were not represented the generalizability is limited. In addition, to generalize the results to other countries and settings, the healthcare organization, culture, and national and local legislation should be taken into account.

Strength of this study is the high completion percentage (83%) of the survey. The widespread variety in answers indicates minimal social desirability bias. The survey was specifically developed for the purpose of this study and scored high on face- and content validity. The development was based on the current quality description of palliative and hospice care(17) and national guidelines(15,16) to optimize completeness of the survey and thus the exploration hospice care. Thirdly, the reliability of the results is ameliorated by peer review and peer debriefing for the qualitative results Methods for data triangulation were used cross checking per participant, to study and confirm the core characteristics on three levels. Identification of the core characteristics in the mission statements, and the quantitative description of characteristics and details related to the main characteristics.

Recommendations

Differences in hospice care can be caused by differences in organizational choices rather than guided by differences in patients' needs and problems. Hospices should be aware of this contradiction to question themselves about the most desirable approach regarding patients' profiles, needs and preferences.

Hospices could play an important role for generalist healthcare providers in their local community to ameliorate palliative care for all patients. They could also provide this specialized palliative care to patients with complex palliative care needs even when their prognosis is longer than three months and generalist palliative care is not 24/7 sufficient. Accepting patients for hospice care based on symptoms, problems and needs instead of life expectancy, could ameliorate palliative care provided by support of generalist palliative care providers caring for patients with complex multidimensional needs. However, such a change needs further exploration of consequences and policy changes needed.

In order to continue the development of a sustainable model of hospice care in the Netherlands, according to the MRC framework, a solid problem identification and problem definition is needed, based on literature or research(7). The lack of existing evidence underpins the importance of future studies in hospice care. Insight into the characteristics, symptoms and needs of patients admitted to hospices, the care provided and the outcomes achieved should be prioritized to identify differences and similarities and establish a foundation for a solid problem definition.

CONCLUSION

To conclude, hospice care in the Netherlands developed between 1989 -2016 from solitary small scaled inpatient facilities to a broad concept of care. Based on these results an operational description of Dutch hospice care is formulated: 'Hospice care is personalized multidimensional care and treatment provided to inpatients as well as patients at home, suffering from the consequences of life limiting illness by a multiprofessional team of professionals and trained volunteers. Those patients and their families are a unit of care. Hospices have a shared responsibility for the improvement of generalist palliative care by transferring knowledge and skills and the development of knowledge through research.'

Future studies should focus on the patient characteristics, the patient centered multidimensional care provided, the perspectives of the multiprofessional team and the outcomes of hospice care, to establish the added value of hospice care for the quality of life, death and bereavement of patients and their families and finally all organizational structures of hospices care. Outcome driven research is the key for quality improvement of world-wide hospice care.

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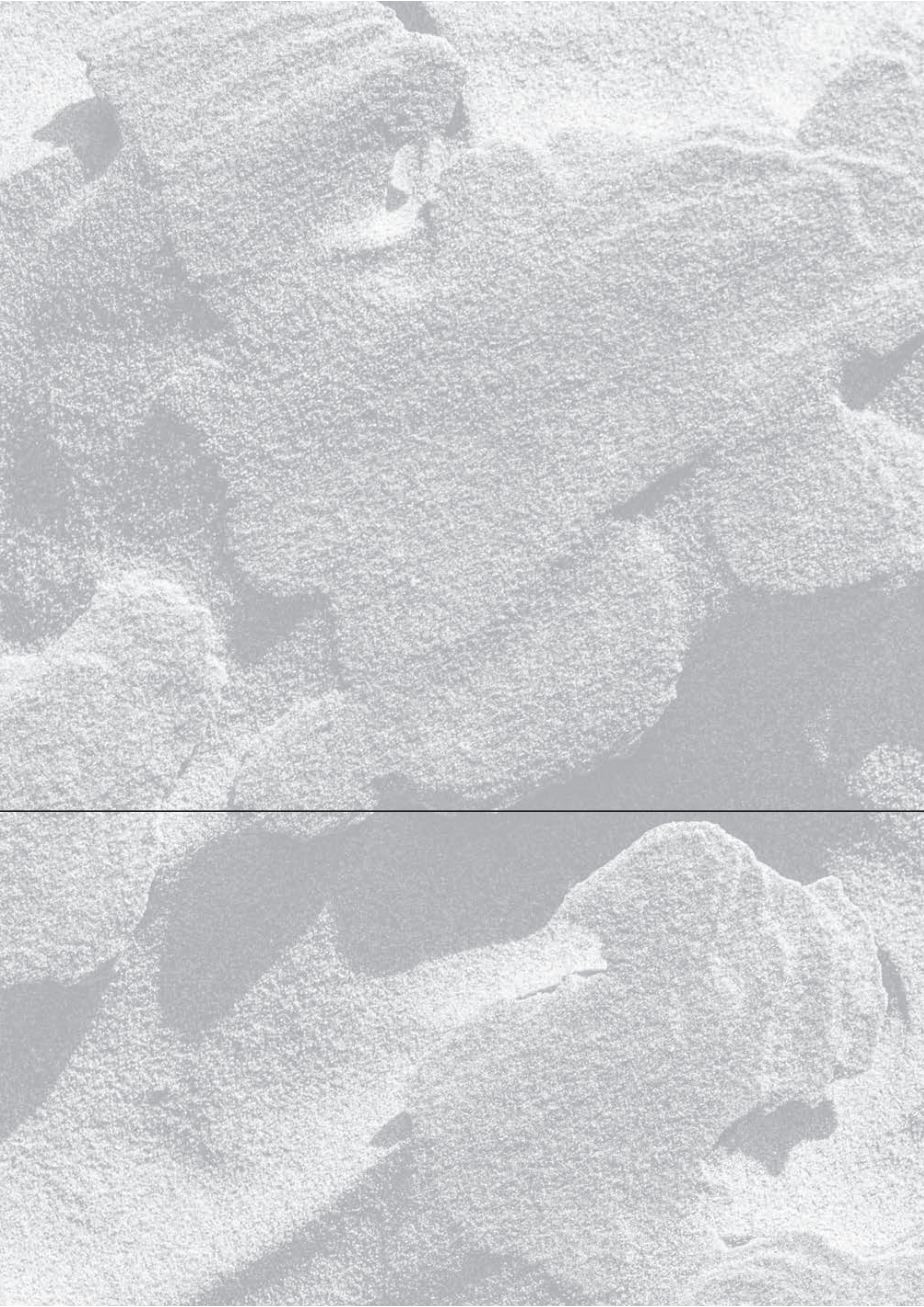

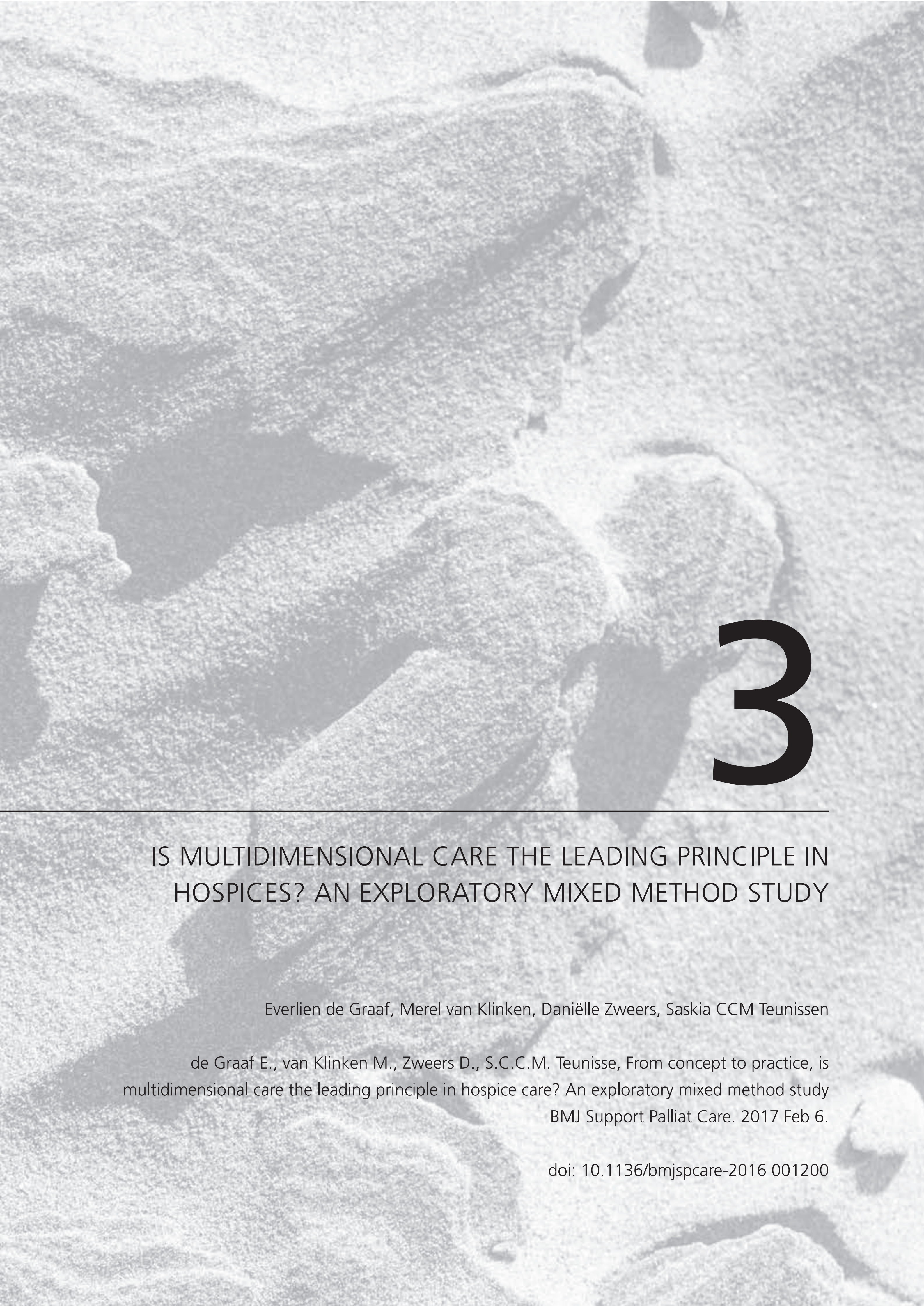

3

IS MULTIDIMENSIONAL CARE THE LEADING PRINCIPLE IN HOSPICES? AN EXPLORATORY MIXED METHOD STUDY

Everlien de Graaf, Merel van Klinken, Daniëlle Zweers, Saskia CCM Teunissen

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ABSTRACT

Hospice care aims to optimize the quality of life of patients and their families by relief and prevention of multidimensional suffering. The aim of this study is to gain insight into multidimensional care provided to hospice inpatients by a multi-professional team and identify facilitators, to ameliorate multidimensional hospice care.

Methods

This exploratory mixed method study with a sequential quantitative - qualitative design was conducted from Jan-Dec 2015.First a quantitative study of 36 patient records (12 hospices, 3 patient records/hospice) was performed. The outcomes were multidimensional care, clinical reasoning and assessment tools. Second, multidimensional care was qualitatively explored using semi-structured focus group interviews with multi-professional hospice teams. Both methods had equal priority and were integrated during analysis.

Results

The physical dimension was most prevalent in daily care, reflecting the patients' primary expressed priority at admission and the nurses'- and physicians' primary focus. The psychological, social and spiritual dimensions were less frequently described. Assessment tools were used systematically by 4/12 hospices. Facilitators identified were interdisciplinary collaboration, implemented methods of clinical reasoning and structures.

Conclusions

Multidimensional care is not always verifiable in patient records however, it is experienced by hospice professionals. The level of multidimensional care varied between hospices. The use of assessment tools and a stepped skills approach for spiritual care are recommended and multidimensional assessment tools should be developed.

Leadership and commitment of all members of the multi-professional team is needed to establish the integration of multidimensional symptom management and interdisciplinary collaboration as preconditions for integrated multidimensional hospice care.

INTRODUCTION

In the Netherlands, 141.245 patients died a non-sudden death in 2014 of whom approximately 10% died in hospice care.(1)

Hospice care (HC) aims to optimize the individual's subjective health related quality of life by minimizing physical, psychological, social and spiritual suffering.(2,3) A multi-professional team (MT) provides optimal multidimensional care (MC), physicians, nurses, chaplains and social workers are recognized as the core members.(3)

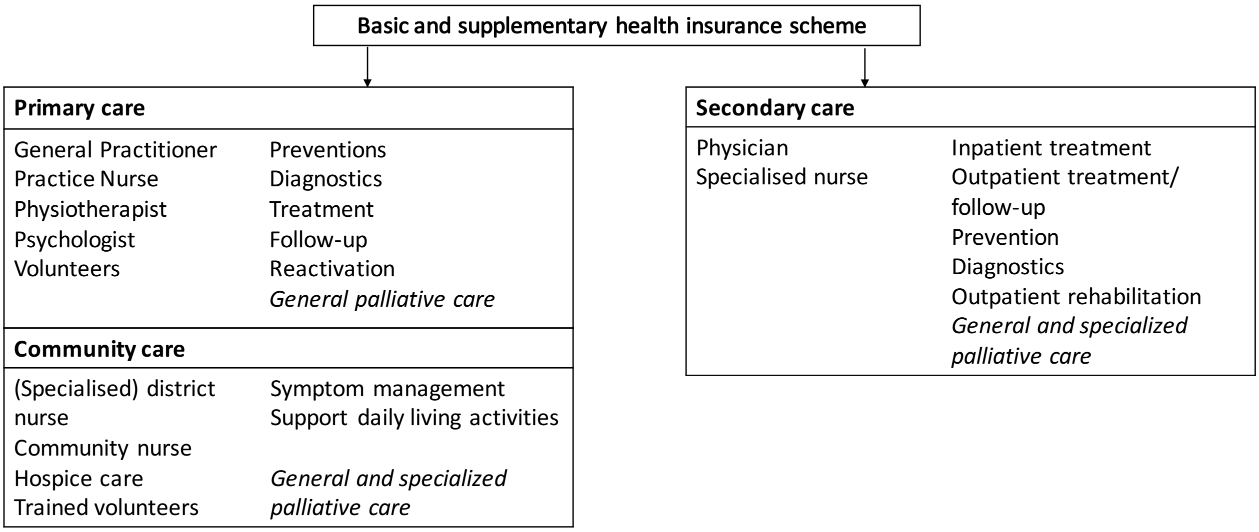

Figure 1. Palliative and hospice care in the Netherlands, De Graaf et al 2016

In the Netherlands, palliative care is not a medical specialty and mainly provided by generalist palliative care providers (figure 1).(4) Inpatient HC is available for patients with a <3 months prognosis. From a historical perspective, hospices are either volunteer- or professional driven (figure 2). Volunteer driven hospices provide 24/7 care by trained volunteers, supported by general practitioners, district nurses and other care providers if indicated. In professional driven hospices, specialist hospice care is provided by 24/7 available specialized nurses, physicians, chaplains and a variety of paramedical therapists (e.g. psychologist, physiotherapist, occupational therapist) and supportive therapists (e.g. therapist for alternative medicine, creative/art therapist, music therapist). The multi-professional team is supported by trained volunteers. Professional driven hospices are either stand-alone small scaled organizations or nursing home hospices. Professional driven stand-alone hospices collaborate in the Dutch Association of Hospice Care (DAHC).

Access	Patients with an estimated life expectancy < 3 months		
Finance	Healthcare Insurance Act Own contribution		Longterm Care Act
	Complementaed with donations from charity and foundations		
Characteristics	Fit local context Religious / Non-religious		
Association	Volunteers Palliative Terminal Care	Dutch Association of Hospice Care	Actiz
Organizational structure	Volunteer-driven hospice	Professional-driven stand- alone hospice	Professional-driven nursing home hospice
Staff	Trained volunteers 24/7 and Patients’ general practitioner District nurses	Specialized nurses 24/7 Physicians (GP, medical specialist, elderly care specialist), Chaplain, Paramedical and supportive specialists Supported by trained volunteers	

Figure 2. Historical development of hospice care in the Netherlands

At admission, hospice inpatients experience seven symptoms concurrently.(5) MC should be embedded in a process of clinical reasoning to ensure an impeccable assessment and analysis of the symptoms and problems experienced.(6) Communication is the key to interdisciplinary collaboration.(7) Communication is supported by reports in the patient records and face to face contact during multi-professional team meetings (MTM) to ensure the continuity and quality of hospice care.(8)

The aim of this study is to gain insight into multidimensional hospice care and to identify facilitators and barriers, to ameliorate multidimensional hospice care provided to all patients in need. The research question was: how is MC provided to hospice inpatients by the multi-professional hospice team? Two sub-questions were formulated:

1 How are the dimensions described in the record notes by nurses, physicians, chaplains, others, and the MTM minutes?
2 How do MT members reflect on multidimensional HC described and provided?

METHODS

Design

A mixed method study with a two-phased sequential exploratory design was performed from January-December 2015.(9) The first phase was a retrospective quantitative study. Data were collected from patient records of 12 hospices across the Netherlands. The second phase was a qualitative focus group study, to explore MC in-depth, gain a broader perspective on MC and adjust for lacking documentation.(10) Both methods had equal priority.(9)

For this report the Strengthening the Reporting of OBservational studies in Epidemiology (STROBE) statement(11) and COnsolidated criteria for REporting Qualitative studies (COREQ)(12) were used.

Population

Hospice facilities in the Netherlands are small scaled facilities, providing care to 4-12 patients.

Quantitative phase

A convenience sample of 12 hospices was drawn from DAHC members. Per hospice three patient records were selected to reduce the risk of selection bias and obtain insight into hospice care provided per hospice during a period of one year. Inclusion criteria were: deceased adult hospice inpatients, admitted >2 weeks, <3 months in January, June and December 2014. If more than one record was eligible, one was selected, using a simple lottery randomization procedure.

Qualitative phase

A purposive sample was drawn from the participating hospices in the quantitative phase, based on 1) the level of multidimensional care (low, middle, high), based on the quantitative data and 2) organizational structure (hospice or hospice unit).

Four hospices, one high-, one middle- and one low level MC and one high level hospice-unit, were selected. To reach data saturation, one low level hospice was added. Per hospice the core MT (a physician, chaplain and 3-4 nurses) was invited by email via the hospice manager to participate in a focus group.(13) Focus groups were organized on location to optimize participation and took 60-75 minutes.

Ethics and anonymity

This study was performed according to the declaration of Helsinki(14), principles of good clinical practice(15) and the Dutch law as approved by the ethics committee of the University Medical Center of Utrecht (14-680/C). Local approval was obtained from the hospice managers. Data from patient records were gathered on location, anonymized and coded per hospice (MK,EG). Focus group participants received information by email and verbal consent was obtained.

Data collection

Quantitative phase

MC was defined as the frequency the physical, psychological, social and spiritual dimension were described in the patient records by nurses, physicians, chaplains, ‘other professionals’ and in the MTM minutes. The physical dimension entailed information on the illness, functional status and physical symptoms (e.g. pain, dyspnea). The psychological dimension was defined as the description of cognitive and emotional problems and psychological symptoms (e.g. anxiety and depressed mood). In the social dimension information about family and relations, and actual and perceived social support were reported and finally the spiritual dimension was defined as information about religion, meaning and existential well-being. The notes of social workers and psychologists were merely not identifiable and therefore grouped as 'other professionals'.

Steps of clinical reasoning were the frequency of assessments, interventions, monitoring and evaluations. Assessment was the initial description of a problem/symptom, all upcoming descriptions were monitoring. Interventions were distinguished in pharmacological- and non-pharmacological interventions. Finally, evaluation was the description of the effect of an intervention.
Measurement tools were all tools used to assess symptoms or quality of life.
To ensure the quality of data, a purpose-developed data-extraction tool (appendix 1) was used to count notes on MC and steps of clinical reasoning per professional or MTM and the assessment tools used. Face- and content validity were tested by the research team (EG,MK,ST). Small adaptions were made for readability.

Qualitative phase
Semi-structured focus group interviews were performed by an experienced moderator (EG) and novice observant (MK). The moderator invited participants to join the discussion, to obtain all views. A member check was performed by providing short summaries during the interviews. Misinterpretations were corrected, and additional ideas were added. The observant took field notes including non-verbal reactions, behavior and identification of individual participants. All interviews were digitally recorded.(9, 16)

DATA ANALYSIS

Quantitative phase

Descriptive statistics were employed using the IBM SPSS, version 21 (IBM Corporation, UK). A trail was logged to support decisions made.

Qualitative phase

Focus group interviews were transcribed thematically, using MC and clinical reasoning as theoretical framework, enabling data reduction into categories. The categories were organized to compare, determine relevance and draw conclusions.(16, 17)

To ensure trustworthiness, the transcriptions and categories were checked using the original records and field notes (EG,MK). Peer debriefing was used to reflect on the findings, differences were discussed in the research team (EG,MK,DZ,ST). During data collection and analysis researchers critically reflected on their preconceptions (EG,MK). One researcher (EG) had prior relationships with

five participants. No differences were identified in questioning, reflecting and summarizing between focus group interviews (EG,MK). Finally, an audit trail was logged.(9,12,16)
The integration of quantitative and qualitative data was performed during data analysis.(9)

RESULTS

The 12 participating hospices admitted 81 patients in 2014 on average. The core MT consisted of Registered Nurses, physicians and chaplains. Records from 36 patients were analyzed, 23 (64%) male, aged 71, admitted for 43 days.
In 3/5 focus groups, all core members of the MT were present, twice a physician was lacking. See table 1 for hospice- and staff characteristics.

Table 1. Hospice characteristics

Hospice	**Beds (N)**	**Patients 2014 (N)**	**Nurses (N)**	**Educational level**	**Physicians (N)**	**Chaplain (N)**
1	7	64	15	NA, RN, MSc	14	1
2	10	84	15	NA, RN	2	1
3	6	62	10	NA, RN	GP	1
4	10	82	16	NA, RN, MSc	2	1
5	5	65	17	NA, RN	3	1
6	5-7	77	10	RN	10 GP	1 On call
7	7	87	14	NA, RN	2	1 On call
8	11	126	17	RN	1	2
9	10	76	13	NA, RN	1	1
10	6	45	7	RN	1	1
11	10	98	11	RN	2	2
12	8	103	10	RN	3	1

general practitioners

Patient records

Nurses were responsible for 76% of the notes, only 2% were made by chaplains (figure 3). Due to the integration of documentation in two hospices, individual professional notes were not verifiable.

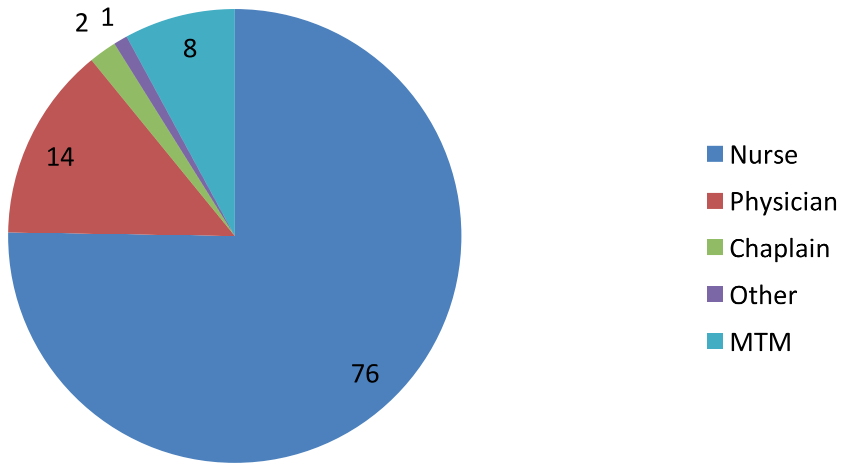

Figure 3. Documentation per discipline

Participants liked the idea of integrated documentation to underpin interdisciplinary collaboration. However, the lack of identifiable information per profession was a negative result. Participants tried to identify the source of documentation using names and dates. Chaplains stated they were a patients' refuge, as a result, two chaplains felt that documentation would hinder their practice. Others documented major themes and interventions to inform the MT.

Multidimensional care

The **physical dimension** was described by physicians 70%, nurses 62% and MTM almost 50% (figure 4). On average, nurses noted 152 (72-277; SD 86.4) physical symptoms per patient during a hospice admission.

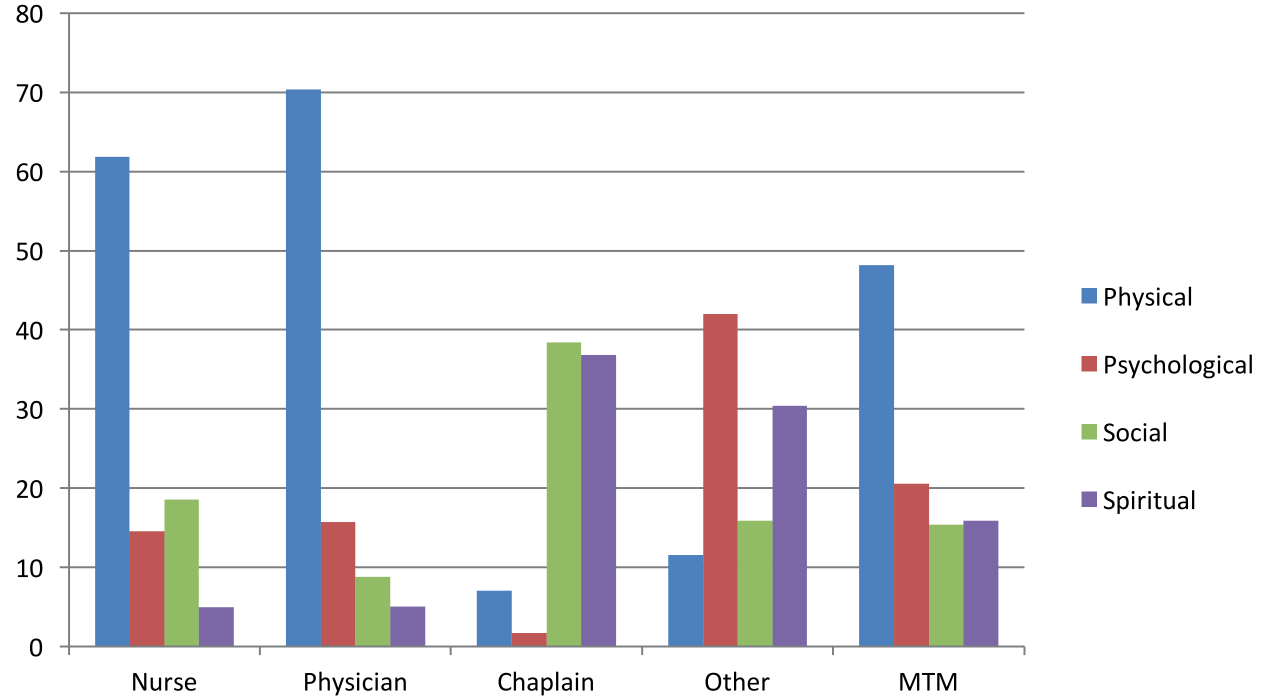

Figure 4. Documentation of dimensions per discipline

Nurses and physicians stated that physical symptoms are easy to spot and to discuss. All participants recognized that physical problems could mask needs in other dimensions. At admission, patients predominantly expressed physical complaints, over time, priorities shifted towards other dimensions. Physicians stated they were trained primarily to address physical problems. Information from other professionals was used to make a multidimensional picture, as a process of thought. These pictures were rarely described in notes, but sometimes discussed during MTM.

The **psychological dimension** was described in notes of physicians 15%, nurses 15%, 'other professionals' 42% and MTM 20%. All participants recognized that less attention was paid to the psychological dimension, compared to the physical dimension. Nurses stated that assessment tools support them to identify anxiety or depressed mood. Nevertheless, symptoms could be mistaken for physical complaints; without an in-depth exploration, the underlying psychological causes could be missed.

The **social dimension** was reported by nurses 19%, chaplains 38% and MTM 15%. Nurses identified an under-representation of the social dimension in their notes. Many observations and interventions, e.g. supportive conversations, being there and providing relief, were interpreted as usual care and therefore not documented. Although some social workers were involved as experts, their contribution was under-represented in the quantitative results.

The **spiritual dimension** was described by chaplains 37%, nurses and physicians, both 5%, and MTM 16%. Chaplains stated to be a refuge for patients and reported only if the patient explicitly consented. One chaplain stated that records contribute to the continuity of care. Others only reported if interventions to provide spiritual support required assistance of other professionals or volunteers, or if they felt that information obtained during guidance would benefit other team members, two chaplains reported nothing. When confronted with spiritual issues, nurses experienced 'finding the right words' problematic and patients' confidentiality a dilemma. As a result, they tend to discuss these problems with their colleagues. Nurses who related spirituality strongly to religion felt more restrained to discuss spiritual needs with patients. One physician specifically stated that she could not provide optimal care when information on the spiritual dimension was lacking.

Steps of clinical reasoning

Nurses assessed 24 (14-44; SD 10.64) new symptoms per patient per admission (figure 5). Consecutively, 152 (71-250; SD 85.16) symptoms/problems were described during the process of monitoring. Physicians and nurses reported pharmacological interventions resp. 11 (2-18; SD 6.81) and 41 (8-99; SD 34.46) and non-pharmacological interventions, resp. 4 (1-14; SD 5.22) and 19 (8-51; SD 14.51). Evaluations were less frequently described by physicians 3 (0-8; SD 3.7) and nurses 9 (2-16; SD 8.06). Most hospices used clinical reasoning to structure MTM. Nevertheless, only 5/12 hospices described all consecutive steps of clinical reasoning.

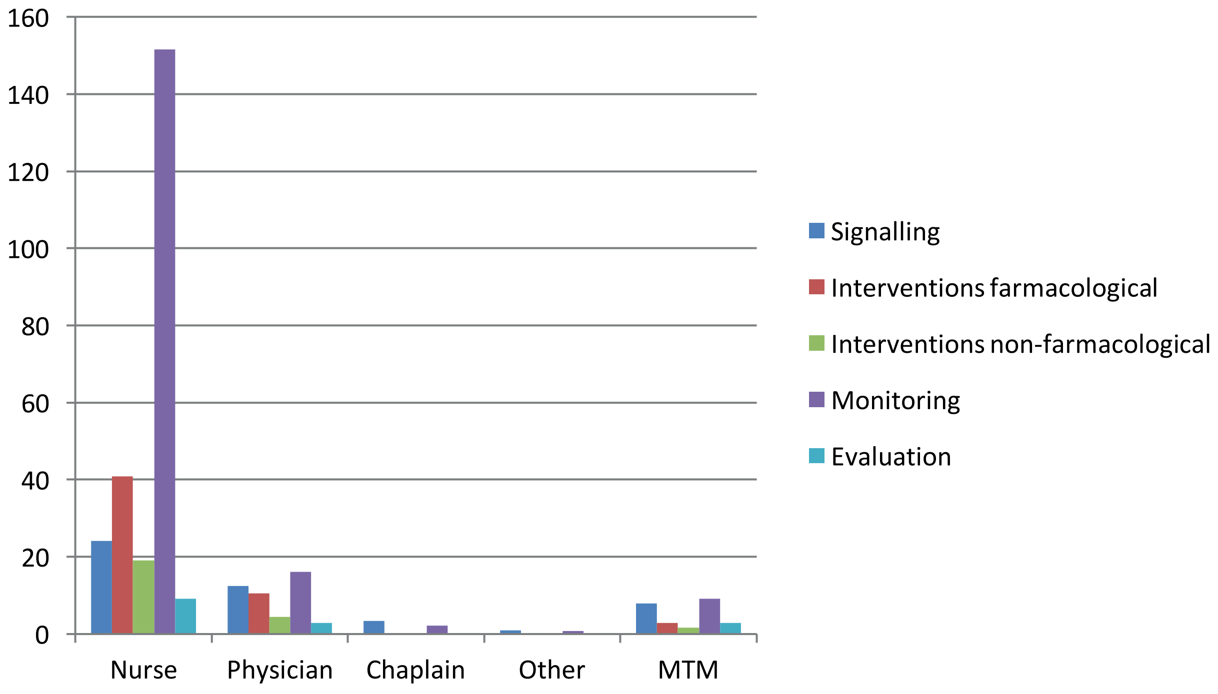

Figure 5. Steps of clinical reasoning per discipline

Nurses recognized the majority of their documentation is about known problems, monitoring symptoms and problems over time. The dispersion between hospices seemed to be influenced by the timing of documentation. Nurses, who reported in the patients' room, directly after care/treatment, were more likely to report in detail and identified and monitored more problems concurrently. In contrast, if nurses reported at the end of their shifts, details became less clear and more likely to be missed. Some participants specified that evaluation was part of daily care but under-represented in the records, others acknowledged that evaluation needs more attention. The steps of clinical reasoning supported a cautious analysis of all dimensions during MTM.

Tools

Tools were used in 10/12 hospices (table 2). Three hospices used the distress thermometer to identify problems/symptoms experienced by patients on admission. The Utrecht Symptom Diary (USD), a Dutch adapted translation of the Edmonton Symptom Assessment System(18), was used in four hospices to monitor symptom intensity of physical and psychological symptoms. The USD-professional for proxy measures, was used concurrently in two hospices and USD4D, with additional social and spiritual items, was used for study purposes. In addition, screening tools were used, the delirium observation scale (DOS) for delirium, a pain assessment tool for pain, a mouth screening tool for mouth sore. The Liverpool care pathway for the dying was used in two hospices. In 4/12 hospices tools were used systematically, 6/12 hospices used tools ad hoc.

Table 2. Overview of applied tools (per hospice)

Hospice	**Thermometer**	**USD**	**USD-professional**	**USD-4Dimensional**	**DSR-R98**	**DOS**	**Mouth assessment**	**Pain assessment**	**REPOS**	**Liverpool carepathway**
1	3	118	0	29	0	10	25	0	0	0
2	0	0	0	0	0	4	0	2	0	0
3	2	19	42	0	0	3	0	2	0	0
4	14	13	0	13	0	0	0	0	0	0
5	0	0	0	0	0	3	0	1	0	0
6	0	0	0	0	0	14	0	4	0	0
7	0	71	0	0	0	6	0	0	0	0
8	0	0	0	0	0	10	0	0	0	2
9	0	0	0	0	0	10	0	0	5	0
10	0	0	0	0	0	0	0	0	0	0
11	0	0	0	0	0	4	0	0	0	2
12	0	0	0	0	0	0	0	0	0	0

Nurses used tools to discuss all dimensions with patients and address underlying and influencing causes. In addition, tools supported unambiguous multi-professional and interdisciplinary communication. Although, not all tools used in daily practice were identified in the records, the use of tools, systematically or ad hoc was identified correctly. One physician strongly opposed the use of tools and felt that a multidimensional assessment based on observations and communication should be sufficient. Although nurses in the MT felt tools could support their observations, they only used tools if specifically indicated by the physician.

Facilitators and barriers

Although the MTM minutes showed a more equal dispersion of all dimensions, only 5% was about the spiritual dimension. Four hospices with high levels of MC, used all consecutive steps of clinical reasoning during MTM.

Three themes emerged when addressing barriers and facilitators to MC: 1) interdisciplinary collaboration 2) methods and 3) supportive structures.

Interdisciplinary collaboration was the main facilitator to MC, nevertheless all teams identified challenges to interdisciplinary collaboration as an ultimate level of multi-professional collaboration. Nurses shared that it took courage and experience to participate in MTM on an equal basis, specifically if more than one physician was present during MTM. Chaplains felt appreciated by other team members, but experienced to be different in personal and work-related characteristics.
The steps of clinical reasoning were helpful to MC, but not always implemented in daily practice. Teams which integrated a stepwise approach for problem analysis, intervention selection, monitoring and evaluation showed higher levels of MC provided by all MT members.

The use of structured documents supporting MC was mentioned as obvious and easy to enhance. In contrast, structured documents could hinder HC, e.g. structures based on long-term care did not always fit the rapid changes of HC. As a result, team members worked their way around the structure.

DISCUSSION

The concept of multidimensional care is not always verifiable in the patient records; it is experienced by professionals in daily practice. This study shows that multidimensional care is provided by multi-professional teams in hospices on various levels. Assessment and monitoring are well described steps of clinical reasoning in contrast to evaluation. Measurement tools are implemented and used methodologically in only 30% of hospices. Facilitating factors are interdisciplinary collaboration, implemented methods and supportive structures.

Multidimensional care

Multidimensional care is essential to provide optimal hospice care. Most attention is paid to the physical dimension since it is the patients' primary focus, specifically at admission. Physicians and nurses stated that without an in-depth exploration of all dimensions, other dimensions causing or influencing symptoms can be missed. Therefore, the under-documentation of these dimensions identifies a potential risk of suffering and inadequate care and treatment.

Although, the psychological dimension is mentioned less frequently than the physical dimension, anxiety and depressed mood are frequently described if the USD is used. This is supported by a previous study where USD-use was related to more frequently described anxiety in patient records.(19) The under-representation of the social dimension can be linked to three reasons. 1) Information on the social dimension is addressed as usual care and therefore not reported. 2) Assessment of the social dimension is not supported by self-assessment tools, inevitable for professionals to gain insight into the patients' experience.(20) Finally, most MT's in Dutch hospices do not include social workers, in contrast to the international hospice model where social workers are member of the core team.(3) Social support in participating hospices is provided by nurses or nurses with additional training on a generalist and specialist level. Expert level social support is not commonsense.

Spiritual suffering is a great threat to the patients' quality of life,(21) but information on the spiritual dimension is scarce. Chaplains state to be a refuge for patients, and nurses lack words to describe spiritual needs and feel that patients' confidentiality is a dilemma. Assessment tools can 1) support nurses to assess the spiritual domain and 2) contribute to communication about spiritual needs with patients, families and MT members.(22)

Interdisciplinary collaboration

Interdisciplinary collaboration is vital to MC.(3) Although MTs were established in all hospices, the dispersion in MC is facilitated by interdisciplinary collaboration by members of the MT.

Interdisciplinary collaboration is supported by interdependence, flexibility, newly created professional activities, collective ownership of goals and reflection on processes.(7) Nurses and physicians use a common language in clinical reasoning and are used to shifting tasks, responsibilities and supporting interdisciplinary collaboration. Nurses and chaplains tend to shift responsibilities for spiritual needs on generalist and specialist / expert levels, nevertheless a lack of common language and the use of steps of clinical reasoning, hinders interdisciplinary collaboration. This is supported by the results showing chaplains, who adjust their language towards clinical reasoning, overcoming that barrier.

Methods and supportive structures

The steps of clinical reasoning and a flexible structure of patient records support MC. Methods and structures developed for long-term care instead of HC did not fit the rapid changes of HC, and were experienced as a barrier. The ability to fit methods and structures to specific settings and the local context is a known facilitator in innovation science.(23)

Strengths and weaknesses

To the best of our knowledge this is the first description of MC in hospices. Strengths of our study are that the research setting is a real-life setting. The mixed method design contributed to an in-depth exploration of MC and identified facilitators.

Although the retrospective design enlarged the risk of bias, the use of qualitative methods reduced weaknesses. Missing items and generalizability of the quantitative results were checked using focus groups. The convenience sample could have caused selection bias, but the diversity in MC indicates a larger population of hospices within the sample. The data collection tool and audit trail contributed to the reliability and replicability of the findings and trustworthiness of the qualitative data was ensured during data collection and analysis.

The results of our study have to be interpreted with caution. The lack of volunteer driven hospices in our sample reduces generalizability and differences in care systems between countries have to be taken into account at all times.

Recommendations

The development of an assessment tool including the psychological, social and spiritual dimension could support teams to assess, monitor and discuss patients' needs. In practice, the use of stepped skills for detection and discussion could support nurses who feel less comfortable talking about spirituality to address spiritual suffering and refer to expert colleagues.(24) For the exchange and interpretation of observations of spiritual needs, further research is required.

Symptom assessment is the first step of symptom management.(25) In addition, monitoring symptoms over time and evaluation of interventions applied are the main reasons to use tools in daily practice.(26) The implementation of a systematic symptom management approach using assessment tools requires a multifaceted strategy entailing education, commitment of MT and integration in daily practice.(23) However, negative attitudes toward symptom assessments of individual professionals hinder adoption in daily hospice care.(27) Outcomes should be incorporated in daily care and clinical decision ensures multidimensional care for all hospice patients.(28) In addition, outcomes can be used to benchmark and identify possibilities to ameliorate the quality of hospice care on an institutional level.(29)

Finally, interdisciplinary collaboration is vital to optimal multidimensional care. The implementation of methods for clinical reasoning and supportive structures support multidimensional care and provide a common language as a base for interdisciplinary collaboration. These methods should incorporate the differences between caregivers as a multifaceted strategy to support all members of the team. A culture shift, from multi- to interdisciplinary collaboration requires leadership, supportive strategic management, and commitment of MT members and management.

CONCLUSION

The integrated provision of MC by members of the MT is still work in progress. Although all dimensions were covered, most attention was paid to the physical dimension. The use of tools improves the assessment of psychological problems. The social and spiritual dimensions are under-represented. Methods of clinical reasoning and supportive structures facilitate multidimensional hospice care.

Multidimensional care requires a cultural shift towards a systematic multidimensional symptom management approach and interdisciplinary collaboration of team members involved. But change does not come easy. Leadership and commitment of team members is needed for a successful implementation of multidimensional symptom management and interdisciplinary collaboration.

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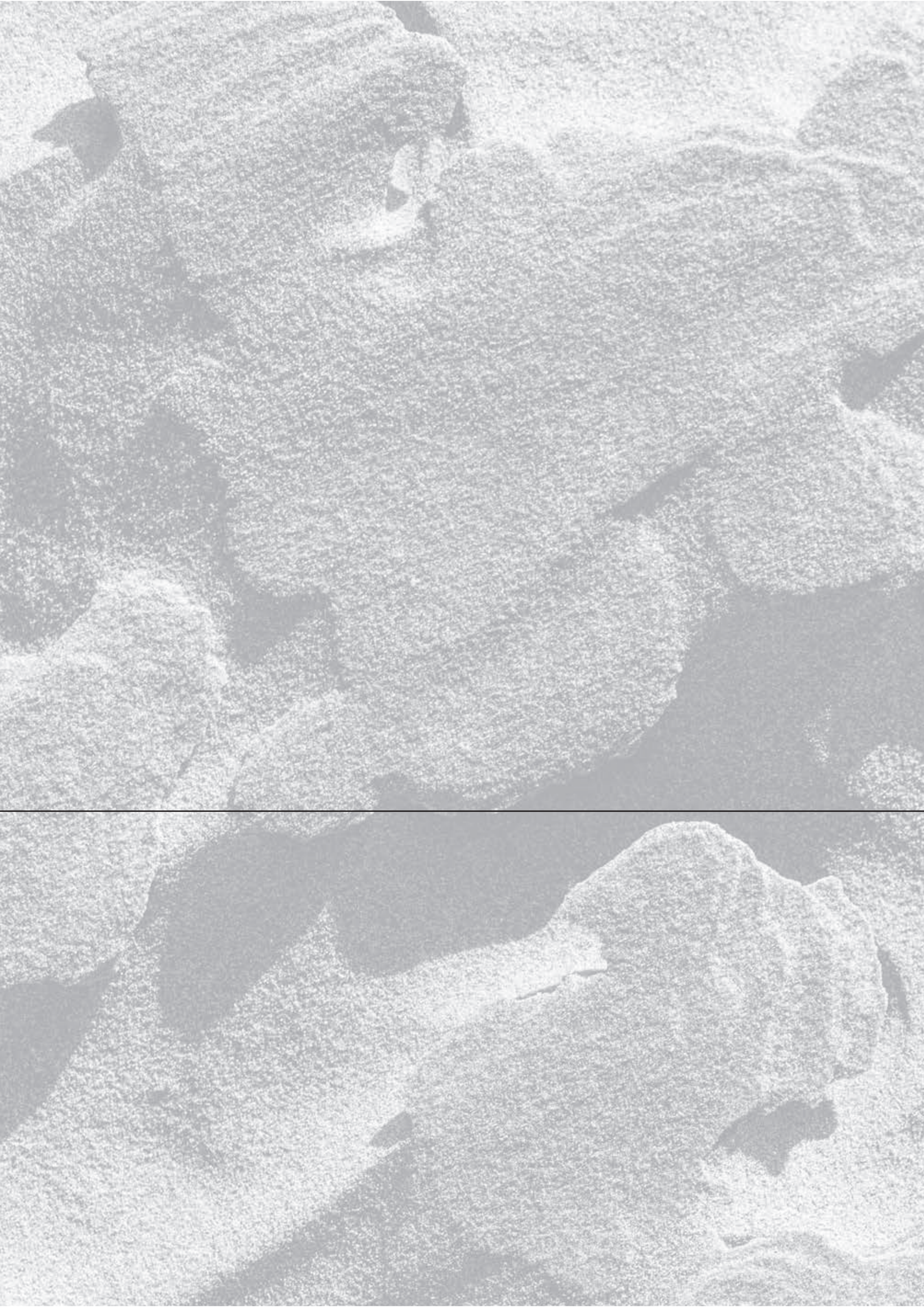

4

HOSPICE ASSIST AT HOME: DOES THE INTEGRATION OF HOSPICE CARE IN PRIMARY HEALTHCARE, SUPPORT PATIENTS TO DIE IN THEIR PREFERRED LOCATION? A RETROSPECTIVE CROSS-SECTIONAL EVALUATION STUDY

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ABSTRACT

Background

A majority of patients prefer to die at home. Specialist palliative care aims to improve quality of life. Hospice assist at home (HaHo), is a Dutch model of general/specialised palliative care within primary care, collaboratively built by GP's and a hospice.

Aim

To explore whether HaHo service empowers patients and relatives at home, to enable patients to express end-of-life preferences and die in their preferred location. Furthermore to gain insight into symptom burden, stability and early referral.

Design

A retrospective cross sectional evaluation study (December 2014 - March 2015), using HaHo patient records and documentation. Primary outcome: congruence between preferred and actual place of death. Secondary outcomes: symptom burden, (in)stability and early identification.

Setting/participants

Between June 2012 - December 2014 130 HaHo patients, living at home with a life expectancy <1 year, were enrolled. HaHo, a collaboration between GP's, district nurses, trained volunteers and a hospice team, facilitates 1) GP initiated consultation by Nurse Consultant Hospice, 2) fortnightly interdisciplinary consultations and 3) 24/7 hospice backup for patients, caregivers and professionals.

Results

130 patients, 62 (48%) men, mean age 72, of whom 107/130 (82%) died and 5 dropped out. Preferred place of death was known for 101/107 (94%) patients, 91% patients died at their preferred place of death.

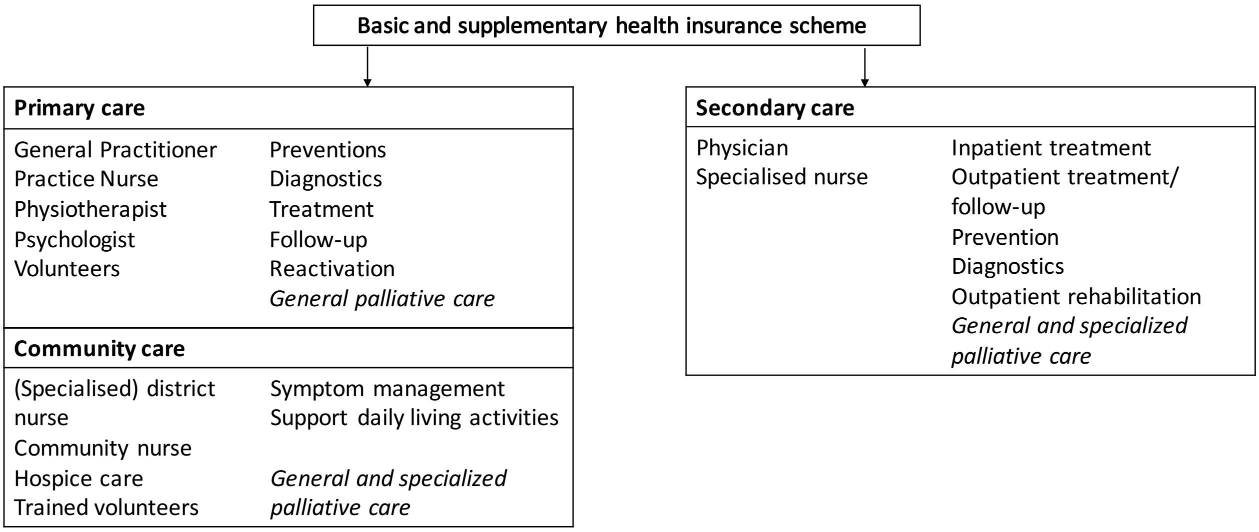
Conclusions

HaHo service supports patients to die in their preferred place of death. Shared responsibility of proactive care in primary care collaboration enabled patients to express preferences. Hospice care should focus on local teamwork, to contribute to shared responsibilities in providing optimal palliative care.

INTRODUCTION

In 2013, 141000 people died in the Netherlands, of whom 69-81% needed palliative care, which means that approximately 105000 patients could have benefitted from palliative care.(1) The majority of patients prefer to live and die at home when faced with an incurable disease.(2-4) However, in the Netherlands, only 29-62% of patients who died between 2009-2012, were able to die at home.(5) Palliative care aims to optimise the quality of life of patients with a life limiting illness and their families by providing relief and prevent suffering caused by physical, psychological, social or spiritual problems.(6) A multidisciplinary team approach of collaboration and consultation between professionals, might be a precondition to provide optimal palliative care.(7)

In the Netherlands, palliative care is provided in all healthcare settings (figure 1). Since most patients prefer to be cared for and die at home, palliative care is most often provided by GP's and district nurses. Multidisciplinary care is the norm in inpatient settings, however in primary care there are less opportunities for similar models of collaboration. This stems from a lack of natural face to face contacts between healthcare providers, a variety of healthcare providers and competing healthcare organisations. All could negatively influence the quality of palliative care to individual patients in the community.



Primary care	
General Practitioner Practice Nurse Physiotherapist Psychologist Volunteers	Preventions Diagnostics Treatment Follow-up Reactivation *General palliative care*

Community care	
(Specialised) district nurse Community nurse Hospice care Trained volunteers	Symptom management Support daily living activities *General and specialized palliative care*

Secondary care	
Physician Specialised nurse	Inpatient treatment Outpatient treatment/ follow-up Prevention Diagnostics Outpatient rehabilitation *General and specialized palliative care*

Figure 1. Palliative Care Healthcare system, Netherlands

Worldwide, two levels of palliative care are distinguished. 1) General palliative care; a basic level of palliative care provided by all professionals who are confronted with patients with incurable diseases and 2) specialist palliative care; an advanced level of palliative care by specialist healthcare professionals and services, specifically focused on providing palliative care during the continuum.(8) Hospice care is specialist palliative care, providing multidimensional care by a multidisciplinary team of formal and informal caregivers. Hospice care in the Netherlands is mainly traditional 24/7 inpatient services. Outpatient hospice services are currently developing. Integration of hospice care services and general practice is not yet established. A tailor made integration of general and specialist palliative care could ameliorate the quality of palliative care for patients and their caregivers at home, and enable patients to die at their preferred location.(9,10)

In 2012, a collaborative team of GP's and a local hospice identified a lack of quality in palliative care for patients at home. The initial problem analysis identified four challenges for improvement: a) individual knowledge and skills, b) coordination of care and treatment, c) out of hours continuity of care for patients, families and healthcare professionals and d) interdisciplinary communication. With the development of a local palliative care service 'Hospice assist at Home'(HaHo), three interventions were implemented: 1) GP requested specialist home site consultation by a Hospice Nurse Consultant (HNC), 2) set up of a structure for multidisciplinary consultation once a fortnight and 3) 24/7 hospice care back up for patients/families, and healthcare professionals. One healthcare professional was primarily responsible for coordination, based on the patients preferences.

The aim of the HaHo service is to empower patients and caregivers in expressing wishes and priorities by active support in the palliative phase. The aim of this evaluation study was to investigate whether amelioration of the quality of palliative care at home enables patients to 1) express end-of-life preferences and 2) die at their preferred location. This study provides insight into a) symptom burden, b) (in)stability and c) early identification of patients at home.

The ultimate goal of the HaHo service is to provide optimal palliative care to patients and caregivers at home through the integration of general and specialist palliative care within the local healthcare system.

METHODS

Design

A retrospective descriptive cross sectional study was performed from December 2014 - March 2015. Data were collected prospectively during HaHo involvement for daily care and research purposes.

Setting and population

This study was performed in the community with local caregivers and a hospice facility in the centre of the Netherlands. Patients living at home, with a life expectancy of less than one year, were referred to the HaHo service by their GP or DN. The patients' life expectancy was estimated by the GP, using the 'surprise' question: 'Would I be surprised if this patient died in the next year?'(11-13) All patients referred to HaHo from June 2012 to December 2014 were enrolled in the study from referral to death or until the end of the study.

Patient anonymity and ethics approval

Patients referred to HaHo were informed by their HaHo coordinator about the study and the ability to decline. Patients were asked consent to use their data for the study. After verbal consent was obtained, written consent was recorded in the patient records, none declined. When patients dropped out of HaHo, consent was obtained to use data until the moment of drop out. Data was collected from the patient records and anonymised by the principal investigator(PI), using an electronic database, SYMPAL, coding the individual patients data. The PI was able to link data to individual cases. The methods of consent, data collection and use of the SYMPAL database for research queries were approved by the local ethics committee of the Utrecht University Medical Centre, the Netherlands (11-113/C).

Hospice assist at Home (HaHo)

The HaHo service consists of four components. 1) A GP requested home visit from the Hospice Nurse Consultant (HNC). The HNC performs a multidimensional assessment, develops a personalised, multidimensional, care plan, and provides specialist support to patients and caregivers. The HNC is available 5 days per week for (un)planned visits. 2) Multidisciplinary consultation, once a fortnight, led by a hospice GP and supported by two HNC. Local GP's, district nurses, oncology nurses, a spiritual caregiver and trained volunteers participate in these sessions. To optimise the process, structure and content, HNC and specialist hospice GP provide coaching on the job and training for district nurses and GP's in systematic symptom assessment, symptom management and palliative reasoning. The frequency of patient consultation depends on the stability of the patient. To complete HaHo, 3) 24/7 hospice care telephone backup for professionals, patients and caregivers, is delivered by the specialist hospice staff. If necessary, patients are guided towards GP out-of-hours services. Furthermore, 4) one healthcare professional, selected by the patient, is responsible for the coordination of care.

To support communication and continuity of care, three documents were developed (AU, ST EG): digital patient record, HaHo-database and HaHo-agenda. The patient record consists of a multidimensional assessment and a personalised multidimensional, anticipatory care plan. The HaHo database provides overview of referred patients including primary diagnosis, patient system stability, end-of-life preferences, patient priorities and the patient preferred care coordinator. The standardised agenda supports the methodological decision making process during multidisciplinary consultation.

Outcomes and measurements

Expressed end-of-life preferences and the congruence between preferred and actual place of death are the primary outcomes. The expressed end-of-life preference is documented during daily care by DN, GP or HNC, assessed through shared decision making with the patient and caregivers and documented in categories: home, hospice, hospital, care home, family and friends, or other. Congruence was reached when the location of death equalled the last documented preferred location of death, when the patient was at home. When congruence was not reached, the individual cases were studied qualitatively for reasons of incongruence e.g. reason for admission. Secondary outcomes were symptom burden, (in)stability and early identification. Symptom burden is described through symptom prevalence, clinically relevant symptoms and symptom intensity. To assess symptom burden, the Utrecht Symptom Diary (USD) was used. The USD is a Dutch adapted version of the Edmonton Symptom Assessment Scale, a self-report symptom intensity scale. The USD contains 12 symptoms: pain, sleeping disturbance, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnoea, fatigue, anxiety, and depressed mood and a 1-item well-being measure. All symptoms were assessed using an 11 point numerical scale (0=no symptom; 10=worst possible intensity). Symptom prevalence was the proportion of patients scoring a symptom>0 on USD. A cut off >3 was used to indicate clinically relevant symptoms.(14) Stability reflected the physical, psychological, social and spiritual status, assessed by the multidisciplinary team, categorised as stable, vulnerable, unstable/critical, or in crisis. Early identification was calculated from the period of HaHo enrolment, days from referral to death, the end of the study period or dropout. Baseline characteristics collected at referral were gender, age, primary diagnosis and phase of illness (treatment of illness, symptom management or comfort care). Data were collected from the HaHo patient record, database, agenda and USD, and entered into the SYMPAL database (EG, AU). Data of all patients were imported from the database to an anonymous research file (EG).

Statistical analysis

Data were analysed using descriptive statistics. Data triangulation was performed using the HaHo patients records, database and agenda. All data were checked on congruence between data sources. Incongruence was discussed with the coordinating healthcare professional, to enhance the quality of data (EG, GU). Data analysis was performed using IBM SPSS statistics (EG, ST).

RESULTS

In total 130 patients, 62 (48%) men, aged 72 (37 – 96, SD 12.1) were enrolled (table 1). During HaHo enrolment, 92 (71%) patients were visited by the HNC at home, 25 (19%) patients were visited by HNC as well as discussed during multidisciplinary consultation. 28 (22%) patients were discussed in one or more multidisciplinary meetings. Five patients (4%) dropped out of HaHo due to: switch to curative intent (N=2), stable disease (N=2) and psychological distress with regards to confronting illness (N=1)

Table 1. Patient characteristics, stability and early referral

Characteristics		N (%)	Mean (SD)
Gender	Male	62 (48)	
Age	Years		72 (12.1)
Age categories	<65	33 (26)	
	65-74	36 (28)	
	75-84	41 (32)	
	>=85	19 (15)	
Primary Diagnosis	Cancer	116 (89)	
	Renal failure	1 (1)	
	Lung Failure COPD	4 (3)	
	ALS	2 (2)	
	Heart failure	1 (1)	
	Dementia	1 (1)	
	Other	3 (2)	
	Missing	2 (2)	
Phase of palliation[1]	Treatment of illness	20 (15)	
	Symptom management	93 (72)	
	Comfort care	17 (13)	
Stability[2]	Stable	18 (14)	
	Vulnerable	59 (45)	
	Instable	39 (30)	

[1] The phase of palliation is identified by the aim of care and treatment within palliative care. [2] Multidimen-sional assessment of the patients stability according the HaHo caregivers, discussed during the multidisciplinary consultation

Cancer was the primary diagnosis (89%). On referral, the aim of treatment and care was mainly symptom management (72%), less frequently treatment of illness (15%) and for 17 (13%) patients comfort care, of whom two patients died on the day of referral.

Place of death

Patients enrolled in HaHo preferred to die at home (68%) or in hospice (22%). For 12 (9%) patients the preferred place of death was not known. During the study, 107 out of 130 patients died, their end-of-life preferences were home (77%), hospice (23%), hospice or home (1%) or unknown (6%). Data on their actual place of death showed that 75 (70%) patients died at home, 26 (24%) patients died in a hospice and six (6%) patients died in a hospital. Congruence between preferred and actual place of death was reached in 92 (86%) patients. If the preferred place of death was known, 92/101 (91%) patients died in their preferred place of death. Table 2 shows an overview of preferred versus actual place of death.

Table 2. Congruence between preferred and actual place of death

		Actual place of death			
		Home N(%)	Hospice N(%)	Hospital N(%)	Total N(%)
Preferred place of death	Home	**70 (91)**	4 (5)	3 (4)	77 (72)
	Hospice	2 (9)	**21 (91)**	*0*	23 (21)
	Home or hospice	*0*	**1 (100)**	*0*	1 (1)
	Unknown	3 (50)	0	3 (50)	6 (6)
	Total	75 (70)	26 (24)	6 (6)	107

Differences between actual and preferred place of death was found in 15 (14%) patients. The main reason was an unknown preferred place of death. Patients were unable to discuss death and dying (N=6), of whom three patients died in a hospital and three died at home. Four patients preferred to die at home, but died in a hospice after a planned admission for respite care (N=3),or last resort, because patient and family carers were in crisis and unable to stay at home (N=1). Three patients, who preferred to die at home, died in a hospital due to a medical emergency not related to their primary illness (N=2) and a multidimensional crisis (N=1). Finally, two patients wanted to die in a hospice but died at home, as their deaths came calm and there was no urge to transfer.

Symptom burden

During HaHo, 298 USD were filled out by 70 unique patients. On referral, patients suffered from six symptoms concurrently, of which four symptoms were clinically relevant. Fatigue was most prevalent

Table 3. Symptom burden at referral

	Prevalence N(%)[1]	**Clinical relevance N(%)**[2]	**Intensity Mean (SD)**
Pain	49 (70)	25 (36)	2.72 (2.497)
Sleeping problems	40 (57)	24 (34)	2.61 (2.882)
Dry mouth	42 (60)	29 (41)	3.03 (3.018)
Dysphagia	16 (23)	6 (9)	0.83 (1.819)
Anorexia	52 (74)	42 (60)	4.48 (3.016)
Constipation	38 (54)	22 (31)	2.42 (2.714)
Nausea	30 (43)	13 (19)	1.60 (2.425)
Dyspnoea	24 (34)	17 (24)	1.97 (3.187)
Fatigue	66 (94)	58 (83)	6.31 (2.394)
Anxiety	21 (30)	10 (14)	1.29 (2.339)
Depressed mood	42 (60)	24 (34)	2.64 (2.684)

[1] Patients scoring over 0 on USD at referral [2] Patients scoring >3 on USD at referral

in 94% of patients. Other highly prevalent symptoms were anorexia 74% and pain 70%. Most intense symptoms were fatigue 6.31 (SD 2.394), anorexia 4.48 (SD 3.016) and dry mouth 3.03 (SD 3.018). Well-being was low, scoring 4.97 (SD 2.429) on average. Symptom burden at referral is shown in table 3.

Stability

When referred to HaHo only 18 (14%) patients were identified as ‘stable’. Most patients were either vulnerable (45%) or unstable (30%). Eleven (8%) patients were in crises at referral.

Early identification

The median length of referral was 61,5 days (mean 119.8; range 0-911; SD 163.5). Median survival was 59.5 days (mean 102.7; range 0-671; SD 132.7) from enrolment to death of 107 patients who died.

DISCUSSION

HaHo integrates general palliative care and specialist palliative care in primary care by interdisciplinary collaboration, consultation, and 24/7 telephone support from specialist hospice staff. During the first two years, 130 patients were referred to the service. The preferred place of death was known for 94% patients of whom 91% died in their preferred location. This study shows that an integration of general and specialist palliative care services in the community can support patients to express their end-of-life preferences and die in their preferred location.

Strengths and weaknesses

We have to make several considerations on strengths and weaknesses. A strength is that it reflects the real life care environment experienced by patients and their families, since HaHo was initiated and developed by professionals working in daily practice. The HaHo service continued to develop during the two years of the study as needed to adapt to the local primary care. Due to this changing, dynamic process, a retrospective descriptive design was the most suitable strategy for this study. While we aimed to develop structured documents to support methods and content of HaHo, these documents were developed in close collaboration between the professionals and researchers.
Using an observational design, we were not able to draw solid conclusions, because this design is not suited to detect causality. Nevertheless, we were able to compare our outcomes with previous studies in similar study populations.

The period of enrolment is characterised by a broad range, and the primary diagnosis was cancer. Comparing patient characteristics to the Dutch patients who died, the very old and chronically ill, were under-represented in our study population.(15) These results might indicate that early identification of patients at home was sub-optimal and more patients in the community could benefit from HaHo. Although the ´surprise question´ was used to identify all patients with a life expectancy of less than one year, we cautiously conclude that we have not identified all patients within the target population. An improvement to HaHo would be to systematically assess all patients within the general practice with palliative care needs. Lessons learned from the Gold Standard Framework, levels of adoption will continue to differ between GP's.(16) Specialist practice nurses working in the GP practice could be the key to overcome these barriers, leading to early identification of the frail elderly and patients suffering from chronic illness.

Finally, like all studies, the generalisation of our results have to be considered with caution, due to the specific characteristics of the Dutch healthcare system.

Congruence between actual and preferred place of death

In congruence with international studies, our study shows that most patients prefer to die at home(17,18) and the congruence between the preferred and actual location is high when a preferred location is known.(15,18) In addition to previous studies, 94% of the patients had explicit preferences for place of death towards the end-of-life,which contributed to dying on their preferred place of death.(15)

Anticipatory care, including communication about end-of-life care preferences, is recognised to be important in primary care. However, GP's state it is difficult to find the right timing to initiate a conversation.(19) In our study the only barriers to proactive communication were patient related factors: not able (too ill), or not willing to communicate (too confronting, denial). These differences can be explained by the multidisciplinary collaboration of the service; anticipatory care was not only performed by the GP, but a shared responsibility within the team. This continuous attention to patient's preferences led up to 94% of patients expressing their preferred place of death, which is high when compared to previous studies. Studies of representative Dutch patients who died from 2009 –2011, found known preferences for 54-72% patients.(5,18,20) Internationally, Bell et all. found only three studies where all patients expressed their preferences, and 13 studies 35% - 82% of patients expressed their preferences.(21) Therefore, HaHo seems to empower patients and caregivers to express their preferences during the active supported palliative care trajectory.

Early identification

HaHo patients suffered from over six symptoms concurrently, of which over four were clinically relevant. The symptom burden of HaHo patients is comparable to the symptom burden of Dutch hospice inpatients on referral.(22) The multidimensional stability of patients was vulnerable or unstable, and 8% of patients were in crisis. Both indicate that patients referred to HaHo, had specific and complex palliative care needs, and could benefit from combined general and specialist palliative care. HaHo integrates general and specialist palliative care, to overcome challenges within a local health care system. As a result, we enabled patients to express and die at their preferred place of death. Gardiner et al identified communication, shared learning, coordination, definition of roles and responsibilities and timely access to specialist palliative care services, as success factors for collaboration.(23) Although HaHo entails a framework, requiring these factors, the working mechanism of the components was not studied.

To conclude, this study suggests that HaHo enabled patients to express their preferred place of death and to die at their preferred place of death. Areas for future study include 1) Analysis of the successful and unsuccessful components of the HaHo service in order to develop the model of integrative general and specialist palliative care more elaborately. 2) Further study of the patterns and course of symptoms in order to better understand the interventions required from the multidisciplinary team in order to optimise the patients' quality of life.

This study emphasises the need for a conscientious role for specialist hospice services to support high quality palliative care within the local primary care system. Using an integrative approach, which does not take over responsibilities, but confirms established relationships with GP, district nurses and volunteers, realizes interdisciplinary collaboration in generalist and specialist palliative care.

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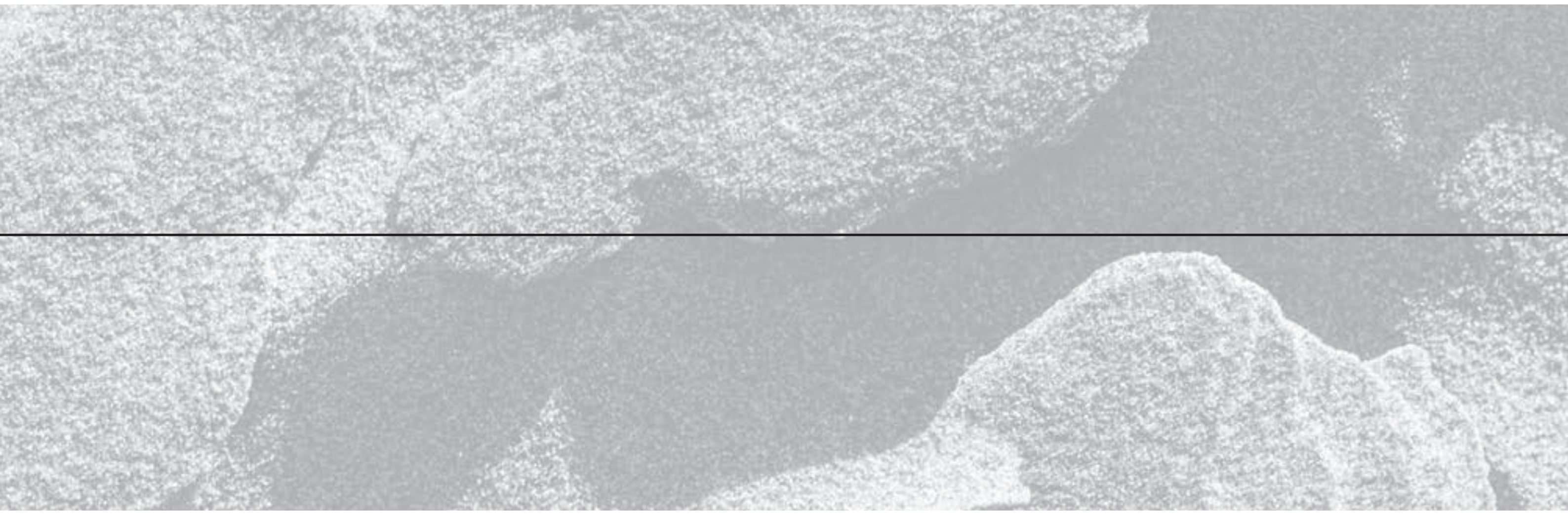
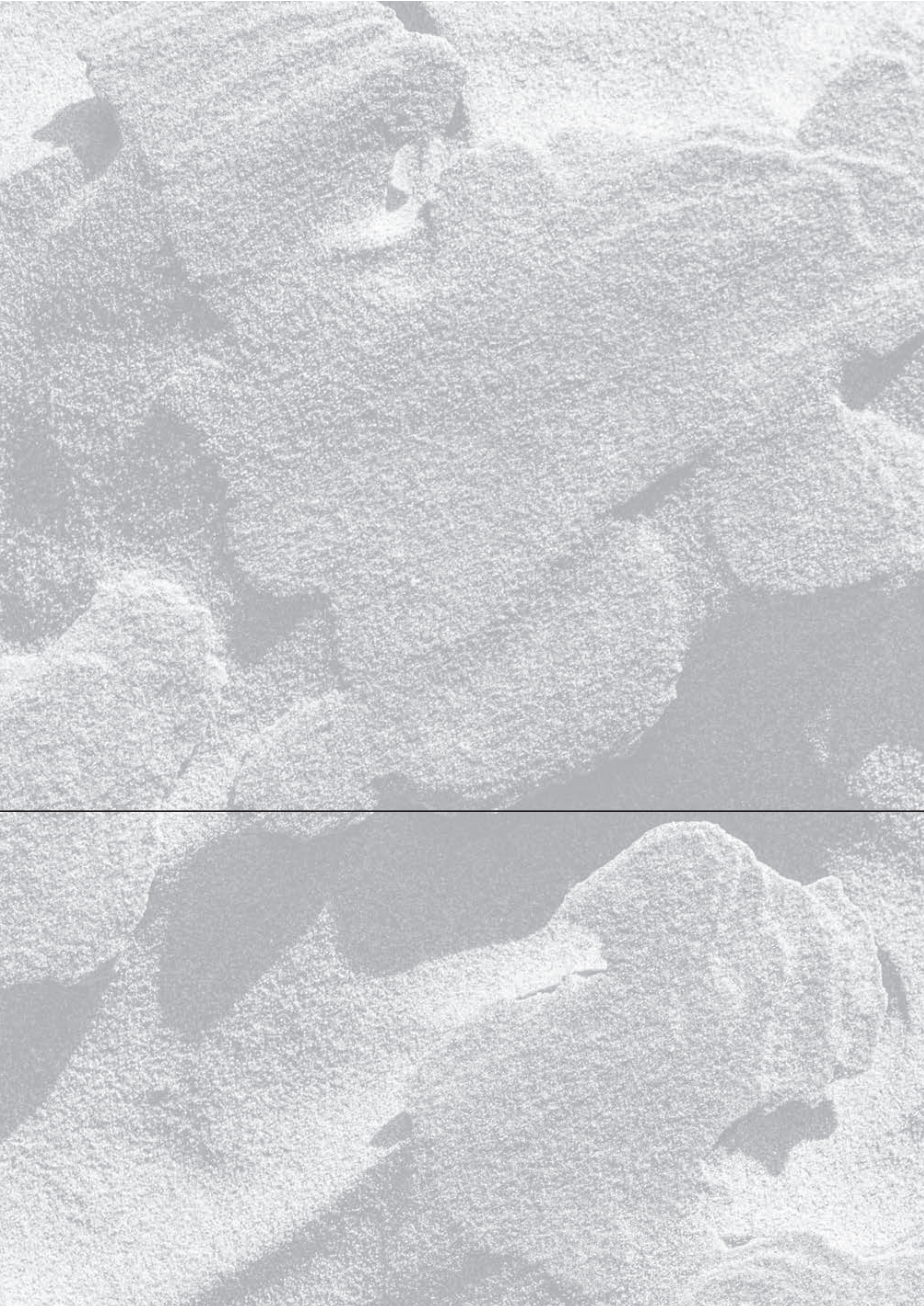


Part 2

SYMPTOMS AND WELL-BEING OF HOSPICE PATIENTS



5

DOES AGE INFLUENCE SYMPTOM PREVALENCE AND INTENSITY IN HOSPICE PATIENTS, OR NOT? A RETROSPECTIVE COHORT STUDY

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Abstract

Elderly are a growing population in hospice care. Palliative- and hospice care is less accessible to elderly due to difficulty in marking the palliative phase and identifying palliative care needs. The aim of this study was to gain insight into symptoms of hospice patients of different ages, to improve hospice care for elderly.

Method

A retrospective cohort study of patient admitted to a high care hospice facility from June 2007 to 2013 was conducted using prospectively collected data, from the first week after admission. Four age groups were selected: <65, 65-75, 75-85 and >85. The Utrecht Symptom Diary, a Dutch adapted translation of the Edmonton Symptom Assessment System, self-assessing the 12 most prevalent symptoms and well-being on a 0 -10 numerical scale was used to collect data on symptom prevalence and intensity. Primary outcomes: symptom prevalence (score >0), and symptom intensity. Secondary outcomes: clinically relevant symptoms (score >3) and quality of life.

Results

A total of 227 patients were included. Patients suffered from 6.3 symptoms concurrently. Of those 4.7 were clinically relevant. Fatigue was the most prevalent and intense symptom in all age groups, followed by dry mouth and anorexia. Pain was more prevalent and intense for patients < 65 and anorexia was more prevalent in the oldest old. Quality of life was decreased for all ages, mean well-being score 4.3 and most impaired for <65, (un)well-being score 4.72.

Conclusion

Over 70% of all hospice patients were able to self-assess their symptoms. Little differences were identified, supporting the evidence that individualized hospice care is needed for all ages. Future research should focus on determination of appropriateness of the current set of symptoms for the oldest patients as well as exploration of the meaning of symptoms and underlying mechanisms in different age groups.

INTRODUCTION

Worldwide, elderly become an increasingly important population for palliative care services, due to the aging demographics and increased treatment options. Elderly are less and later transferred to palliative- and hospice care, due to difficulties in palliative phase marking and identifying palliative care needs within the older population.(1)

The World Health Organization defined palliative care as: 'An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'(2)

Older hospice patients differ from their younger counterparts in various aspects. Elderly have less cancer diagnosis and more comorbidity, therefore, symptoms and problems experienced by older hospice patients are hypothesized to be different.(3) To improve access of elderly patients and to enable healthcare professionals to provide optimal prevention and relief of symptoms, insight into specific symptoms of the aged population is needed.(4)

Self-assessment is the gold standard to assess symptom intensity.(5) The Edmonton Symptom Assessment System (ESAS) is a worldwide recognized and validated tool to self-assess symptom intensity.(6,7) A cutoff over three on the numerical scales indicates clinically relevant symptoms in need of interventions.(8) The last item of the ESAS is a single item well-being measurement, showing good congruence with quality of life measurement tools.(9)

Early detection of symptom prevalence and monitoring of symptom intensity enables caregivers to anticipate on problems and treat symptoms in an early stage to prevent crises. Suitable application of assessment tools supports the communication between the patient, their families and professionals.(10)

Research studies on symptoms in palliative care are mostly conducted within a relatively young advanced cancer population. A former study within an advanced cancer inpatient population found fewer differences than expected in symptom prevalence between different age groups.(11) In hospice care the patient population is more heterogenic due to different diagnoses and comorbidity causing different illness trajectories.(12) In the last three months of life hospitalization caused by symptom burden is more likely and increases towards death.(13,14) Towards the end of life the symptom-profile seems to be less stable.(15) Differences in symptom experience between age groups could therefore be clearer within the hospice population.

Differences between age groups are hypothesized to be more prevalent and obvious in the hospice care population. Symptoms are more prevalent and more fluctuant during this last phase of life. Insight into the differences on symptom prevalence and intensity within age groups supports the ability of symptom recognition and anticipation in care and treatment by healthcare professionals providing more optimal symptom treatment and relief.

The aim of this hospice study is to gain insight into symptoms of hospice patients of different ages, to improve hospice care for elderly.

METHODS

A quantitative retrospective cohort study with a cross sectional design, using prospectively collected data from a 11-point numerical scale collected during admission to a hospice facility. The data were collected from a database in June 2014.

Setting and population

This single center study was conducted in high care hospice facility in the center of the Netherlands, providing inpatient and outpatient care. The study population consisted of all adult inpatients, admitted to the hospice, from June 2007 to December 2013. Patients were categorized in four age groups: < 65, 65-74, 75-84 and ≥ 85 years of age.

Patients unable or unwilling to self-assess their symptoms were excluded from this research study. All patients were informed about research within our hospice facility and the ability to decline. None of our patients declined. Some patients were not able to use the self-assessment instrument, and some were not willing to fill out the self-assessment instrument.

Data were collected anonymously, using an electronic database, SYMPAL, where personal data are separated from other characteristics. Only the principal investigator could link data to individuals using a decryption key, separately stored within the database. The use of SYMPAL data for research queries was approved by the local ethics comity of the Utrecht University Medical Center.

Data sources and measurement

A Dutch adapted translation of the ESAS, the Utrecht Symptom Diary (USD), was used to asses symptom prevalence and symptom intensity. The instrument assesses the twelve most prevalent symptoms: pain, sleeping problems, dry mouth, dysphagia, anorexia, constipation, nausea, shortness of breath, fatigue, anxiety, depressed mood and confusion. The USD measures symptom intensity on a 0-10 point numerical scale. Patients can add four more symptoms if necessary. Finally, quality of life is assessed using a 1-item well-being measure.

The USD was filled out twice a week (standard care) and more often if clinically indicated. All USD were prospectively collected during hospice stay and entered in the SYMPAL database with patient- and illness characteristics.

The SYMPAL database was specifically developed (2009) to collect data from palliative care patients in a diversity of palliative care settings. From the database the data of all hospice patients meeting the eligibility criteria were collected. Patient and illness characteristics were retrieved from the database and finally the USD data from all patients were imported from the database to a separate research file.

Data from the first symptom assessment after admission were included. Symptom assessments, collected over 7 days after admission were excluded from this research study, symptom prevalence and intensity is hypothesized to be influenced by hospice care and treatment.

Outcomes

The primary outcomes of this hospice study were symptom prevalence and symptom intensity. A symptom was prevalent at admission when a patient scored one or higher at the USD. Symptom intensity was determined by the numerical USD score the patient gave per symptom.

Secondary outcomes were: clinically relevant symptoms, number of concurrent symptoms and concurrent clinical relevant symptoms per patient, quality of life and patient characteristics. Clinical relevant symptoms were all USD symptoms scored over the cutoff of three. The number of prevalent symptoms and the number of clinical relevant symptoms per patient were calculated, adding all prevalent symptoms and all clinical relevant symptoms per patient. Quality of life was assessed using the USD well-being item.

Patient characteristics were gathered using demographics: age, gender, marital status and living situation. Illness related factors were determined by the primary diagnosis and phase of illness (treatment directed, symptom directed or dying phase). The patients' performance status was assessed using the WHO score. Finally, admission time was concluded as the number of days a patient was admitted to the hospice facility and survival as the number of days from admission to death.

Analysis

The primary and secondary outcomes were analyzed using descriptive statistics. Group differences of symptom intensity, number of symptoms, number of clinically relevant symptoms and well-being were analyzed using Kruskall Wallis, since the data did not meet the assumptions to perform an ANOVA analysis. The categorical data, symptom prevalence, clinically relevant symptoms, were analyzed using the Pearson Chi Square.

Demographics were analyzed using ANOVA for continuous data or non-parametric if necessary, and Pearson Chi Square for categorical data. Statistical significance (two-sided) was set on p<0.05. Statistical software IBM SPSS 22 was used to analyze the data.

RESULTS

A total of 342 patients were admitted to the hospice facility from June 2007 to December 2013, 246 patients (71,9%) were eligible, having at least one USD measurement. 19 patients were excluded because of the lack of any USD measurements within the first week after admission. Data of 227 patients (66.4%) were included in the study, 87 were men (38%) and the median age was 74 (mean 71.7; 31-96; SD 12.782).

Analysis of characteristics excluded patients showed significant differences between the eligible and non-eligible population. Patients unable or unwilling to self-assess symptoms were more likely to be over 85, or had a low WHO performance status, or a life expectancy of less than 14 days, or a survival period of less than 14 days, or a short admission time (p<0.05).

Demographics and illness characteristics

Patients in diverse age groups did not differ significantly regarding overall patient characteristics and illness characteristics. However, the illness characteristics of the oldest old, over 85, showed a lower proportion of oncology as primary diagnosis. Demographics differed significantly in marital status. The living situation differed between groups: the oldest patients were more likely to be widowed and living alone, patients under 85 were more likely to live with a partner. Nevertheless, the availability of family caregivers did not differ over groups. Demographic and illness characteristics are shown in detail in table 1.

Hospice admission

The admission duration and survival of patients differed largely in individual cases due to outliers in the quantity of days. The median admission time and survival of patients over 85 were longer than the other three groups, 28 days, however not significant (table 1).

Table 1. Patient characteristics

Age group			**<65**	**65-74**	**75-84**	**≥85**	**Total**
Number of patients		N	66	53	75	33	227
		%	29%	23%	33%	15%	100%
Gender	Men	N	25	22	27	13	87
		%	38%	42%	36%	39%	38%
Marital status*	Married / Living together	N	35	27	31	6	99
		%	53%	51%	41%	18%	34%
	Widowed	N	4	10	34	21	69
		%	6%	19%	45%	64%	30%
	Divorced	N	6	7	5	2	20
		%	9%	13%	7%	6%	9%
	Single	N	20	9	5	4	38
		%	30%	17%	7%	12%	17%
	MIssing	N	1	-	-	-	1
		%	2%				0%
Living situation	Alone	N	28	26	45	27	126
		%	42%	49%	60%	82%	56%
	with at least 1 other adult	N	37	26	29	6	98
		%	56%	49%	39%	18%	43%
	with child(ren) (<21)	N	1	-	1	-	2
		%	2%		1%		1%
	Missing	N	-	1	-	-	1
		%		2%			0%
Availability informal caregivers	Yes	N	56	49	63	27	195
		%	85%	93%	84%	82%	86%
	No	N	8	4	9	5	26
		%	12%	8%	12%	15%	12%
	Missing	N	2	-	3	1	6
		%	3%		4%	3%	3%
Religion	Yes	N	29	25	45	20	119
		%	44%	47%	60%	61%	52%
	No	N	34	21	26	13	94
		%	52%	40%	35%	39%	41%
	Missing	N	3	7	4	-	14
		%	5%	13%	5%		6%
Primary diagnosis	Cancer	N	63	49	67	25	204
		%	96%	93%	89%	78%	90%
	Renal failure	N	-	1	2	-	3
		%		2%	3%		1%
	COPD	N	-	2	2	-	4
		%		4%	3%		2%
	Heart failure	N	1	-	2	5	8
		%	2%		3%	15%	4%
	Other	N	2	1	2	2	7
		%	3%	2%	3%	6%	3%

Table 1. To be continued

Age group			<65	65-74	75-84	≥85	Total
Stage of illness	Illness directed palliation	N	2	-	2	-	4
		%	3%		3%		2%
	Symptom directed palliation	N	57	51	64	31	203
		%	86%	96%	85%	94%	89%
	Dying phase	N	7	2	9	2	20
		%	11%	4%	12%	6%	9%
WHO score	1	N	1	3	2	-	6
		%	2%	6%	3%		3%
	2	N	8	6	12	5	31
		%	13%	12%	17%	16%	15%
	3	N	30	22	34	15	101
		%	48%	45%	48%	47%	4%
	4	N	23	18	23	12	76
		%	37%	37%	32%	38%	36%
Admission time[1]	Median		19	21	20	28	20
	Mean		31.9	46.7	32.7	42.9	37.2
	SD		35.360	73.388	32.176	53.0	48.75
Survival[2]	Median		19.5	20.5	21	28	21
	Mean		35.4	50.2	36.8	43.2	40.5
	SD		41.185	78.887	41.234	54.364	54.267

[*]Significant at <0.05 level; [1]days from admission to discharge; [2]days from admission to death

Symptom prevalence

At admission patients in hospice care suffered from 6.3 symptoms concurrently. Age groups differences were minimal, respectively 6.64; 6.33; 6.09 and 6.39 over the four age groups. The most prevalent symptom in all age groups was fatigue, with prevalence as high as 100% for the oldest old. The other symptoms relevant to all age groups were anorexia, dry mouth, pain, dysphagia and constipation. Pain is more prevalent in younger patients (0.001), anorexia is more prevalent in patient over 85 years of age (p=0.047). Details on symptom prevalence are presented in table 2.

Symptom intensity

The symptom intensity scored on the USD was highest for fatigue. Dry mouth, loss of appetite, pain, constipation and sleeping problems had the highest intensities. Pain intensity scores differed significantly between groups. Pairwise comparisons showed a significant difference (0.007) between the age groups < 65 and 75-85. Symptom intensity for all USD symptoms is presented in table 3.

Table 2. Symptom prevalence (P)and clinical relevance (CR)

Age groups		**<65**	**65-75**	**75-85**	**>85**	**Total**	**P**
Pain	$P^{N (\%)}$	52 (80)	36 (69)	36 (50)	16 (49)	140 (63)	.001*
	$CR^{N (\%)}$	33 (51)	25 (48)	24 (33)	10 (30)	92 (41)	.075
Sleeping problems	$P^{N (\%)}$	32 (53)	24 (48)	34 (49)	18 (55)	108 (51)	.910
	$CR^{N (\%)}$	23 (38)	18 (36)	25 (36)	13 (39)	79 (37)	.983
Dry Mouth	$P^{N (\%)}$	53 (84)	42 (82)	58 (84)	29 (91)	182 (85)	.773
	$CR^{N (\%)}$	44 (70)	33 (65)	48 (70)	21 (66)	146 (68)	.916
Dysphagia	$P^{N (\%)}$	25 (42)	19 (36)	20 (28)	10 (32)	74 (34%)	.434
	$CR^{N (\%)}$	18 (30)	17 (32)	13 (18)	6 (19)	54 (25)	.219
Anorexia	$P^{N (\%)}$	43 (74)	43 (88)	50 (74)	27 (93)	163 (80)	.047*
	$CR^{N (\%)}$	36 (62)	33 (67)	42 (62)	22 (76)	133 (65)	.541
Constipation	$P^{N (\%)}$	34 (59)	27 (53)	42 (65)	16 (62)	119 (60)	.641
	$CR^{N (\%)}$	27 (47)	20 (39)	26 (40)	11 (42)	84 (42)	.858
Nausea	$P^{N (\%)}$	22 (34)	19 (37)	29 (39)	9 (29)	79 (36)	.780
	$CR^{N (\%)}$	11 (17)	14 (28)	16 (22)	5 (16)	46 (21)	.511
Dyspnea	$P^{N (\%)}$	30 (48)	26 (49)	29 (40)	14 (44)	99 (45)	.728
	$CR^{N (\%)}$	18 (29)	18 (34)	20 (28)	10 (31)	66 (30)	.893
Fatigue	$P^{N (\%)}$	59 (97)	46 (90)	67 (97)	31 (100)	203 (96)	.127
	$CR^{N (\%)}$	54 (89)	43 (84)	64 (93)	30 (97)	191 (90)	.243
Confusion	$P^{N (\%)}$	14 (24)	11 (22)	18 (25)	10 (33)	53 (25)	.687
	$CR^{N (\%)}$	8 (14)	8 (16)	9 (13)	3 (10)	28 (13)	.905
Anxiety	$P^{N (\%)}$	16 (27)	11 (23)	16 (24)	6 (19)	49 (24)	.894
	$CR^{N (\%)}$	6 (10)	7 (15)	9 (13)	5 (16)	27 (13)	.828
Depressed mood	$P^{N (\%)}$	26 (43)	12 (25)	28 (39)	9 (28)	75 (35)	.149
	$CR^{N (\%)}$	13 (22)	9 (18)	19 (26)	6 (18)	47 (22)	.710

* Significant at < 0.05 level

Clinical relevant symptoms

At admission patients suffered from 4.66 symptoms scoring over the cutoff indicating clinical relevance for symptom treatment. The age groups show differences however small, scoring 4.83; 4.78; 4.49 and 4.57 respectively. Clinical relevant symptoms reveal a pattern within the age groups that is similar to the symptom prevalence. Fatigue is highly prevalent in the higher scores, as well as anorexia and dry mouth; where pain, constipation and sleeping problems showed scores between 50% and 30% clinical relevance in all age groups. Pain is a more often clinical relevant for younger patients under 65. Anorexia is more often clinical relevant in patients over 85. Details on clinical relevant symptoms are presented in table 2.

Table 3. Symptom intensity scores per age group (mean USD scores)

Age groups	**<65** M(SD)	**65-75** M(SD)	**75-85** M(SD)	**>85** M(SD)	**Total** M(SD)	**P**
Pain	3.78 (2.84)	3.15 (2.82)	2.28 (2.73)	2.39 (3.04)	2.94 (2.88)	.005*
Sleeping problems	2.77 (3.20)	2.68 (3.24)	2.27 (2.74)	2.64 (2.95)	2.57 (3.01)	.845
Dry Mouth	5.17 (3.09)	4.82 (3.13)	4.91 (3.05)	4.91 (2.84)	4.97 (3.03)	.949
Dysphagia	2.1 (3.00)	2.06 (3.05)	1.34 (2.53)	1.68 (2.95)	1.78 (2.86)	.411
Anorexia	4.59 (3.51)	5.29 (3.11)	4.43 (3.28)	6.1 (3.13)	4.92 (3.32)	.131
Constipation	3.53 (3.77)	3.18 (3.66)	3.31 (3.35)	3.54 (3.74)	3.37 (3.58)	.924
Nausea	1.27 (2.23)	1.96 (2.91)	1.57 (2.39)	1.13 (2.08)	1.51 (2.44)	.638
Dyspnea	2.11 (2.84)	2.72 (3.35)	1.96 (2.86)	2.38 (3.27)	2.25 (3.03)	.652
Fatigue	6.54 (2.44)	6.04 (2.78)	6.75 (2.22)	6.35 (1.82)	6.46 (2.38)	.481
Confusion	0.88 (1.88)	0.96 (1.15)	1.15 (2.48)	1 (2.05)	1.01 (2.15)	.825
Anxiety	1.02 (2.16)	1.17 (1.13)	1.13 (2.41)	1.03 (2.36)	1.09 (2.30)	.959
Depressed mood	1.77 (2.51)	1.14 (2.00)	2 (2.97)	1.47 (2.83)	1.66 (2.65)	.228

Quality of life

The quality of life at hospice admission is relatively low, showed by a well-being score of 4.3. Over the different age groups, the differences are minimal, non-significant, scoring respectively 4.72; 3.81; 4.26; 4.07.

DISCUSSION

Fatigue, dry mouth, and anorexia are the most prevalent, intense symptoms and clinically relevant for all hospice inpatients on admission. Nevertheless, differences of symptoms were shown in pain, being more prevalent and intense in patients under 65 years of age and anorexia being more prevalent in the oldest patients. The mean number of symptoms is approximately constant over all age groups as are the number of clinically relevant symptoms.

This study was performed retrospectively, but the strength is that the data from the USD were collected prospectively of all inpatients over six years. A limitation is that patients who were unable or unwilling to fill out an USD were excluded. Analysis of patient's characteristics showed a specific subgroup of hospice patients of whom we have no information on their symptoms. Due to the specific characteristics this group appears to be divided in two subgroups, the very ill patients and very old patients over 85 years of age. Therefore, the results of this study are probably an underestimation of the real overall symptom prevalence, intensity and quality of life. Although patients were all inpatients from one high care hospice facility, basic characteristics of hospice patients in the Netherlands show a good resemblance. The number of patients in this study increases the generalizability of these results. Although, differences in cultural and organizational aspects of hospice care over the world should always be taken into account.

Overall approximately 70% of all hospice patients were able to self-assess their symptoms. Of the oldest and severely ill patients much less patients were able to do so. Therefore, future research should focus on the development and validation of assessment tools individualized to elderly and proxy assessments, as their symptoms are most likely to differ from the other subgroups. Clinical experience has indicated that patients find it hard to express their feelings, the intensity of a symptom, in a figure. Historically other options were tried, using a visual analogue scale initially and faces scales for some specific symptoms like pain or anxiety. The current ehealth and interactive innovations like apps and personalized web based support, could be an option to help patients self-assess their symptoms more easily, using numerical scales with visual support of the figures. Further research should focus on exploring which support patients prefer.

Pain is a lesser problem in elderly; this is in concordance with other research studies on symptoms in a cancer population.(16) Anorexia is more problematic in the oldest patients, over 85. Older patients suffer from at least as many concurrent symptoms and clinically relevant symptoms as their younger counterparts do. This is supported by the similar indication of reduced quality of life scores and previous research in cancer patients.(11,16) Hospice and palliative care needs and problems are at least as prevalent and intense in elderly as in their younger counterparts. This means that elderly patients and even the oldest old deserve a similar approach of personalized systematic monitoring of symptoms and problems to reach individualized total care. The challenge of future research is to explore if the current set of symptoms is fully appropriate for the oldest patients and to discover the meaning of symptoms and explore underlying mechanisms in different age groups, to optimize personalized support and symptom treatment, reduce symptom prevalence and intensity and improve quality of life and death for all hospice patients.

CONCLUSION

Over 70% of all hospice patients were able to self-assess their symptoms while admitted to a hospice facility. The oldest patients were significantly less able to assess their symptoms, as were the very ill patients. Hospice patients suffer from 6 to 7 symptoms concurrently. Fatigue, dry mouth and anorexia are most prevalent and intense. Patients under 65, suffer from pain more often and more intense where the oldest patients, over 85, suffer from anorexia more often. Concurrently almost five symptoms score over three, the cutoff for clinically relevant symptoms. The quality of life is limited, scoring between 3.8 and 4.7 for well-being on the USD.

Although elderly and very ill were underrepresented within the research population, their problems were just as intense as their younger counterparts, indicating the need for personalized hospice care for all patients.

There is no further need for future research in the hospice population to focus on differences in symptom burden between different age groups. There is an urge for a creative collaboration between geriatric and palliative care specialists together with general practitioners to develop research models to determine clinical significant themes of hospice care in the ageing population.

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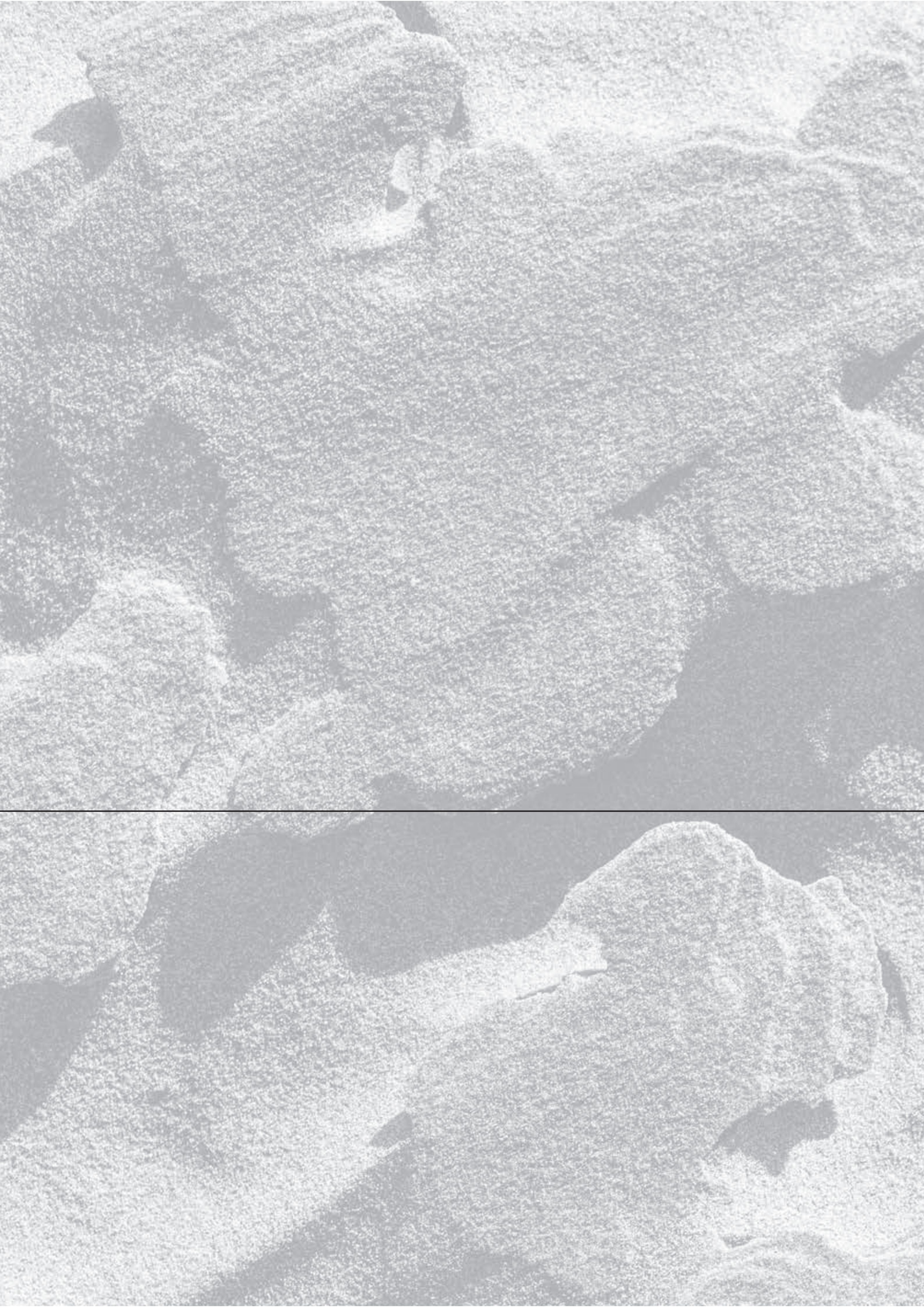

6

WHICH SYMPTOMS PREDICT THE QUALITY OF LIFE OF CANCER PATIENTS IN HOSPICE CARE? A CROSS-SECTIONAL AND LONGITUDINAL ANALYSIS

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Submitted

Abstract

Hospice patients suffer from multiple symptoms concurrently. Assessing symptoms is a major focus of hospice care.

Aim

The identification of symptoms predicting well-being of hospice patients suffering from advanced cancer, to optimize care, and to prioritize in symptom treatment.

Design

A multi-method cross-sectional and longitudinal study of patient reported outcomes. Cancer patients, admitted to hospice from June 2007 to June 2015 were enrolled. A symptom diary was used to measure the intensity of 11 symptoms and well-being on an 11-point numerical scale. Data were analyzed using linear regression and a Generalized Estimated Equation. Both analyses were adjusted for known confounders: age, gender, marital status, cancer diagnosis and survival.

Results

Fatigue (B=-0.364), depressed mood (B=-0.273) and anorexia (B=-0.217) predicted 48.7% of the variance of well-being at admission. During admission, fatigue (B=-0.37), depressed mood (B=-0.186), pain (B=-0.169), anorexia (B=-0.127), dyspnea (B=-0.082) and anxiety (B=0.096) predicted well-being.

Conclusions

Fatigue is the most important predictor for the patients' well-being. At admission, fatigue, anorexia and depressed mood explain nearly 50% of the variance in well-being. During admission, pain, dyspnea and anxiety were found to be additional predictors for well-being.

A structural assessment of fatigue, anorexia, depressed mood, pain and dyspnea and a pro-active exploration of the individually underlying mechanisms and dimensions should be performed to tailor personalized interventions. This personalized approach will improve well-being of patients suffering from the consequences of advanced cancer.

INTRODUCTION

Hospice care is multidimensional care, optimizing the quality of life by relieving physical, psychological, social and spiritual suffering. Adequate symptom management is essential in hospice care and should be based on an impeccable assessment of patients' symptoms.(1) Hospice patients experience an average of seven symptoms concurrently on admission.(2) Symptom intensity increases as the illness progresses.(3)

The gold standard to assess symptom burden, is self-assessment by patients themselves.(4) Patient reported outcomes (PRO's) are used increasingly in daily care, to identify symptoms, to monitor symptom intensity, and to evaluate the effect of interventions.(5)

The aim of hospice care is to optimize the quality of life of patients.(1) Quality of life is a subjective measure of a complex multidimensional concept, including physical, psychological, social and spiritual dimensions.(6) The feeling of well-being is an indicator of how patients feel overall and reflects overall quality of life.(7) Well-being may be regarded as a practical surrogate for an overall quality of life measure in hospice patients.(7)

The identification of symptoms contributing to the patients' well-being may support caregivers to prioritize symptoms for treatment and to incorporate the patients' needs and preferences. The Edmonton Symptom Assessment System (ESAS) is a well-known, internationally widely used clinical tool to assess symptom burden.(8) The outcomes of the ESAS are used in clinical care to assess symptom burden, to communicate with patients about their symptoms and to evaluate the effect of interventions.(9) In this study, the Utrecht Symptom Diary (USD), a Dutch adapted translation of the ESAS was used.

The aim of this study was to explore which symptoms contribute to the well-being of cancer patients admitted to a hospice.

METHODS

A retrospective multi-method study with a cross-sectional and longitudinal design was conducted from June 2016 to March 2017 in cancer patients admitted to a hospice.
To ensure the completeness of this report, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement was used.(10)

Setting and population

Patients with an estimated life expectancy of less than three months have access to hospice care in the Netherlands. For this study, all cancer patients consecutively admitted to a seven bed, professional-driven hospice in the center of the Netherlands between June 2007 and June 2015 were enrolled in this study if the patient had completed at least one USD during admission. Patients who lived longer than three months after admission were excluded from the study.

Ethical considerations

This study was performed according to the Declaration of Helsinki, the guidelines of good clinical practice and Dutch law.(11,12)

Patients admitted to hospice were informed by the hospice nurse about the study and the ability to decline. Patients were asked consent to use their data for the study. After verbal consent was obtained, written consent was recorded in the patient records, none declined. Data was collected from the patient records and anonymised by the principal investigator (PI), using an electronic database, SYMPAL, coding the individual patient data. The PI was able to link data to individual cases. The methods of consent, data collection and use of the SYMPAL database for research queries were approved by the local ethics committee of the Utrecht University Medical Centre, the Netherlands (11-113/C).

Outcomes and measurement

The main variables of this study were well-being and symptom intensity. Baseline characteristics (age, gender, marital status, primary cancer diagnosis, WHO performance status at admission and survival (number of days from admission to death)) were also used for the analysis.

Symptom intensity and well-being were measured using the Utrecht Symptom Diary (USD), a Dutch adapted translation of the Edmonton Symptom Assessment Scale. The USD assesses the intensity of 11 symptoms: pain, sleeping problems, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnea, fatigue, anxiety and depressed mood and well-being. All symptom items are scored on an 11-point numerical scale (0=no or best possible – 10=very severe or worst possible). For well-being we reversed the score (0=worst possible – 10=best possible). The USD was completed by the patient twice a week, or more often if indicated.

Analysis

We performed a cross-sectional analysis and a longitudinal analysis. For the cross-sectional analysis, only the first USD's completed in the first week were used. All patients with a first USD after the first week were excluded for the cross-sectional analysis. For the longitudinal model, all USD's collected during admission were included.

For the cross-sectional analysis, a multiple linear regression analysis was performed, using the 11 symptoms of the USD as the independent variables and well-being as the dependent variable. Since, according to the literature, age, gender, marital status, cancer diagnosis and survival affect symptom intensity and well-being, these confounding variables were entered first into the model, followed by a stepwise entry of the symptom variables of the USD. To account for correlation of measurements within patients, the longitudinal analysis was performed using generalized estimating equations (GEE) with an independent working correlation structure. Age, gender, marital status and cancer diagnosis were entered as factors in the model. Survival was entered as a time-varying predictor in the model, taking different time points of measurement into account, resulting in a multivariable model of symptoms contributing to well-being.

Data analyses were performed using IBM SPSS version 23 and the significance level was set at 0.05.

Sample size

A sample size of 101 patients achieves 80% power to detect an R-Squared of 0.15 attributed to eleven independent variables using an F-Test with a significance level of α=0.05. The variables tested are adjusted for an additional four independent variables with an R-Squared of 0.05.(13) Since data were collected in daily care, missing items were to be expected, we strove to enroll 200 patients.

For the longitudinal analysis, the number of repeated measures and the timeframes between measures differ. As a result, a sample size for the GEE analysis was difficult to calculate. We estimated that 200 patients, each contributing more than one measurement, would be sufficient for eleven predictors.

RESULTS

From June 2007 to June 2015, 481 patients were admitted, of whom 371 were eligible for our study (figure 1). 141 patients were excluded for not having any USD measures. For the longitudinal analysis 1545 USDs of 230 patients (range 1-48 USDs per patient) were included. Of the 213 patients with a USD within the first week after admission, 98 cases were excluded for having missing items; as a result, USDs from 115 patients were included in the cross-sectional analysis.

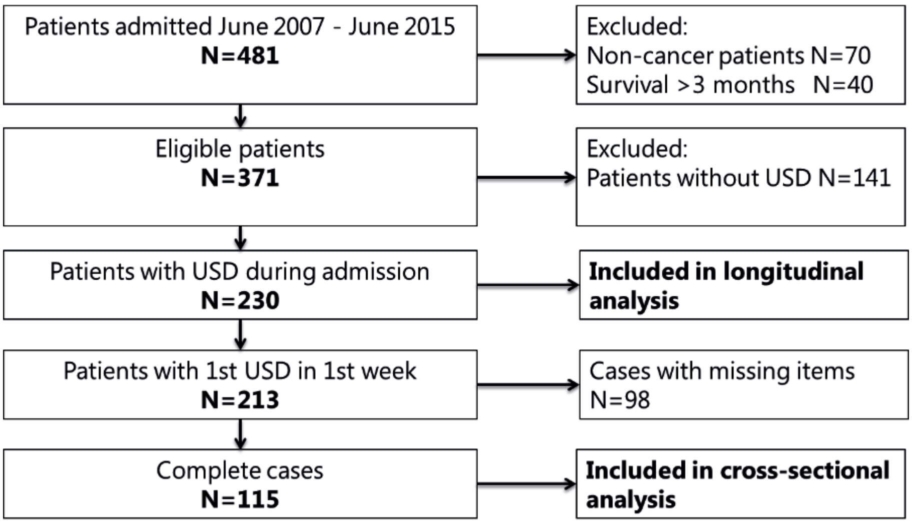


Figure 1. Flowchart enrollment

Table 1. Patient characteristics

		Cross sectional	Longitudinal	Eligible but no USD
Patients	N	115	230	141
Age	years	69	69.6	71.0
Survival	days	29,5	28.6	12.7
Gender	Female	71 (62%)	133 (58%)	86 (61%)
WHO performance score	1	2 (2%)	2 (1%)	2 (1%)
	2	22 (19%)	35 (15%)	5 (4%)
	3	59 (51%)	111 (48%)	39 (28%)
	4	31 (27%)	70 (30%)	90 (64%)
	Missing	1 (1%)	12 (5%)	5 (4%)
Marital status	Married/living together	50 (44%)	102 (44%)	65 (46%)
	Widowed	28 (24%)	56 (24%)	37 (26%)
	Divorced	11 (10%)	20 (9%)	12 (9%)
	Single	26 (23%)	50 (22%)	22 (16%)
	Missing		2 (1%)	5 (3%)
Cancer site	Breast	1 (10%)	17 (7%)	13 (9%)
	Gastro-intestinal	35 (30%)	70 (30%)	36 (26%)
	Respiratory tract	28 (24%)	55 (24%)	30 (21%)
	Female genital	11 (10%)	27 (12%)	13 (9%)
	Kidney/urinary tract	9 (8%)	16 (7%)	13 (9%)
	Other	21 (18%)	45 (20%)	36 (26%)

Patient characteristics are depicted in table 1. The mean age was 69 and 70 for the cross-sectional and longitudinal analysis respectively. Most patients were women, 71 (62%) and 133 (58%) respectively, and the mean survival after admission was 29.5 and 28.6 days, respectively.
The 141 eligible patients excluded for not having any USD measurements, had more advanced disease, a worse performance status and a shorter survival (data not shown).

For the cross-sectional analysis, 98 (45%) patients had missing items. Well-being was the item most frequently missing in 78 patients (37%). Characteristics of patients with missing items did not differ from patients without missing items. We performed a multiple imputation of the independent symptoms on the cross-sectional data. The results of the individual imputed sets and the pooled results supported the results found in the original data (data not shown). The missing symptom items were therefore addressed as missing at random.

For the longitudinal analyses, all items had less than 10 % missings, therefore an in-depth analysis of missing items was not necessary.

Symptom prevalence and intensity

At admission, well-being was decreased, scoring 5.17 (SD 2.472) on average. Fatigue, dry mouth and anorexia were the most severe and prevalent symptoms. Anxiety, nausea and dysphagia had the lowest mean scores and were the least prevalent symptoms (table 2).

Table 2. Symptom burden at admission

	Mean (SD)	Prevalence (USD score >0)	Clinically relevant (USD score >3)
Pain	2.52 (2.792)	59	29
Sleeping problems	2.51 (2.957)	54	34
Dry mouth	4.89 (3.131)	84	66
Dysphagia	1.43 (2.517)	32	21
Anorexia	4.78 (3.176)	84	64
Constipation	3.72 (3.389)	70	49
Nausea	1.40 (2.420)	35	19
Dyspnea	1.95 (2.784)	44	25
Fatigue	6.55 (2.284)	97	90
Anxiety	1.13 (1.994)	30	16
Depressed mood	1.86 (2.688)	43	21

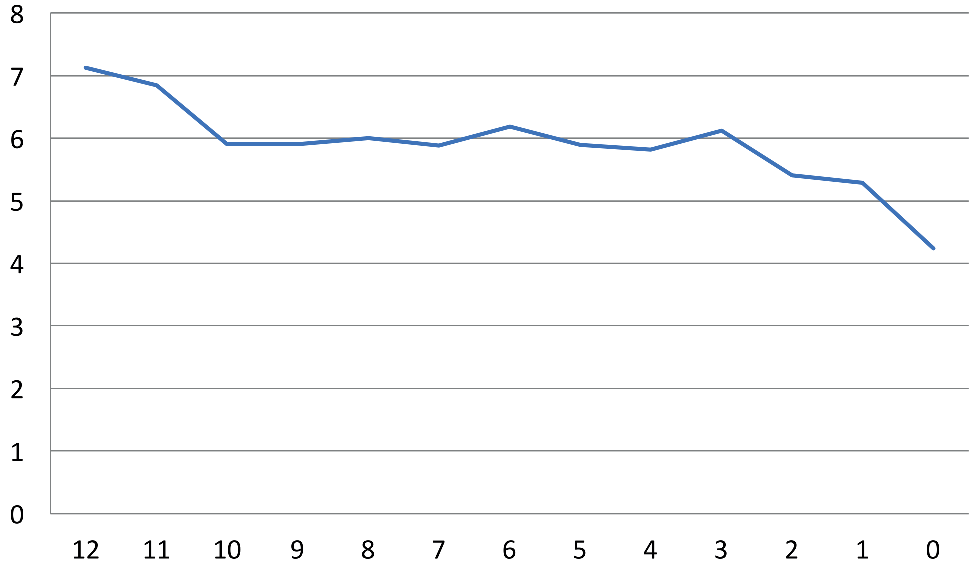


Figure 2. Trajectory of well-being towards death (mean reversed USD well-being scores 0=worst possible – 10=best possible).

During admission, well-being decreased towards death (figure 2). The symptom intensity of fatigue, anorexia, and dry mouth increased to over 5 on average, in the last weeks of life. Dyspnea, constipation and dysphagia increased more than 1 point on average in the last two weeks before death. All other symptoms showed more stable trajectories of the mean intensity scores (figure 3).

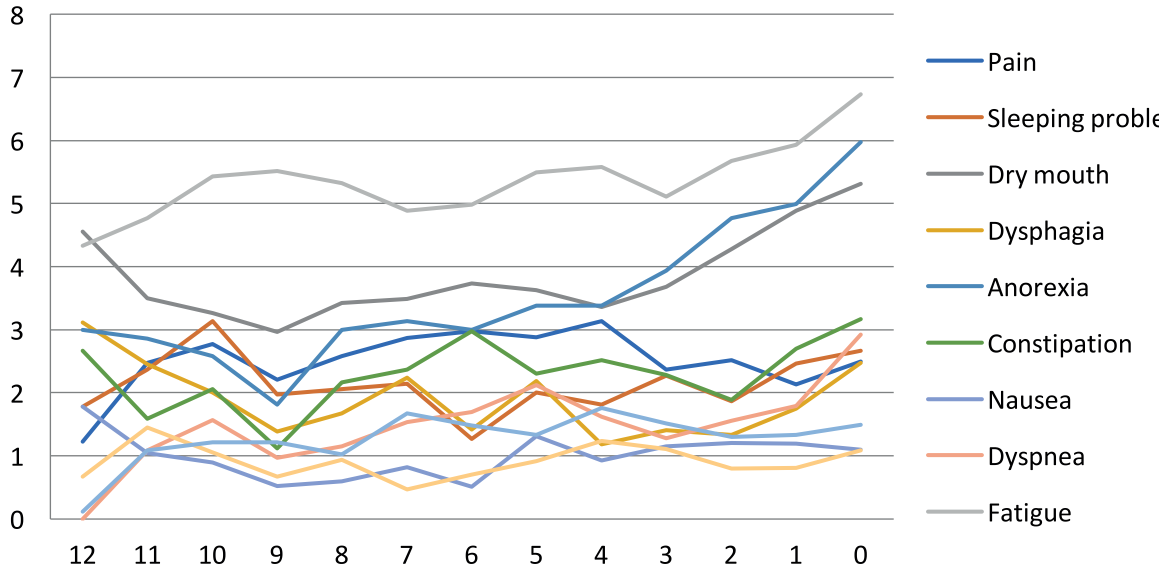
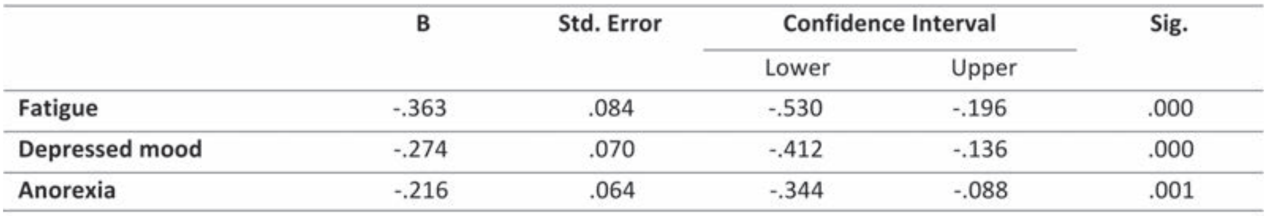


Figure 3. Symptom trajectories towards death (mean USD scores per week)

Symptoms predicting well-being at admission (cross-sectional analysis)

After correcting for age, gender, marital status, cancer diagnosis, and survival, fatigue, depressed mood, and anorexia were found to be independent predictors of well-being (table 3). Together, they explained 48.8% of the variance of well-being at admission. Higher degrees of fatigue, depressed mood and anorexia were associated with lower degrees of well-being.

Table 3. Symptoms predicting well-being at admission



	B	Std. Error	Confidence Interval		Sig.
			Lower	Upper	
Fatigue	-.363	.084	-.530	-.196	.000
Depressed mood	-.274	.070	-.412	-.136	.000
Anorexia	-.216	.064	-.344	-.088	.001

Table 4. Symptoms predicting well-being during admission

	B	Std. Error	Confidence Interval		Sig.
			Lower	Upper	
Pain	-.169	.0326	-.233	-.105	.000
Anorexia	-.127	.0266	-.179	-.075	.000
Dyspnea	-.082	.0417	-.164	-.000	.049
Fatigue	-.370	.0404	-.449	-.291	.000
Anxiety	.096	.0473	.004	.189	.042
Depressed mood	-.186	.0406	-.265	-.106	.000

Symptoms predicting well-being during admission (longitudinal analysis)

The longitudinal analysis showed that, after correcting for confounding variables, fatigue, depressed mood, pain, anorexia, dyspnea and anxiety were independent predictors of well-being (table 4). Higher degrees of fatigue, depressed mood, anorexia, pain and dyspnea were associated with lower degrees of well-being. For anxiety, the relation was reversed: higher degrees of anxiety were related to a higher degree of well-being. If the GEE analysis was performed without depressed mood the relation between anxiety and well-being did not change (data not shown).

DISCUSSION

Fatigue, dry mouth and anorexia are the most prevalent and severe symptoms of advanced cancer patients admitted to a hospice and their severity increased towards death. Well-being decreased towards death. Fatigue, depressed mood and loss of appetite were significant predictors for well-being of advanced cancer patients at admission. At admission, fatigue, depressed mood and anorexia explained almost half of the variance of well-being. Longitudinally, pain, anxiety and dyspnea were identified as additional predictors. All symptoms were negatively associated with well-being, with the exception of anxiety. Overall, fatigue was the most important predictor of well-being.

Strengths and weaknesses of the study

The strength of this study is that the data were gathered prospectively during daily hospice care in a large number of patients. To the best of our knowledge this is the first study of symptoms predicting well-being in hospice patients suffering from cancer which combined a cross-sectional and longitudinal analysis. This combined analysis enlarged the number of measurements. In addition, due to the increase of symptom severity and instability towards death, individual symptom scores tend to fluctuate more.(14, 15) As a result, additional predictive symptoms could be identified.

However, there are also some limitations of our study. First, for 141 patients, no USD was available. These patients were found to have more advanced disease, a worse performance status and a shorter survival. Thus, our results do not apply to the very ill patients with a very short survival.(2) Second, the missing items rate for the first USD was high, in particular for the well-being item. For the symptom items, a multiple imputation analysis showed the same results.(16) However, the omission of the USD's with a missing well-being item may have introduced selection bias for the cross-sectional analysis. Third, quality of life is influenced by physical, psychological, social and spiritual factors.(17) In our study, we only examined physical and psychological symptoms. Finally, in the longitudinal analysis well-being and symptom intensity were analyzed at identical time points.(18) One could argue that changes in symptom intensity could affect well-being over time. As a result, other symptoms affecting well-being, could be identified. This time effect was not included in our analysis, but should be explored in the future.

Symptoms and well-being

Our study results show that well-being decreased towards death. Concurrently, fatigue, dry mouth and anorexia increased. Seow et al. also found a decrease of well-being and an increase of fatigue and anorexia.(14) Fatigue, depressed mood and anorexia explained almost 50% of the variance in well-being at admission. Previous studies were mostly performed in advanced cancer patients during treatment, or focused on a specific symptom. Thus, there is little literature to compare our findings with. In cross-sectional univariate analyses pain(19), depression(19-21), fatigue(19,20), anxiety(19-21), drowsiness(19), dyspnea(19), anorexia(19) and sleeping problems(19,20) were negatively associated with well-being of advanced cancer patients. Barata et al. described a symptom cluster consisting of tiredness, anorexia, dyspnea, depression, anxiety and well-being in a population of patients admitted to an acute palliative care unit.(22) However, literature on symptom clusters in advanced cancer patients is inconclusive.(23,24) Finally, a recently performed multivariate analysis showed that fatigue, anxiety and anorexia were related to well-being in patients at an outpatient palliative care clinic. These results support most of our findings, except for anxiety. However, as well-being and symptom intensity were dichotomized for this analysis, a direct comparison with our results was not possible.(19)

As to be expected, fatigue, depressed mood, anorexia, pain and dyspnea were associated with less well-being. In contrast, we found in the longitudinal analysis that anxiety was associated with increased well-being, which is not in line with the literature, clinical experience and logic. Omitting depressed mood from the analysis did not change this finding, indicating that the relation between anxiety and depressed mood did not cause the dispersed relation. An explanation may be that the Dutch translation of anxiety has a different meaning compared to the original version of the ESAS. Translation of this term in other translations of the ESAS has been found to be problematic.(25,26) Moreover, patients found it difficult to distinguish between anxiety and depression.(27) This could explain the low mean scores and large bottom effect of anxiety scores in our study and more research is needed.

The findings of our study emphasize the importance of symptom assessment in daily hospice care. Even when treating a symptom is difficult, it should be addressed. Fatigue, anorexia and depressed mood are all difficult symptoms. Fatigue and anorexia are the most prevalent and severe symptoms experienced by hospice patients, strongly related to disease progression and difficult to treat.(2,15) Depressed mood is less intense and prevalent, but since cut off values for depressed mood are not established conclusively, this might lead to an underestimation of depressed mood. Therefore, fatigue, anorexia and depressed mood should be assessed and further explored for all patients when admitted to a hospice.

Difficulty in treating these symptoms should not lead to a nihilistic approach, as effective interventions have been described.(28) In treating these symptoms, the underlying psychological, social and existential dimensions and the consequences for mobility and autonomy should be explored.(29) In doing so, the influence of specific symptoms on well-being might be decreased, even if their severity does not change.

CONCLUSION

Fatigue, anorexia, pain, dyspnea and depressed mood affect well-being of hospice cancer patients. Structural assessment of these symptoms and a pro-active exploration of the individually underlying mechanisms and dimensions should enable the multi-professional team to tailor personalized interventions to improve well-being of patients suffering from the consequences of advanced cancer.

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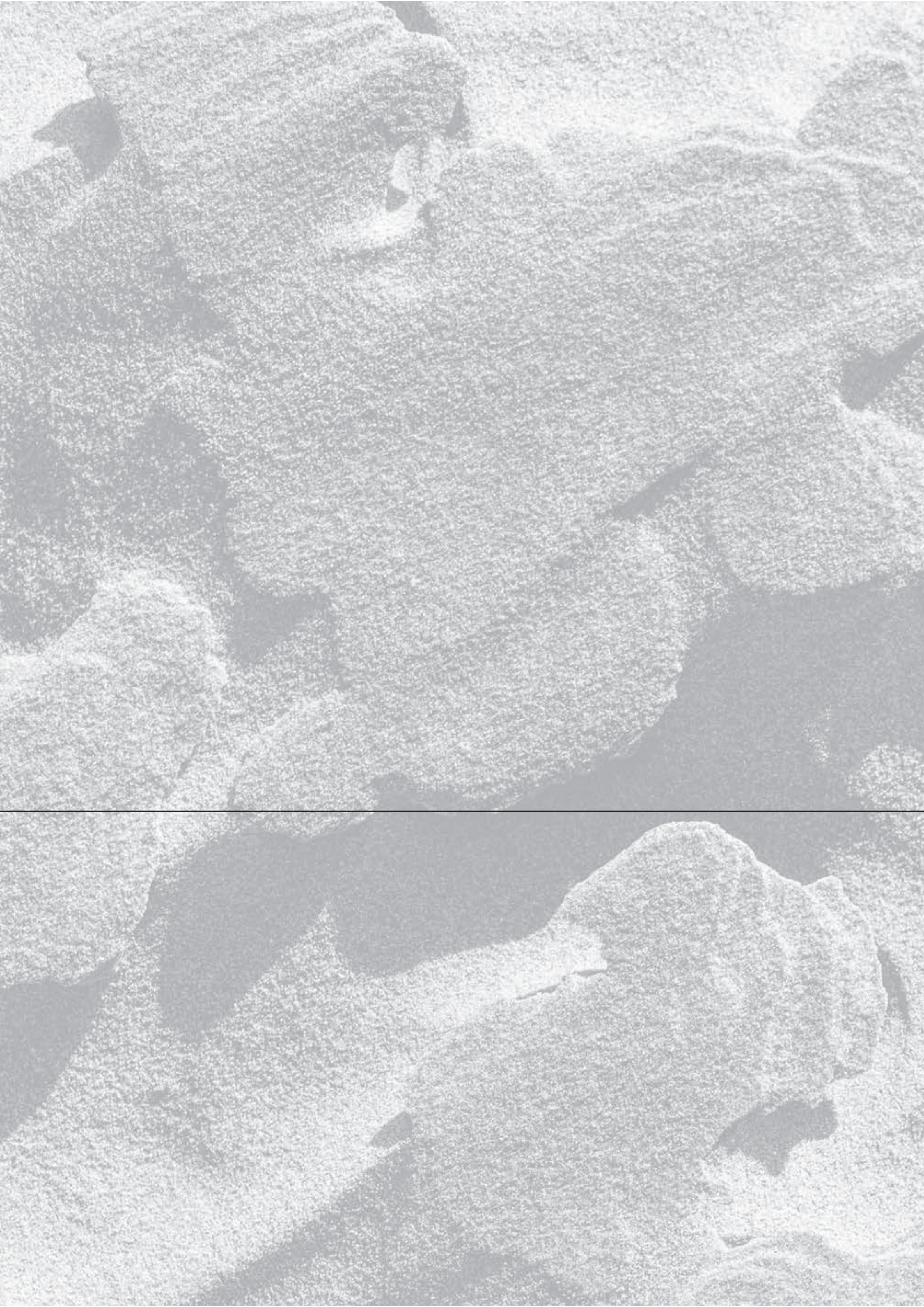

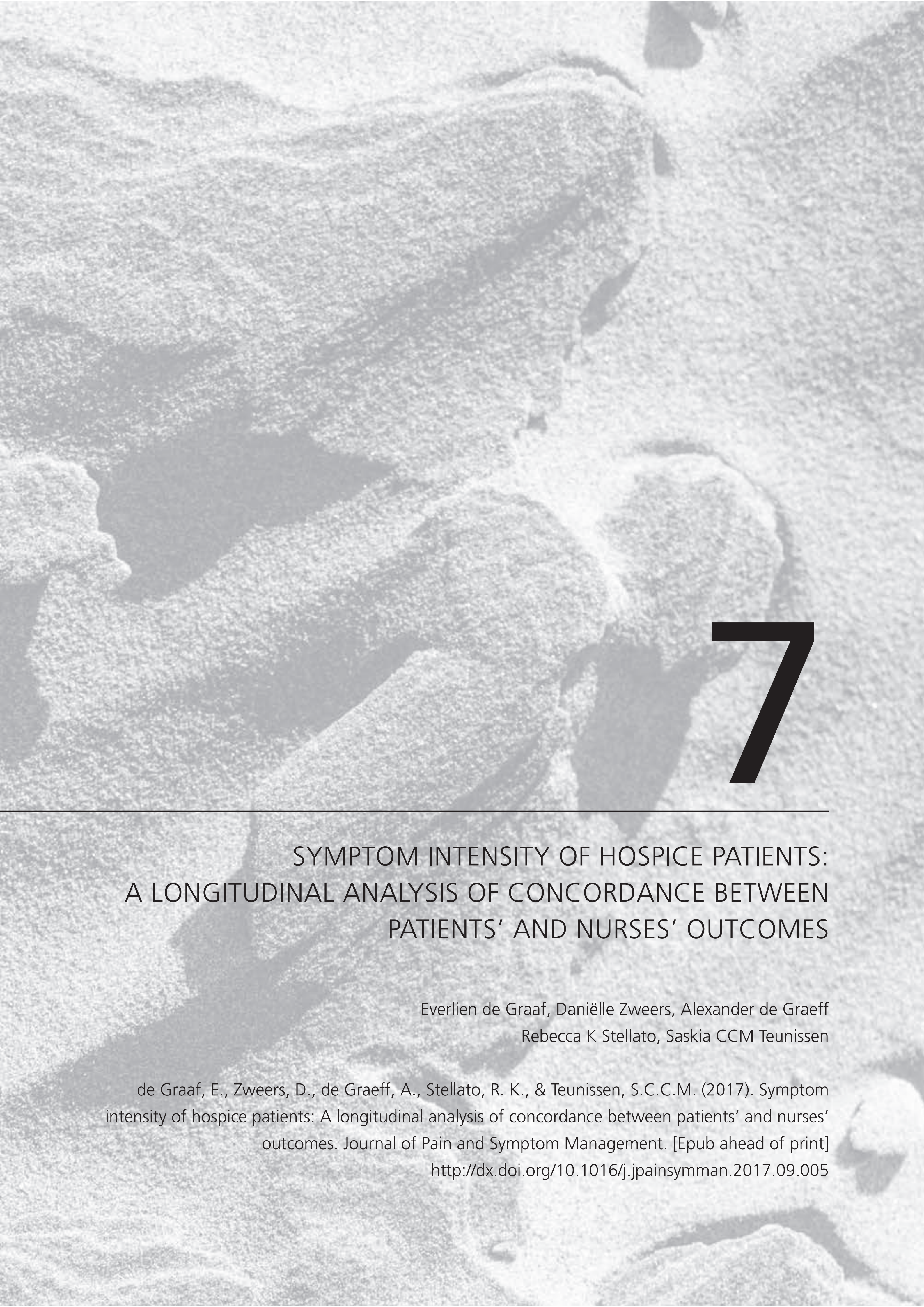

7

SYMPTOM INTENSITY OF HOSPICE PATIENTS: A LONGITUDINAL ANALYSIS OF CONCORDANCE BETWEEN PATIENTS' AND NURSES' OUTCOMES

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Abstract

Nearing death, hospice patients are increasingly unable or unwilling to self-report their symptom intensity and rely on nurses' assessments. We hypothesized that concordance between patients' and nurses' assessments of symptom intensity improves over time.

Method

A prospective longitudinal study was conducted from January 2012 to June 2015 using dyads of patients' and nurses' reported outcome measures, collected in daily hospice practice in the first three weeks after admission. Main outcomes were symptom intensity and well-being, measured using the Utrecht Symptom Diary (USD) and USD-Professional (USD-P).

Absolute concordance was the proportion of dyads with no difference in scores between USD and USD-P per week after admission. For agreement beyond chance, the squared weighted Kappa for symptom intensity, and the one-way agreement intraclass correlation coefficient for well-being were used.

Results

The most prevalent symptoms, fatigue, dry mouth and anorexia, also had the highest intensity scores assessed by patients and nurses. Symptom intensity was underestimated more frequently than overestimated by the nurses. The absolute concordance was fair to good (35% - 69%). Agreement beyond chance was low to fair (0.146 – 0.539) and the ICC for well-being was low (0.25 - 0.28). Absolute concordance and agreement beyond chance did not improve over time.

Conclusion

Concordance between patients' and nurses' assessment of symptom prevalence is good and both patients and nurses reveal identical symptoms as most and least prevalent and intense. However, nurses tend to underestimate symptom intensity. Concordance between patients and nurses symptom intensity scores is poor and does not improve over time.

BACKGROUND

Hospices aim to optimize the quality of life of patients with a short life expectancy by diminishing physical, psychological, social and spiritual suffering.(1,2) Patients with advanced diseases suffer from multi-symptomatology and complex symptom patterns.(3-6) When admitted to a hospice, patients suffer from a mean of 6 to 8 symptoms concurrently, of which 4 symptoms are graded as moderate to severe.(7,8) Therefore, symptom management is a major focus of hospice care. Patient reported outcome measures are vital in symptom management. Outcomes are used in daily care to assess symptom burden, to monitor symptom burden over time, to evaluate the effect of interventions, and to support communication between patients and healthcare providers and between members of the multi-professional team.(9,10) Moreover, patient reported outcomes are increasingly used to evaluate the quality of services provided and to benchmark between services.(11-13)

Self-assessment is the gold standard for assessing symptom intensity.(14) However, not all hospice patients are able or willing to self-report their symptoms. Patients who have a low performance status, patients with cognitive impairment and patients who are very old are less able to self-report symptoms.(7)

If patients are unable or unwilling to report their symptom burden, proxy measures are used to assess symptom intensity. Professionals and family caregivers can be the patients' proxy. Although studies are inconclusive, it can be stated that professionals tend to underestimate symptoms and family caregivers tend to overestimate symptoms, in particular psychological symptoms. Furthermore, nurses underestimate less than physicians and family caregivers were closer to the patients' experience than nurses.(15-24) However, most studies were performed in hospitals, during palliative oncology treatment and none in an inpatient hospice setting.

In many hospices nurses are available 24/7 for inpatients, and are responsible for symptom assessment in daily hospice care.(25) In the hospice where this study was performed, a Dutch adapted translation of the Edmonton Symptom Assessment System (ESAS) is used to self-report symptom intensity in daily care.(14,26) For patients unable or unwilling to report their symptom intensity, the Utrecht Symptom Diary for healthcare professional (USD-P) was developed in collaboration with hospice nurses, to be used as a proxy measure for assessment of symptoms. The USD-P entails identical items as the USD for patients.

In previous studies, concordance between patients and nurses reported outcomes was studied in a clinical setting mostly for patients with active treatment with an unknown life expectancy or survival time and short admission times or treatment contacts. In contrast, patients admitted to hospice have a life expectancy of less than three months, are predominantly 70 and older and the median admission time is three weeks.(7,25) Although at admission a large proportion of patients are able to self-report symptoms, along the illness trajectory, towards death, this ability decreases rapidly. Insight into the concordance between patient and hospice nurses gives information about the reliability of assessment by nurses of symptom intensity of patients unable or unwilling to assess it themselves. This knowledge will help the multi-professional team to improve symptom management and the quality of life and dying of hospice patients.

We hypothesized that concordance increases during admission, since nurses can learn from observing the patients' experience. This learning curve should be established within the first three weeks after admission, in relation to the median hospice admission time of approximately three weeks.(7,25)
The aim of this study was to establish whether concordance between hospice inpatients' self-report symptom burden and nurses' proxy measures increases during the first three weeks of admission.

METHODS

A prospective longitudinal study was conducted from January 2012 to June 2015 using dyads of patient and nurse outcome measures, prospectively collected in daily hospice practice.
For the report of this study the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) statement was used.(27)

Setting and patients

For this study, patients admitted to a professional-driven seven-bed hospice in the center of the Netherlands, were enrolled between January 2012 and June 2015. Patients had to be able and willing to assess their symptom intensity and dyads of patient self-report and nurse's assessed symptom intensity on the same day, had to be available. For patients with more than one dyad per week available, the first dyad per week was selected.

Patient anonymity and ethics approval

Admitted patients were informed by the hospice nurse about the study and their right to decline. Patients were asked consent to use their data for the study. After verbal consent was obtained, written consent was recorded in the patient records. Data was collected from the patient records and anonymised by the principal investigator, using an electronic database, SYMPAL, coding the individual patient data. The principal investigator was able to link data to individual cases. The methods of consent, data collection and use of the SYMPAL database for research queries were approved by the local medical ethics committee of the University Medical Centre Utrecht, the Netherlands (11-113/C).

Outcomes and measures

Patient self-report of symptom intensity and well-being

Symptom intensity and well-being were assessed twice a week using the Utrecht Symptom Diary (USD). The USD is a Dutch adapted version of the Edmonton Symptom Assessment System, a self-report symptom intensity scale.(28,29) The USD contains eleven symptoms: pain, sleeping disturbance, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnoea, fatigue, anxiety, and depressed mood and a one item well-being measure. All symptoms are assessed using an 11-point numerical scale (0=no symptom, best possible to 10=worst intensity, worst possible). The recall period of the USD is now/ at this moment. Patients usually completed the USD in the late afternoon.

Patient assessed symptom prevalence is described as the percentage of patients scoring over 0 on the USD.

The nurse assessment of symptom intensity and well-being was performed by nurses using the USD-P on a daily basis at the end of the day shift. The USD-P is the USD related proxy assessment tool, entailing the same 11 symptoms. Symptom intensity is measured on a 5-point verbal rating scale (0=no symptom to 4=overwhelming), in concordance with the Palliative care Outcome Scale.(30) Well-being is measured on a 0 – 10 scale (0=best possible – 10=worst possible) in concordance with the USD.

Data analysis

To study concordance between patient and nurse assessments of symptom intensity, both the absolute concordance and agreement beyond chance were used. Complete concordance is defined as the proportion of dyads with no difference between patient and nurse measures. In order to compare USD and USD-P scores, the USD scores were categorized. Cutoffs were used to categorize the symptom items of the USD into 5 categories: none (USD-score = 0), mild (USD-score 1-3), moderate (USD-score 4-6), severe (USD-score 7-9), very severe (USD-score = 10).(31,32)

For all symptoms and well-being, the USD-score was subtracted from the USD-P score, where 0 indicated absolute concordance. The USD difference was analyzed using descriptive statistics.
Agreement beyond chance is defined as the measure of agreement adjusting for chance, reducing the measure of agreement. Agreement beyond chance was analyzed using the weighted Kappa statistic for the categorical outcomes and the intraclass correlation for the numerical scales. Since the categorized USD and USD-P entail 5 categories, the squared weighted Kappa was used to correct for the chance of disagreement due to the large number of categories.(33) Kappa value of 0 or lower was considered poor; 0.01-0.2 slight; 0.21- 0.4 fair; 0.41-0.6 moderate; 0.61-0.8 substantial; and 0.81-1 almost perfect.(34) The one-way agreement intraclass correlation was calculated for the well-being scores on USD and USD-P, since the patients and nurses are from a larger pool of persons and agreement in measures was of interest.(35) Since the Kappa statistic can over- or under-correct

the agreement between measurements based on the distribution of responses(36), the absolute concordance and agreement beyond chance are both presented as well as the distribution of the differences between USD-P and the categorized USD scores.

To study agreement over time, the USD and USD-P differences, the squared weighted Kappa and the Intra Class Correlation (ICC) were calculated and described for the first three weeks after admission. In addition, a secondary analysis was performed with dyads from patients with dyads in all three weeks after admission.

Statistical analyses were performed using IBM SPSS 23 for descriptive statistics and Kappa. To calculate the weighted Kappa and intraclass correlation coefficient, R version 3.1.1 (2014-07-10) complemented with irr version 0.84 and psy 1.1 package. The level of significance was set at = 0.05.

RESULTS

In total 263 patients were admitted in the study period. After selection of the first dyad per week per patient, 295 dyads from 147 unique patients were included, of whom 45 patients had dyads in all three weeks and were included for the secondary analysis (figure 1).

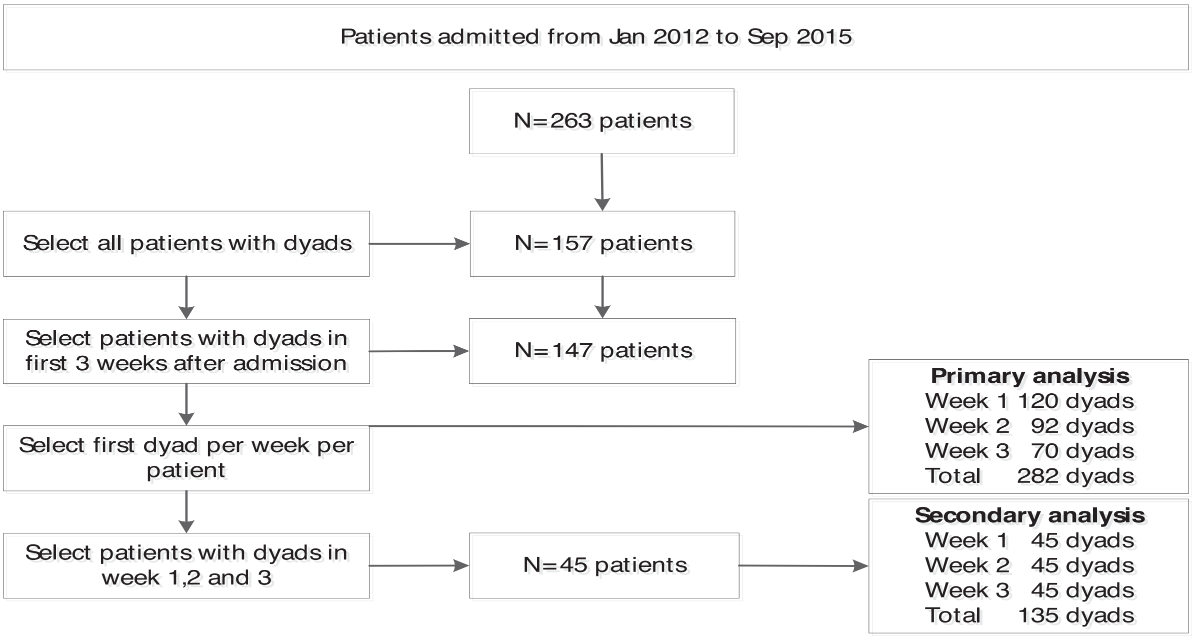

Figure 1. Flowchart study enrollment

The mean age of patients was 69.6 and 58% were women (table 1). The primary diagnosis of most patients was cancer (88%) and patients were admitted predominantly for last resort (84%).

Table 1. Patient characteristics

		Patients in the study (N=147)	
Characteristic	***Specified***	**Mean**	**SD**
Age	*Years*	69.6	13.39
		N	**%**
Gender	*Female*	85	58
Primary diagnosis	*Cancer*	130	88
	Organ failure	9	6
	ALS	2	1
	Other	6	4
Prognosis at admission	*<7 days*	*2*	*1*
	7 days - 4 weeks	43	29
	4 weeks - 3 months	*77*	*52*
	> 3 months	13	9
	Unknown	12	8
Performance score (WHO)	*1*	2	1
	2	26	18
	3	*80*	*54*
	4	*34*	*23*
	Unknown	5	*4*
Marital status	*Married/living together*	69	47
	Widowed	33	22
	Divorced	11	8
	Unmarried	32	22
	Unknown	2	1
Reason for admission	*Last resort*	124	84
	Respite	23	16
End admission	*Death*	123	84
	Transfer to home	*18*	*12*
	Transfer to other caresetting	6	4
		Median	**SD**
Admission	*Days*	*24*	*40.89*

USD-Ps were completed by 21 nurses. All nurses were women, with a mean age of 44 years. At the start of this study, 15 nurses worked in the hospice for 1.7 years on average (95% CI 0.7 – 2.8). Nurses worked three shifts per week on average, mostly consecutive shifts to ensure continuity of care. During the study period, two nurses left the hospice team and six nurses were added to the team.

Symptom prevalence and intensity

During the first three weeks after admission, fatigue, dry mouth and anorexia were the most prevalent symptoms and had the highest mean intensity scores. Nausea, anxiety and dysphagia were the least prevalent symptoms and depressed mood, anxiety and nausea had the lowest mean intensity scores (table 2). The mean well-being scores were 4.5, 4.5 and 3.9 in the first three weeks.

Table 2. Patient-reported symptom intensity (intensity = mean USD score)

USD	Week 1 N=126	Week 2 N=97	Week 3 N=72
Pain	2.18	2.20	2.17
Sleeping problems	2.67	2.89	1.86
Dry mouth	4.62	4.16	3.81
Dysphagia	1.71	1.73	1.22
Anorexia	4.58	3.80	2.88
Constipation	3.96	2.82	3.13
Nausea	1.08	1.08	.85
Dyspnea	2.17	2.05	1.48
Fatigue	6.20	5.49	5.23
Anxiety	1.43	1.38	1.31
Depressed mood	1.79	1.84	1.74

Fatigue, dry mouth and anorexia were the most prevalent symptoms according to the nurses. In addition, nausea, dysphagia and anxiety were the least prevalent symptoms. Nurses only scored fatigue as moderate to severe for most patients and dry mouth was scored predominantly as mild. The intensity of anorexia shifted from predominantly mild in the first week to predominantly none in the third week after admission. For all other symptoms, nurses scored none for the majority of patients. In table 3 the categorized USD scores and USD-P scores are displayed. Well-being decreased over time, scoring 3.9, 3.8 and 3.6, respectively.

Table 3. Patient reported, and nurse reported symptom intensity and well-being, absolute concordance and agreement beyond chance

			Week 1		**Week 2**		**Week 3**	
			N=126		***N=97***		***N=72***	
			USDcat	**USD-P**	**USDcat**	**USD-P**	**USDcat**	**USD-P**
Pain	**None**	*N (%)*	54 (43)	63 (50)	37 (38)	46 (47)	30 (42)	36 (50)
	Mild	*N (%)*	42 (33)	41 (33)	39 (40)	33 (34)	22 (31)	23 (32)
	Moderate	*N (%)*	20 (16)	15 (12)	13 (13)	14 (14)	11 (15)	10 (14)
	Severe	*N (%)*	8 (6)	7 (6)	8 (8)	4 (4)	8 (11)	1 (1)
	Very severe	*N (%)*	1 (1)	-		-		1 (1)
	Concordance	*%*	50.4		45.7		52.9	
	Agreement	*Kappa (95% CI)*	0.446 (0.26-0.63)		0.343 (.19-.5)		0.435 (.23-.64)	
Sleeping problems	**None**	*N (%)*	50 (40)	81 (64)	26 (37)	57 (59)	32 (44)	56 (78)
	Mild	*N (%)*	30 (24)	27 (21)	20 (21)	22 (23)	22 (31)	13 (18)
	Moderate	*N (%)*	24 (19)	11 (9)	25 (26)	12 (12)	13 (18)	2 (3)
	Severe	*N (%)*	16 (13)	4 (3)	15 (16)	4 (4)	3 (4)	1 (1)
	Very severe	*N (%)*	2 (2)	-	1 (1)	1 (1)	1 (1)	-
	Concordance	*%*	46.9		39.6		49.3	
	Agreement	*Kappa 95% CI*	0.321(0.17-0.47)		0.36 (0.21-0.51)		0.328 (0.12-0.53)	
Dry mouth	**None**	*N (%)*	18 (14)	34 (27)	18 (19)	27 (28)	10 (14)	27 (38)
	Mild	*N (%)*	28 (22)	64 (51)	24 (25)	49 (51)	23 (32)	33 (46)
	Moderate	*N (%)*	39 (31)	18 (14)	31 (32)	17 (18)	25 (35)	11 (15)
	Severe	*N (%)*	35 (28)	7 (6)	20 (21)	3 (3)	11 (15)	1 (1)
	Very severe	*N (%)*	3 (2)	1 (1)	3 (3)	-	2 (3)	-
	Concordance	*%*	36.5		35.2		31.9	
	Agreement	*Kappa 95% CI*	0.367 (0.24-0.49)		0.367 (0.23-0.5)		0.176 (0.05-0.3)	
Dysphagia	**None**	*N (%)*	77 (61)	93 (74)	65 (67)	77 (79)	44 (61)	60 (83)
	Mild	*N (%)*	16 (13)	20 (16)	6 (6)	15 (16)	15 (21)	7 (10)
	Moderate	*N (%)*	17 (14)	6 (5)	14 (14)	4 (4)	10 (14)	4 (6)
	Severe	*N (%)*	8 (6)	2 (2)	11 (11)	1 (1)	2 (3)	
	Very severe	*N (%)*	3 (2)	1 (1)		-		
	Concordance	*%*	63.1		64.8		63.2	
	Agreement	*Kappa 95% CI*	0.484 (0.29-0.68)		0.414 (0.23-0.6)		0.214(-0.01-0.44)	
Anorexia	**None**	*N (%)*	19 (15)	36 (29)	31 (32)	37 (38)	23 (32)	46 (64)
	Mild	*N (%)*	30 (24)	52 (41)	12 (12)	27 (28)	21 (29)	17 (24)
	Moderate	*N (%)*	33 (26)	16 (13)	32 (33)	23 (24)	16 (22)	6 (8)
	Severe	*N (%)*	28 (22)	12 (10)	14 (14)	6 (6)	9 (13)	2 (3)
	Very severe	*N (%)*	9 (7)	5 (4)	6 (6)	3 (3)	1 (1)	-
	Concordance	*%*	34.5		47.2		44.1	
	Agreement	*Kappa 95% CI*	0.457 (0.31-0.6)		0.592 (0.43-0.75)		0.366 (0.21-0.52)	

Table 3. To be continued

			Week 1		**Week 2**		**Week 3**	
			N=126		***N=97***		***N=72***	
			USDcat	**USD-P**	**USDcat**	**USD-P**	**USDcat**	**USD-P**
Constipation	**None**	*N (%)*	31 (25)	66 (52)	34 (35)	65 (67)	18 (25)	50 (69)
	Mild	*N (%)*	31 (25)	29 (23)	21 (22)	19 (20)	25 (35)	16 (22)
	Moderate	*N (%)*	29 (23)	14 (11)	27 (28)	6 (6)	16 (22)	3 (4)
	Severe	*N (%)*	10 (8)	6 (5)	9 (9)	2 (2)	10 (14)	-
	Very severe	*N (%)*	17 (14)	2 (2)	2 (2)	1 (1)	1 (1)	-
	Concordance	*%*	30.8		45.2		38.5	
	Agreement	*Kappa 95% CI*	0.233 (0.08-0.38)		0.29 (0.12-0.46)		0.198 (0.05-0.35)	
Nausea	**None**	*N (%)*	87 (69)	97 (77)	67 (69)	79 (81)	48 (67)	62 (86)
	Mild	*N (%)*	19 (15)	16 (13)	17 (18)	13 (13)	17 (24)	8 (11)
	Moderate	*N (%)*	14 (11)	9 (7)	7 (7)	5 (5)	4 (6)	2 (3)
	Severe	*N (%)*	3 (2)	1 (1)	4 (4)	-	1 (1)	-
	Very severe	*N (%)*		2 (2)		-		-
	Concordance	*%*	72.4		67.8		66.2	
	Agreement	*Kappa 95% CI*	0.539 (0.37-0.71)		0.293 (0.05-0.53)		0.293 (0.02-0.57)	
Dyspnea	**None**	*N (%)*	70 (56)	80 (64)	51 (53)	70 (72)	41 (57)	54 (75)
	Mild	*N (%)*	18 (14)	18 (14)	23 (24)	14 (14)	20 (28)	8 (11)
	Moderate	*N (%)*	18 (14)	17 (14)	11 (11)	8 (8)	6 (8)	6 (8)
	Severe	*N (%)*	15 (12)	9 (7)	10 (10)	4 (4)	3 (4)	3 (4)
	Very severe	*N (%)*	3 (2)	1 (1)	1 (1)	1 (1)	1 (1)	1 (1)
	Concordance	*%*	58.1		58.2		62.3	
	Agreement	*Kappa 95% CI*	0.648 (0.53-0.76)		0.524 (0.35-0.7)		0.609 (0.42-0.8)	
Fatigue	**None**	*N (%)*	5 (4)	3 (2)	5 (5)	4 (4)	8 (11)	6 (8)
	Mild	*N (%)*	13 (10)	23 (18)	15 (16)	27 (28)	10 (14)	25 (35)
	Moderate	*N (%)*	43 (34)	62 (49)	40 (41)	34 (35)	24 (33)	25 (35)
	Severe	*N (%)*	54 (43)	31 (25)	30 (31)	23 (24)	26 (36)	15 (21)
	Very severe	*N (%)*	8 (6)	6 (5)	4 (4)	9 (9)	3 (4)	1 (1)
	Concordance	*%*	44.4		42.7		39.1	
	Agreement	*Kappa 95% CI*	0.478 (0.36-0.6)		0.307 (0.1-0.52)		0.426 (0.24-0.62)	
Anxiety	**None**	*N (%)*	79 (63)	97 (77)	59 (61)	74 (76)	45 (63)	59 (82)
	Mild	*N (%)*	21 (17)	22 (18)	18 (19)	16 (17)	15 (21)	13 (18)
	Moderate	*N (%)*	14 (11)	6 (5)	8 (8)	6 (6)	5 (7)	-
	Severe	*N (%)*	6 (5)	-	7 (7)	-	4 (6)	-
	Very severe	*N (%)*	1 (1)	-		-	1 (1)	-
	Concordance	*%*	64.9		64.0		64.7	
	Agreement	*Kappa 95% CI*	0.232 (0.07-0.4)		0.364 (0.15-0.58)		0.146 (-0.02-.31)	

Table 3. To be continued

			Week 1		**Week 2**		**Week 3**	
			N=126		***N=97***		***N=72***	
			USDcat	**USD-P**	**USDcat**	**USD-P**	**USDcat**	**USD-P**
Depressed mood	**None**	*N (%)*	71 (56)	97 (77)	46 (47)	69 (71)	36 (50)	54 (75)
	Mild	*N (%)*	24 (19)	20 (16)	24 (25)	22 (23)	17 (24)	13 (18)
	Moderate	*N (%)*	18 (14)	6 (5)	12 (12)	4 (4)	9 (13)	3 (4)
	Severe	*N (%)*	7 (6)	1 (1)	9 (9)	1 (1)	6 (8)	2 (3)
	Very severe	*N (%)*	1 (1)	-		1 (1)		-
	Concordance	*%*	57.9		47.7		47.0	
	Agreement	*Kappa 95% CI*	0.461 (0.3-0.62)		0.206 (0.00-0.41)		0.194 (0.02-0.37)	

Concordance = absolute concordance; Agreement = agreement beyond chance; Kappa = weighted Kappa

Concordance

The difference between the USD-P and the categorized USD scores is displayed in figure 2. The green bars (indicating complete concordance) are shifted to the right, indicating an underestimation of symptom intensity by the nurses.

The complete concordance (table 3) was over 60% on average for nausea, anxiety, and dysphagia. For dyspnea and depressed mood complete concordance was over 50%. The complete concordance was lowest for dry mouth, constipation, and anorexia. The least intense symptoms, nausea, anxiety and dysphagia, showed the highest complete concordance.

Agreement beyond chance (table 3) was moderate for dyspnea, and fair for anorexia, fatigue, nausea, and pain, and low for anxiety.

Complete concordance over time

The complete concordance for anxiety and dysphagia were over 60 percent and stable in the first three weeks after admission. Furthermore, complete concordance for fatigue, nausea and dry mouth decreased slightly and absolute concordance for dyspnea and constipation increased over the first three weeks after admission.

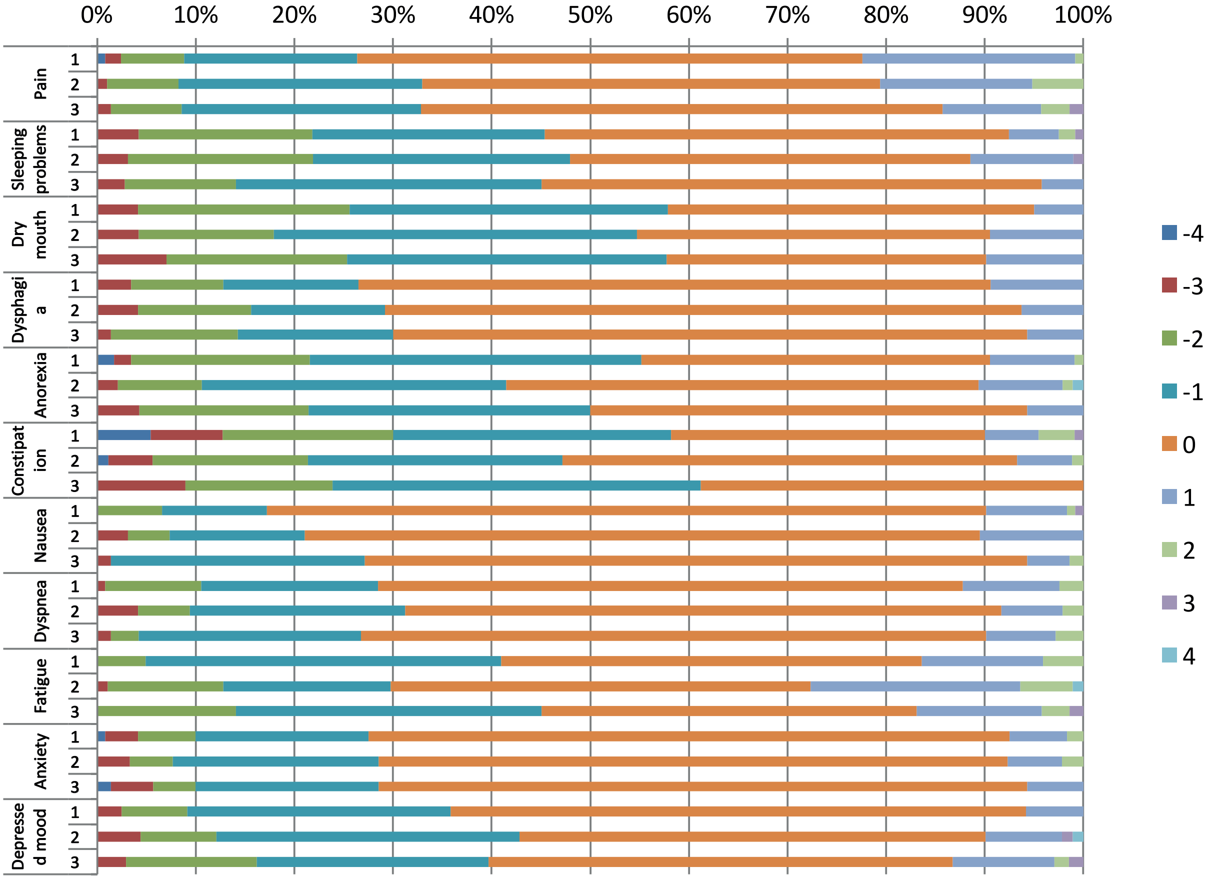

Figure 2. Difference USD-P and USD (USD-P minus USD categorized score)

Agreement beyond chance over time

The trajectory of weighted Kappa showed a stable pattern over time, during the first three weeks after admission. The secondary analysis of data from the patients with complete data (n=45), neither absolute concordance nor agreement beyond chance showed improvement for any of the symptoms over time (data not shown).

Agreement beyond chance in well-being was poor and stable over time with comparable confidence intervals (ICC week 1 0.27 (95% CI 0.09 - 0.44), week 2 0.28 (95% CI 0.07 - 0.46) and week 3 0.25 (95% CI 0.01 - 0.46)).

The secondary analysis (N=45) showed a higher agreement in week 3 (ICC 0.30, 95% CI 0.01-0.55) but with a wide confidence interval, confirming that agreement does not improve over time (data not shown).

DISCUSSION

Concordance between patient and nurse' reported symptom intensity was studied in the first three weeks after admission to a hospice. Fatigue, dry mouth and anorexia were the most prevalent and intense symptoms according to both patients and nurses. Nausea, anxiety and dysphagia were the least prevalent symptoms and depressed mood, anxiety and nausea had the lowest mean intensity scores according to patients. Nurses scored the identical symptoms as least prevalent but in a different order. Both patients and nurses indicate a decreased perceived well-being, although nurses overestimated well-being. The difference between USD-P and USD showed that nurses predominantly underestimate symptom intensity. Absolute concordance was relatively high for low intensity symptoms. The weighted Kappa analysis shows that only dyspnea reaches modest agreement while well-being and depressed mood scores showed only slight agreement and anxiety only reaches poor agreement. There was little agreement with regard to well-being. Neither absolute concordance nor agreement beyond chance increased over time. An analysis restricted to patients for whom three subsequent dyads were available, confirmed this lack of improvement of concordance.

Strengths and limitations

The primary strength of this study was that it was conducted in a real-life setting, using prospectively collected data. As a consequence, bias and confounding likely affect our results. Four considerations of the results are discussed.

First, patients in the last days before death are underrepresented in this study, since they are less able to self-report their symptoms.(7) Since concordance is lowest in more intense symptoms, and symptom intensity increases and well-being decreases towards death, the absolute concordance in this study could be an overestimation of the true concordance in symptom intensity for all patients. Second, hospice inpatients are less able to self-report towards death and their ability to self-report fluctuates during admission. This could potentially have decreased the concordance over time. However, if the analysis was restricted to patients for whom three dyads were available, the concordance still did not improve over time. Third, there could be differences between nurses in their capacity to assess symptoms in their patients. As we were unable to link measurements to specific nurses, we were unable to test this hypothesis. Finally, to enable a comparison between USD and USD-P, USD cutoffs were used for categorization purposes. These cutoffs are not well established for most symptoms, except of pain and fatigue. This might have contributed to the low concordance scores.(31)

Concordance

The agreement beyond chance is mostly lower than the absolute concordance, except for anorexia and dyspnea. Although anorexia itself is not observable, appetite and eating patterns are. Meals are important daily routines and are considered important by patients, their families and nurses. This seemed to have resulted in a better understanding of appetite or a lack of appetite and intake of food, but requires an in-depth inquiry to be sure. Dyspnea, or shortness of breath, is observable for nurses and discussed, since it is a known stressor for patients and their families. This could explain why both symptoms show a higher agreement even though the symptom intensity was higher. For nausea, depressed mood and anxiety, a large degree of concordance was found but a small weighted Kappa. A large proportion of patients scoring zero on the USD could explain this difference. Apparently, nurses are able to observe the absence of a symptom but assessing the intensity is problematic.

Overall, nurses' underestimation occurs much more frequently than overestimation. This underestimation of both physical and psychological symptoms is congruent with most previous studies, though Dawber et al. found an overestimation of physical and psychological symptoms in an acute hospital population.(30) Although it is known that psychological symptoms are difficult to interpret and are more likely to be overlooked and undertreated in daily care(24), our results indicate that both physical and psychological symptom are at risk for underestimation and thus under-treatment in the absence of self-report.

The fluctuations of symptom intensity could be an alternative explanation for the low concordance between patients and nurses. The USD and USD-P both assess symptom intensity "at this moment". As the symptoms are assessed on the same day but not necessarily at the same time, concordance might be lower. However, both patients and nurses usually assessed symptoms in the afternoon. An assessment where the timing is set at 'in the last 24 hours' might be preferred for fluctuating symptoms.(37)

Concordance over time

The stability of complete concordance over time suggests that the ability of nurses to assess symptom intensity does not increase. This could be influenced by the fact that most nurses do not work full time, resulting in few consecutive workdays per period. In addition, nurses generally work day-, evening- and nightshift. As a result, the number of comparable observations and contact with individual patients is low and, consequently, there is little possibility for nurses to learn from the patients' expressions of suffering from symptoms. Even in a hospice environment with solely specialized nurses, nurses tend to underestimate symptom burden of patients and should consequently emphasize to all patients and their families the importance of self-assessment. To level out the nurses' tendency to underestimate symptom intensity, a combined strategy of nurses' and family caregivers' assessments could be used when patients are unable or unwilling to self-report since family caregivers caring tend to overestimate patients' symptom intensity.(38) However, research is needed to establish if concordance is improved by a combined strategy and to study the feasibility of this strategy in daily practice.

To conclude, our results indicate that skilled hospice nurses are able to detect the absence of symptoms, but are less competent to assess the intensity of symptoms, specifically severe symptoms. There did not seem to be a learning curve: the estimation of symptom severity did not improve during admission. Observable symptoms such as dyspnea and dysphagia have a better concordance than symptoms that are not easily observed.

Hospice care is multidimensional care aiming to optimize the quality of life of terminally ill patients. Symptom management is vital to an optimal quality of life and self-report is the gold standard to assess symptom intensity. However, patients and the multi-professional hospice team have to rely on proxy assessment when patients become unwilling or unable to self-assess their symptoms. In daily practice, nurses should be aware of the likelihood of underestimation of symptom intensity, specifically for symptoms that are difficult to observe. Nurses could develop strategies to overcome their underestimation, by reflecting on their estimates using concurrent patients’ self–report measures and the use of dyads of family members’ symptom intensity scores and nurses’ symptom intensity scores concurrently for patients who are unable or unwilling to self-report. These strategies may increase concordance and decrease the chance of under-assessment and as a result under-treatment for these symptoms.

Symptom management by a multi-professional team is founded on an impeccable assessment of symptom prevalence and intensity. Nurses have a major responsibility to assess symptom intensity. Therefore the assessment of symptom intensity and the integration of these results in daily practice should be key in the nursing basic education and specialized palliative care courses.

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8

GENERAL DISCUSSION

The studies described in this thesis concern the field of hospice care in the Netherlands, which is a relatively unusual area for research. In this final chapter, we will discuss our main findings with regard to the two aims of the study: to explore the concept of hospice care and to assess the symptoms, well-being and needs of hospice patients. The results from the six studies described in this thesis will be summarized, methodological considerations discussed and a general reflection on the most important issues in these studies and recommendations for practice and future research presented.

MAIN FINDINGS

Part I Exploration of hospice care in the Netherlands

For the exploration of hospice care in the Netherlands, a convenience sample was drawn consisting of the 42 members of the Dutch Association of Hospice Care (DAHC). 36/42 professional-driven hospices were included in the study (chapter 2). These hospices have 7.5 beds on average and 11.5 years of experience in hospice care.

An explorative survey identified six core characteristics:

1. Patients with an estimated life expectancy of <3 months have access to hospice care. Hospices described their patients in terms of 'being in the terminal (palliative) phase' and/or as 'patients with advanced illness'.
2. In addition to patients, their families were explicitly described as a unit of care.
3. All hospices provided inpatient care. Admitted patients usually stayed until death (last resort care). Respite care and unplanned admissions for crises were provided by 25/36 (70%) and 16/36 hospices (44%), respectively. Three hospices (8%) provided day-care and extended home care was provided by 11/36 hospices (31%).
4. Care was provided by a multi-professional team consisting of professionals (nurses and physicians) and trained volunteers. Chaplains were included in the core team in 28/36 (78%) hospices; three hospices made use of psychologists and two hospices had a social worker instead of a chaplain.
5. Hospice care was described as multidimensional, addressing the physical as well as the psychological, social and spiritual dimensions, and as personalized care, based on the needs and wishes of patients and their families. The multidimensional assessment of patient needs was based predominantly on expert opinion, supported by tools in 18/36 hospices (50%). Eleven hospices (31%) used tools to assess the burden of care on family caregivers.
6. Atmosphere and attitude were major themes in the mission statements. The atmosphere was described as home-like, welcoming, and comfortable. Professionals and volunteers were expected to respect all patients, regardless of their social, cultural or spiritual background. Patients were treated as equals and staff had to respect the patients' privacy.

The multidimensional approach as reflected in the results of the survey was further explored in a sample of 12 hospices, all of which are members of the Dutch Association of Hospice Care (chapter 3). First, a quantitative study of 36 patient records (3 patient records per hospice) was performed.

The intended outcomes concerned 1) multidimensional care (MC), assessed on the basis of the frequency of the descriptions of the physical, psychological, social, and spiritual dimensions in patient records, 2) the description of the steps of clinical reasoning: assessment, pharmacological and non-pharmacological interventions, monitoring, and evaluation, and 3) the use of assessment tools during the hospice stay.

Second, MC was qualitatively explored using semi-structured focus group interviews with multi-professional hospice teams.

In total, the records of 36 patients (64% male, mean age 71 and admitted for 43 days on average) were included. Nurses were responsible for 76% of the descriptions in the records. The greatest part of the notes dealt with physical problems (70% of the content of the notes by physicians and 62% by nurses). In the focus groups, nurses and physicians specified that physical symptoms were easy to spot and to discuss and that they were trained primarily to address physical problems. Of the minutes from multi-professional team meetings (MTM) 49% dealt with the physical, 20% with the psychological, 15% with the social and 16% with the spiritual dimension. The attention to the social dimension and basic interventions in the social dimension are considered ‘normal care’ and only documented if problems or escalations occur. The lack of documentation on spiritual issues was influenced by chaplains who felt that documentation would interfere with their position, as the patients’ confidential refuge. Furthermore, nurses explained that they lacked the vocabulary to report on spiritual issues in the patient records.

The steps of clinical reasoning were recognized in the patients’ records. Nurses spent most of their notes on monitoring symptoms and problems. Of all parts of palliative reasoning, the evaluation of interventions was described the least in the records. Participants in the focus groups explained that evaluation was easily forgotten or overlooked during busy shifts. In addition, evaluations were underreported since many evaluations took place verbally and were not documented.

Assessment tools were used in 10/12 hospices, 4/10 systematically and 6/10 ad hoc. Tools used in daily care were the distress thermometer (N=2), the Utrecht Symptom Diary (USD), an adapted Dutch translation of the Edmonton Symptom Assessment System (N=4) and the Liverpool Care Pathway for the Dying (N=2). Other tools were used to support a further exploration of specific problems, such as delirium, mouth problems and pain. Professionals who used tools felt that these tools supported both conversations with patients and communication with other professionals.

Participants in the focus groups indicated that the adoption of the steps of clinical reasoning, supported by structure in care plans and the use of assessment tools resulted in better communication, better interdisciplinary collaboration and higher levels of multi-dimensional care provided by all members of the multi-professional team.

Historically, hospices in the Netherlands were oriented to inpatient care. Following international examples, however, a third of hospices developed outpatient and consultation functions. These functions of hospice care were operationalized in an innovative initiative of hospice care assistance at home, the HaHo-service (chapter 4).

This service aims to support patients with a life expectancy <1 year at home by means of 1) home consultations by hospice nurses, 2) interdisciplinary team meetings every two weeks with two hospice nurses, a hospice physician, general practitioners, district and oncology nurses, a spiritual caregiver and trained volunteers, 3) a 24/7 hospice telephone backup, and 4) a central caregiver responsible for the coordination of the care for each patient.

A retrospective cross-sectional evaluation study was performed between December 2014 and March 2015 of 130 HaHo-patients (89% cancer patients, 52% female, mean age 72), using patient records and documentation. During the study period, 107 patients died, and five patients dropped out. The median period of survival from the time of enrolment was 59.5 days (range 0-671).
The primary outcome was congruence between the preferred and the actual place of death. Secondary outcomes included early identification of patients in need of palliative care, symptom burden and (in)stability.

The preferred place of death was known for 122/130 patients and 91% of these patients died in their preferred location. On referral, patients suffered concurrently from six symptoms, of which four were clinically relevant, scoring >3 on the USD. Fatigue was the most prevalent symptom in 94% of patients. Other highly prevalent symptoms were anorexia (74%) and pain (70%). The most severe symptoms were fatigue (mean score 6.31 (SD: 2.394)), anorexia (4.48 (SD: 3.016)) and dry mouth (3.03 (SD: 3.018)). Scores for unwell-being were high (mean score 4.97 (SD: 2.429)), indicating a poor quality of life. Eleven patients (8%) were in crisis when they were referred to HaHo. Most patients were either vulnerable (45%) or unstable (30%). Only 18/130 patients (14%) were in a stable condition. Information about stability was lacking for three patients.

The study emphasized the high symptom burden and lack of stability of patients at home in the last months of their life. Specialized palliative care is indicated for these patients. Consultation at home by hospice nurses and interdisciplinary team meetings may support general practitioners and district nurses and may also result in the great majority of these patients dying at their preferred location.

Part II Symptom burden and well-being of hospice patients

The second part of this thesis aimed to gain insight into symptom burden and well-being of patients admitted to a hospice.

Patients admitted to a 7-bed hospice facility were studied between June 2007 and June 2016. During this period, 481 patients were admitted, of whom 85% were diagnosed with cancer. 59% of these patients were women, with a mean age of 72 (range 31-100). The median period for their stay was 20 days.

Three studies were performed, using prospectively gathered data of these patients during daily hospice care. The implemented tool for data collection was the Utrecht Symptom Diary (USD), the translated and adapted Dutch version of the Edmonton Symptom Assessment System, assessing symptom intensity on an 11-point numerical scale from 0=no symptoms, best possible well-being to 10=most intense symptom, worst possible well-being.

In the first study (chapter 5), symptom prevalence and intensity and the effect of age were examined in a cross-sectional approach. The first USD, collected in the first week after admission in 227/342 patients, admitted from June 2007 to December 2013, was used for this analysis. Four age groups were created (<65, 65-74, 75-84 and ≥85 years) in order to enable comparison. In the first week after admission, patients suffered concurrently from six symptoms. The mean score for unwell-being was high (4.3), reflecting a poor quality of life. Fatigue (96%), dry mouth (85%) and anorexia (80%) were the most prevalent symptoms. The mean scores were 6.46, 4.97, and 4.92, respectively. Pain had a significant higher prevalence in patients younger than 65 (<65: 80%, 65-74: 69%, 75-84: 50%, ≥85: 49%), and their pain was more severe than that of older patients (mean score 3.78. 3.15, 2.28 and 2.39, respectively). In contrast, anorexia occurred most often in patients ≥85 years (<65: 74%, 65-74: 88%, 75-84: 74%, ≥85: 93%). The scores for (un)well-being did not differ significantly between the age groups.

The study demonstrated the high symptom burden of hospice patients. For most symptoms there were no significant differences related to age.

The aim of the second study (chapter 6) was to investigate the predictive value of symptoms for cancer patients' well-being. Symptoms and (un)well-being were analyzed cross-sectionally in the first week of their stay, and longitudinally during their stay. All cancer patients admitted from June 2007 to June 2015 were enrolled if they had self-reported symptom intensity scores, collected with the USD. The cross-sectional analysis included 115 with data available for the first week with a mean age of 69 (62% women), and the longitudinal analysis 230 patients (mean age 70 and 58% women) with a total of 1545 USD's. The mean survival period after admission was 29 days.

In the cross-sectional analysis we corrected for five confounders: age, gender, marital status, cancer diagnosis and survival. Fatigue, depressed mood and anorexia were found to be independent predictors of well-being. Together, these symptoms explained 48.8% of the variance in well-being at admission. Higher degrees of fatigue, depressed mood and anorexia were associated with lower degrees of well-being.

The longitudinal analysis showed that four physical symptoms (fatigue, pain, anorexia and dyspnea) and two psychological symptoms (depressed mood and anxiety) were independent predictors of well-being. A higher intensity of fatigue, depressed mood, anorexia, pain and dyspnea were associated with lower degrees of well-being. For anxiety, the relation was reversed: higher degrees of anxiety were related to higher degrees of well-being.

The study showed that fatigue was the most important predictor for well-being, followed by anorexia, pain, dyspnea, depressed mood and anxiety. The reverse relation between anxiety and well-being is difficult to explain. The large bottom effect of the anxiety scores, most patients scoring very low, may be an explanation.

In chapter 7 we studied the concordance between hospice patients' and nurses' assessments of symptom intensity, using dyads of patients and nurses' symptom intensity scores. Although a patient's self-report is the gold standard for assessing symptom prevalence and intensity, not all hospice patients are able or willing to complete a symptom diary. In those cases, nurses may be practical proxies for symptom monitoring. An adapted version of the USD was developed in collaboration with hospice nurses, the USD professional (USD-P). The USD-P entails the original USD items, assessed on a 5-point verbal rating scale (0=no symptoms to 4=overwhelming symptoms). Well-being is measured on a 0 – 10 numerical scale (0=best possible to 10=worst possible) in accordance with the USD. The first dyad of paired USD and USD-P measures per week for the first three weeks after admission was selected per patient. In total 147 patients were included, of whom 45 had dyads for all three weeks. The USD-P were completed by 21 nurses during daily care. Fatigue, dry mouth, and anorexia, were the most prevalent and severe symptoms, according to both patients and nurses. Nurses predominantly underestimated symptom intensity. The complete concordance was over 60% on average for nausea, anxiety and dysphagia. For dyspnea and depressed mood complete concordance was between 50% and 60%. Concordance was lowest for dry mouth, constipation and anorexia. The least severe symptoms (nausea, anxiety and dysphagia) showed the highest complete concordance. Complete concordance did not improve over time during admission.

Agreement beyond chance (concordance corrected to account for chance) was moderate for dyspnea, fair for anorexia, fatigue, nausea, and pain, and low for anxiety. Agreement beyond chance did not improve over time. The agreement beyond chance of well-being was poor and stable over time.

At the start of the study we hypothesized that nurses would be able to learn from the patients experience and that concordance would improve over time, but the study showed that they tend to underestimate the patient's symptom intensity and that this does not improve over time.

METHODOLOGICAL CONSIDERATIONS

Part I Exploration of hospice care in the Netherlands

Measurement bias

This thesis concerns the field of Dutch hospice care, a field in which scientific research is relatively new and no existing, validated measurements are available. Therefore, we developed measurement tools, specifically constructed for each study. A survey was developed for the exploration of hospice care (chapter 2). The original survey had 91 items, structured in 14 main themes. Face and content validity were judged by a team of experts and the research team. Because of the opinion of the experts, four items were changed to improve readability and two items were added. For this specific study, this was the most convenient measure to use, but it may have reduced the quality of the data and the validity of the results.

To study the multidimensional approach of care in the participating hospices (chapter 3), data were retrospectively collected from patient records using a standardized data extraction tool, to count descriptions of multidimensional care and the steps of clinical reasoning. Face and content validity were tested by the research team and small adaptions were made to improve usability. Two researchers discussed the decisions made during data collection. Most discussions were about the descriptions of the psychological and spiritual problems and the steps of clinical reasoning. All decisions were logged in a research file. This strategy enlarged the rigor of the data.

The qualitative data were gathered during focus group interviews. The interviews were performed by two researchers and digitally recorded. Focus group interviews were transcribed thematically, using the four dimensions and steps of clinical reasoning as framework. To ensure trustworthiness, the transcriptions and categories were checked using the original records and field notes. Peer debriefing was used to reflect on the findings and differences were discussed in the research team.

This combined quantitative and qualitative design established in-depth insight into the multidimensional care provided. The results of the quantitative part of the study were recognized by the focus groups participants as a reflection of multidimensional hospice care in daily practice.

Given the rigor of the steps followed both in the quantitative and the qualitative part of the study and the recognition of the quantitative data by the focus group participants, the results of this study are likely to be valid.

Selection bias

We only studied hospices that are a member of the Dutch Association of Hospice Care (chapters 2 and 3). These professional-driven hospices provide multi-professional care. Other Dutch hospices, which are volunteer-driven, make different choices in the provision of professional care. A previous study in Dutch hospices found no differences in basic patient characteristics (age, gender, and diagnosis) between professional- and volunteer-driven hospices.(1) Information about differences in patient symptom experiences was lacking. There were significant differences in care provided, however, with volunteer-driven hospices being less likely to perform medical technical interventions and hospice-units in nursing homes providing more paramedical support. These findings suggest that organizational differences result in differences in care.(1)

Obviously, our results only apply to professional-driven hospices and their admitted patients between 2007 and 2015.

Selection bias was also introduced in the evaluation of the integrated hospice at home service (chapter 4) since it was a single hospice study implemented in a particular local setting. It should be regarded as a pilot study.

Part II The symptoms and well-being of hospice patients

Measurement bias

The Utrecht Symptom Diary (USD), an adapted Dutch translation of the Edmonton Symptom Assessment System (ESAS), was used as a patient reported outcome measure to self-assess the intensity of 11 symptoms and well-being and to prioritize care (chapter 5, 6, and 7). The ESAS is a validated instrument for assessing and monitoring symptoms.(2-5) The USD psychometric properties of the USD are currently under study for use in the hospice population.

The USD is a short and practical clinical tool, easy to administer. Nonetheless:

- The USD only assesses physical and psychological symptoms and thus does not provide a multidimensional assessment.
- The recall period of the USD is 'right now'/ 'at this moment'. As a result, fluctuating symptoms could be underestimated or overestimated, depending on the moment of assessment.(6,7) This may have influenced concordance between patients and nurses (chapter 7).
- The USD contains a one item well-being measure, assessing the level of overall well-being on a numerical scale, ranging from 0= best possible well-being to 10= worst possible well-being. The

well-being measurement is associated with quality of life measures.(8,9) In clinical practice, nurses explained that patients find the well-being item harder to understand than physical symptoms, and error could occur in understanding the direction of the scale.

- For the first USD after admission (chapter 6), the well-being measure was lacking for 78 patients (37%). There were no significant differences in the characteristics of patients with and without a missing well-being item. In addition, a multiple imputation procedure did not alter the results of the analysis. Based on these results, we concluded that the data were missing at random.
- Overall, <10% of the USD items were missing. No imputations were performed (chapters 4 and 5).
- An analysis was performed to address the possible consequences of missing questionnaires; patients who were unable or unwilling to self-report symptom intensity. Of all admitted patients, 72% were able to complete at least one USD. A low performance status and a survival <2 weeks were significantly associated with missing questionnaires.. Furthermore, the proportion of patients >85 years old ($p=0.04$) was higher in patients who did not fill in any diary. Cognitive impairment among elderly patients may have played a role.
- The USD cut-offs, used for categorization purposes, are not well established for most symptoms, except of pain and fatigue. This might have contributed to the low concordance scores.(10)

Despite these shortcomings, many of which are inherent to all patient reported outcomes assessing symptoms, the USD seems to be a reliable and valid instrument for assessing and monitoring the physical and psychological symptom burden of hospice patients.

Selection bias

Selection bias should be taken into account, since the data (chapter 5, 6, and 7) were gathered from a single setting. The hospice under study was a seven-bed professional-driven hospice in the center of the Netherlands. Care and treatment are 24/7 provided by a multi-professional team and trained volunteers.

The application of symptom diaries in daily care was implemented as standard care as well as for research goals from the start of the hospice in 2007. As a result, the team developed skills and competences to improve the use and completion of the USD by the patients and to discuss the results with patients, their family members and the multi-professional team. This is likely to have improved patient compliance.

Since only patients from a single hospice were included, patient selection bias may have played a role. However, the patient characteristics with respect to gender, age, cultural background, marital status, and diagnosis do not differ from described hospice populations.(11) As mentioned previously, patients >85 years old or with a low performance status and a short estimated life expectancy were less able or willing to complete the USD. The influence of age on the symptom burden was found to be minimal. Since symptom intensity is likely to be higher in patients with a low performance status and increases as the patients nears death, this probably implies that the severity of the symptoms of hospice patients is underestimated in our studies.

INTERPRETATION OF THE RESULTS

Essentials of hospice care

Dame Cicely Saunders described the essentials of hospice care: 1) small scaled autonomous units, 2) multidimensional symptom relief, 3) patients and their families, 4) spiritual care for patients and caregivers, 5) admissions for symptom control and terminal care, 6) inpatient and home care, 7) multidisciplinary team and trained volunteers, 8) open and flexible communication (staff, family and caregivers), and 9) education and research.(12)

The Dutch Association of Hospice Care (DAHC) defines hospice care as: 'Multidimensional care for patients in the palliative terminal phase and their loved ones, provided by a multidisciplinary team of formal and informal caregivers, aiming to optimize the quality of life, bereavement and dying. Hospice care is specialized palliative care provided in a hospice facility or at home, provided or supported by a multidisciplinary hospice team.'(13)

Quality standards are essential for optimal hospice care. The PREZO Quality Mark Hospice Care (2014) is a performance oriented quality system.(14) It includes seven domains of quality of life (living, spiritual, social, physical, psychological, dying and aftercare) and four pillars to achieve this (autonomy, individual care-plan, information and communication/safety).

Finally, the national Quality Framework Palliative Care (2017) sets standards for palliative care in general.(15) It focuses on core values and principles, structure and process, the physical, psychological, social and spiritual dimensions, dying, bereavement, cultural issues and legal and ethical issues.

Thus, a variety of themes related to hospice care emerge with regard to:

- structure;
- involvement of professionals and volunteers;
- multidimensional care for both patients and family (including bereavement care);
- symptom relief;
- information and communication;
- education;
- research.

Hospice care in the Netherlands

At the present time, a variety of professional-drive and volunteer-driven hospice care models and initiatives exist in the Netherlands. The results of the study reported in chapter 2 show that many of the themes mentioned above are well recognizable in the core characteristics and aims of professional-driven hospices in the Netherlands. Without exception, these hospices are small-scaled units in which a multidisciplinary professional team together with volunteers aims to provide optimal multidimensional care to patients and their families, supporting the patients in their autonomy and respecting their beliefs and values. Atmosphere and attitude were major themes in all mission statements. The atmosphere was described as home-like, welcoming, and comfortable.

Care and collaboration

Multidimensional care was recognized as a crucial approach by all caregivers. However, the study reported in chapter 3 showed that, at least in the patient notes, most attention was paid to physical symptoms. Whether this reflects a true lack of a multidimensional approach is a matter of assumption. However, interventions with regard to the social dimension were regarded as usual care and only reported when social problems were escalating. Nurses indicated that it was hard to find words to the spiritual dimension and chaplains indicated that documentation of spiritual issues was sometimes seen as a violation of confidentiality. Thus, the focus group interviews suggested that there is room for improvement of multidimensional care provided and its documentation in the patient records. Whether this really leads to better symptom control, should be subject of future studies.

Interdisciplinary collaboration as such was not a primary subject of our research. However, its importance was emphasized by the survey (chapter 2) and the focus group interviews (chapter 3). Obviously, collaboration between doctors, nurses, chaplains, volunteers and other caregivers is essential to provide true multidimensional care. Interdisciplinary collaboration does not come easy. It requires preparedness and willingness to share and cooperate, a common language and continuous attention, not only by all members of the team, but also by the management to support teams in time and to develop competences.(16,17)

We only studied professional-driven hospices. There is an urgent need for clarification of possible differences in the care provided by professional- and volunteer-driven hospices and the consequences this might have for patient selection. However, this discussion should start with an in-depth exploration of patient profiles (diagnosis, palliative trajectory, demographics, consumption of care), expressed problems, needs and wishes.

Assessment tools in hospice practice

In our survey, there was a large variance in the use of assessment tools. They were used systematically by only 50% of the hospices. The use of assessment tools supports the assessment and monitoring of symptoms and thus contributes to a better symptom control.(18-21)

Hospice care at home

Home care by hospice teams is given much less often in The Netherlands than in the United Kingdom. In our survey, 11 hospices (30%) of the professional-driven hospices provided hospice care at home. In view of the high symptom burden of patients at home in the last year of their lives and the results of our pilot study (chapter 4), it seems that more assistance in home care by hospice teams in The Netherlands is both desirable and feasible, primarily to support general practitioners and district nurses.(22,23) Such an approach may improve palliative and terminal care in general practice, and could result in more patients dying at home, which is almost always their preferred place to die.(24)

Education and research

25 hospices (67%) in our survey indicated that they were involved in education. Clearly, there is an important role for hospices to educate general practitioners, district nurses, medical specialists, hospital nurses and other first and second line caregivers with regard to optimal palliative and terminal care.

With regard to research, despite the fact that in our survey 25 hospices (67%) indicated that they were involved in research, it is obvious that to date, little research has been done with regard to hospice care in the Netherlands. In this regard, there is much room for development from small practice-driven studies to solid multi-center research (chapter 2).

Symptoms and well-being

Symptoms

When patients were admitted to our hospice, they suffered from six symptoms concurrently (chapter 5). Fatigue, anorexia and dry mouth were the most prevalent and severe symptoms. The intensity of many symptoms increased towards death, ash was also found by Seow et al. (2011).(8)

Fatigue is often directly related to advanced disease (not necessarily restricted to cancer). One might argue that attempts to treat fatigue in hospice patients are futile. However, fatigue is eminently a multidimensional symptom and a true multidimensional assessment may result in effective treatment. The same might be true for many other symptoms.

The low scores for anxiety in our studies are remarkable. In addition, the relationship of anxiety with well-being (a higher degree of anxiety being related to better well-being) was skewed and difficult to explain (chapter 6). Translational issues may play a role.(3,25) Concurrently to the studies described in this thesis, the patients' and their families' perspective towards anxiety are under study of our research team.(26-29)

The population under study consisted of predominantly cancer patients aged 65 or older. There were few age-related differences with regard to symptom prevalence and intensity (chapter 4). Thus, there is no reason to support a different approach to symptom management for the elderly. In view of the very low proportion of patients with other life-threatening diseases in our studies, no recommendations can be made about symptom management in these patients.

Well-being

We studied well-being as a surrogate for overall quality of life.(9) Patients reported a low degree of well-being. Well-being was predicted by four physical symptoms (fatigue, pain, anorexia and dyspnea) and two psychological symptoms (depressed mood and anxiety). However, we only analyzed physical and psychological symptoms for their influence on well-being. The social and spiritual dimensions were not measured and as a result, not included in the analysis. In the public opinion, 'being a burden to others' was found to be a major public concern in advanced cancer in the Netherlands, followed by 'being alone'.(30) The main social problems documented in palliative home care were excessive load on family caregivers (15%), organization of care (10%) and loneliness (3%).(31) Unmet social problems and spiritual needs are associated with psychological and spiritual distress and decreased quality of life.(32-34) In order to better understand the determinants of well-being an overall quality of life, assessments and future research should include social and spiritual problems.

Concordance of patient and nurse assessment

In hospice care patients nearing death are increasingly unable to self-report their symptoms, which was confirmed by the analysis of missing questionnaires (chapter 5). Patients who did not complete an USD were more often aged ≥85, had more often a low performance status (ECOG=4) and a survival of less than two weeks after admission.

In daily practice, proxy assessments of nurses are the most practical to apply. In our sample nurses tend to underestimate the symptom intensity of their patients (chapter 7). There was no improvement if they knew the patient for a longer period. Studies in other populations show that family caregivers tend to overestimate the symptom intensity of patients, and (as in our study) nurses tend to underestimate the patients' symptom intensity.(35-41)

A combined strategy of nurse's and family caregiver's assessment of the symptom severity, could result in a better estimation, but should be validated in a new study.

Supportive structures

The recently presented Quality Framework for Palliative Care in the Netherlands(42) and the PREZO Quality Mark(42) emphasize the importance of three supportive structures for optimal palliative and/or terminal care:

- an individual care plan;
- a structured way of assessing and treating symptoms;
- the use of measurement tools.

Individual care plan

Every hospice patient has to have an individual care plan within a few days after admission. Care plans support communication between members of the multi-professional team and trained volunteers, and continuity of care. Although care plans were not an object under study in any of the studies in this thesis, they were mentioned by the participants in focus groups as being potentially either supportive or inhibiting. In a hospice, an individual care plan should reflect a multidimensional and multi-professional approach, be easy to administer and be adaptable to fast changing situations. In contrast, home care plans were felt by the participants to be too monodisciplinary and mono-dimensional and nursing home care plans to be much more aimed at long term care and thus both not suitable for use in a hospice.

Palliative reasoning

Palliative reasoning is an adaptation of clinical reasoning in the context of patients with a short life expectancy.(43) The steps of clinical reasoning are assessment, intervention, monitoring and evaluation.(44) The steps of palliative reasoning are: 1) assess the individual situation, 2) summarize the problem and formulate a proactive care plan, 3) evaluate, and 4) adapt the care plan, if necessary. The use of assessment tools is specifically recommended in steps 1 to 3. Compared to clinical reasoning, adaption is mentioned as a separate phase, expecting to result into more attention for a change of treatment, if necessary.(43) We did not study the effect of palliative reasoning directly, but participants in the focus groups indicated that in the hospices where it was used it contributed to multidimensional care (chapter 3). We found that evaluation was rarely mentioned in the notes of individual caregivers. During multidisciplinary team meetings evaluations were noted more often. Using the methodology of palliative reasoning, supported by measurement tools like the USD, might provide more structure and mutual agreement to reach the goal of "tailored treatment to the stated values, wishes and needs of the patient".(15) It is likely this methodology will also contribute to better multidimensional care.

Use of measurement tool and patient reported outcomes

In our studies, we used the Utrecht Symptom Diary, an adopted translation of the Edmonton Symptom Assessment System which has been proven to be a valid and practical patient reported outcome measure in the domain of palliative care.(45)

The USD only entails physical and psychological items and a one item well-being measure. As a result, only physical and psychological symptoms could be described. In hospice care, the social and spiritual dimensions are of the upmost importance and may receive limited attention (chapter 3). Therefore, the core items of the USD will be complemented in the future with social and spiritual items.
Internationally, several studies show that the use of measurement tools improves clinical practice (19,46-48) In the focus group interviews, the participants indicated that the use of tools facilitated multidimensional care (chapter 2). Both the Quality Mark Hospice Care(14) and the Quality Framework Palliative Care the Netherlands(15), recommend the use of tools. Nevertheless, tools were only used in 50% of the hospices in our sample (chapter 2), indicating that the use of tools is not living to its full potential.

Two main arguments were discussed in the focus groups for not using tools:

- the use of tools is in contrast to the compassionate character of hospice care, and
- information can as well (or better) be obtained in discussions with patients.

However, teams who did use instruments specified that it supported their communication with their patients, empowered patients to express what matters to them most, enabled a rapid assessment and focus, supported inter-professional communication, and ameliorated clinical and shared decision making (chapter 3). Nurses appreciated the value of tools to support the identification of new symptoms and needs and to follow their severity during the hospice admission. They expressed their responsibility in assessing and monitoring symptoms and informing other professionals to improve symptom management. The multi-symptomatology of hospice patients and the multidimensional character of symptoms experienced, make a clear assessment difficult (chapter 4, 5, and 6). The USD supports caregivers to systematically assess the physical and psychological symptoms experienced. However, it takes commitment of the multi-professional team to implement the use of tools successfully (chapter 3). Tools should never be considered an aim in itself, but a basis for communication with the patient, his family and other members of the multi-professional team. In addition, symptom scores collected by the USD can be used to evaluate the effect of interventions, supporting clinical decision making. Finally, Patient Reported Outcomes, like the USD, can be used to assess the quality of care on a routine basis.(49) However, before PROMs can be used as a quality indicator, population specific numerator and denominators have to be established in future studies.

Research in the domain of hospice care

Research is relatively new and unknown in the Dutch hospice domain. Empirical evidence concerning the outcomes of hospice care in the Netherlands and the needs and wishes of patients is scarce but nonetheless needed, if care is to be improved and quality standards are to be met.

Barriers for research in hospice patients

Hospice patients are a population of very ill, frail, and often elderly patients. It is difficult to accrue patients, resulting in studies not started or discontinued prematurely and/or studies with limited power. For longitudinal studies a high drop-out rate may be expected.

Conducting studies in this vulnerable population is often considered too burdensome for those patients. Gatekeeping is a protective mechanism where "others" e.g. professionals or family members, decide not to inform patients about the possibility of participating in a study, because they feel it is too great a burden for the patient.(50) Gatekeeping is a known problem in research in fragile populations, resulting in limited accrual.(51,52) Gatekeeping by hospice management or by medical ethical committees may also play a role.

Obviously, gatekeeping is at odds with patient autonomy, except perhaps for very frail and/or cognitively impaired patients. Collaboration between researchers, caregivers, patients and their families, hospice management and medical ethical committees is essential to find the right balance between protecting patients and reaping the benefits of research in hospice patients.

The ethical committee of the UMCU challenged us to find the least burdensome strategies for consent procedures and data collection. As a key issue in communication about participation in our research, we complemented the information about clinical care provided by nurses with information about research. Measurements aimed to support daily clinical practice, in particular the data of the Utrecht Symptom Diaries, were also used for research purposes.(53-55)

All patients, except patients with a mental disorder (dementia, psychiatric diagnosis) received information about the use of their anonymized clinical data for research purposes by the nursing team in the first 48 hours after admission. Initially an opt-out procedure was used, where patients were informed about the study and could choose not to participate.(56,57) The information about the opt-out procedure was part of the admission process and included in the admission checklist. If patients opted out, this was noted in the records. Before entering data in the database, researchers checked if the information and disconsent was checked.

Over the years, the opt-out procedure was under discussion. On the one hand, it is a simple procedure in general practice aimed to enroll an optimal number of patients in a study. On the other hand, it cannot be checked by the researcher whether patients are informed. Therefore, in 2014 the procedure was altered into a consent procedure ('opt-in'). Consent was noted on a separate form in the patient file. A year later, from June 2015, the affirmation of consent by a digital signature was implemented, integrated in the USD e-health application.

In the HaHo study (chapter 4) the opt-out procedure was used. The coordinating nurses provided information about the study and the opt-out possibility when patients were introduced to the service. If patients opted out, this was noted in the patient record.

Due to the initial use of the opt-out procedure and the academic assignment in the hospice under study, gatekeeping was probably not a large problem in patient accrual. However, it could have affected the use of assessment tools in the ill and very old, although gathering of these data were part of standard care.

For this thesis we performed retrospective studies, using patient related outcome data collected during daily care. As a result, we were able to collect a large amount of data without burdening patients and families. This makes observational studies using data collected in daily care in this frail and vulnerable population possible. Future studies will have to include a consent procedure.
Observational studies requiring data not routinely collected during daily care, and certainly interventional studies will put more burden on the patients and caregivers. Thus, there are many barriers for research in hospice care patients. There are a number of vital requirements:

- Communication skills and competences and, in particular, motivation of nurses and doctors regarding the introduction of studies;
- Clear and practical consent procedures;
- With regard to design: short-term studies, easily measurable endpoints and simple interventions.
- Motivation of hospice management and medical ethical committees;
- Finances and an adequate infrastructure for performing research;
- Involvement of statisticians;
- Collaboration of hospices in order to perfom multi-hospice studies.

National Palliative Care Program

The ZonMw National Palliative Care Program (NPCP) aims "to achieve a noticeable improvement in palliative care for patients and their families, with collaboration, identification and stimulation as the keywords: collaboration where possible and necessary, identification of what is going well or could be done better, and stimulation of new initiatives."(58,59) The joint mission is described as "to take palliative care in the Netherlands to another level by 2020" which perfectly matches the objectives of this thesis: to contribute to a collaborative program to take hospice care to another, more patient-oriented and future-proof level.(58-60)

The NCPC defined goals based on the NCPC matrix, which includes three activities: 'research', 'training' and 'care practice', as well as four themes (see figure 1):

1 Awareness and culture:
  - Public awareness of palliative care to be enhanced and it should become normal to consider the end of life;
  - Awareness of palliative care among care providers to be enhanced and it should become normal to consider the question of whether treatment should be continued.
2 Organization and continuity of care:
  - More people able to die at the place of their choosing (generally at home);
  - Care arranged as close to home as possible, and primary and secondary care to be more joined up;
  - Palliative care to be part of regular healthcare provision, and to be better coordinated with care services for the elderly and the welfare sector, for example;
  - Specialist and multidisciplinary knowledge to be made available quickly, with more consideration of the social and spiritual dimensions during the palliative phase.
3 Care innovations and standards:
  - Standards of palliative care to have improved;
  - Everyone working in care to have a good basic knowledge of palliative care (including the social and spiritual dimensions);
  - Fewer people to suffer unnecessary pain and respiratory distress as they die.
4 Patient participation and support:
  - The needs and wishes of people in the final phase of life and their families are to be the key focus. People in the final phase of life, including special groups, to be more involved as a partner in palliative treatment;
  - Informal carers to suffer overload less frequently;
  - Deployment of trained volunteers in the final phase of life to be possible in all places where people spend their final weeks.(58)

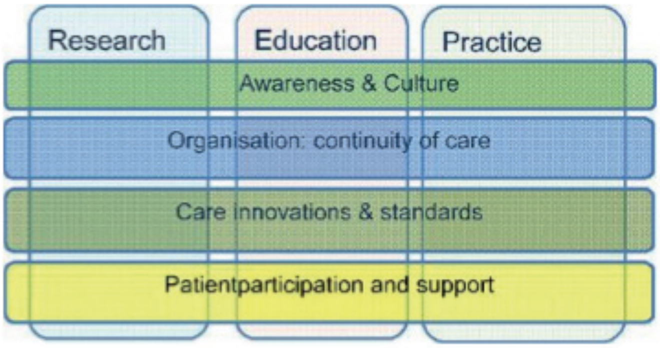

Figure 1. Matrix National Palliative Care Program(58)

The studies described in this thesis have contributed to many of these themes:

- Increased awareness of hospice care in all of its varieties: last resort, crisis management, respite care, and assistance in home care (awareness & culture, organization, and continuity of care)
- Importance of Multidimensional Care (care innovations & standards)
- Use of (care innovations & standards, patient participation and support):
  - Patient Reported Outcome Measures, such as the Utrecht Symptom Dairy (USD);
  - Proxy measures (families and nurses) if the patient is unable or unwilling to complete the USD;
  - Structural assessment using the methodology of palliative reasoning.

TO CONCLUDE

Patients in the terminal phase of life are an important target group in palliative care. Appropriate high-quality care, avoiding overtreatment as well as undertreatment, and finally dying in the preferred place, sometimes a hospice, is essential. This is underpinned by the Quality Mark Hospice Care(14) and the Quality Framework Palliative Care.(15) The overall objective of this thesis was to explore the hospice care concept from a provider and caregiver perspective. Moreover, we aimed to get a deeper understanding of hospice patients' symptom burden and well-being as a patient reported outcome of multidimensional hospice care.

Implementation of the concept of hospice care is still work in progress. Our results show the importance of further development of services, staffing and competencies in order to deliver solid multidimensional care with balanced and structured attention for physical, psychological, social, and spiritual needs and priorities of patients and their families.

The use of the Utrecht Symptom Diary questionnaire as a patient reported outcome measure, supports vulnerable patients of all ages receiving hospice care in a hospice or at home. Implementation of a stepwise approach for systematic assessment and monitoring creates opportunities to ameliorate the quality of multidimensional hospice care. The results of multidimensional assessment of symptoms should structurally be discussed with patients to explore their meaning, and identify the priority of patients, to provide optimal patient directed care. Caregivers should be aware of the likelihood of their underestimation of symptom intensity, in particular for symptoms that are difficult to observe.

To ensure high quality hospice care in a hospice or at home, more insight is needed into patient characteristics, patient profiles of symptoms, needs and wishes as well as into the effects of the multidimensional approach and implementation of palliative reasoning and evidence based guidelines. The collection of routine care data could be of tremendous help as well as a structural participation of patient delegates in the design of research projects. The long way ahead asks for national collaborative studies and a shared responsibility for further development of the concept and practice of hospice care. Hospice care will be studied further in collaboration with the umbrella organizations and professionals involved in hospice care in the HOPEVOL project, which aims to give shape to appropriate hospice care optimizing the quality of life of all patients at the preferred location.

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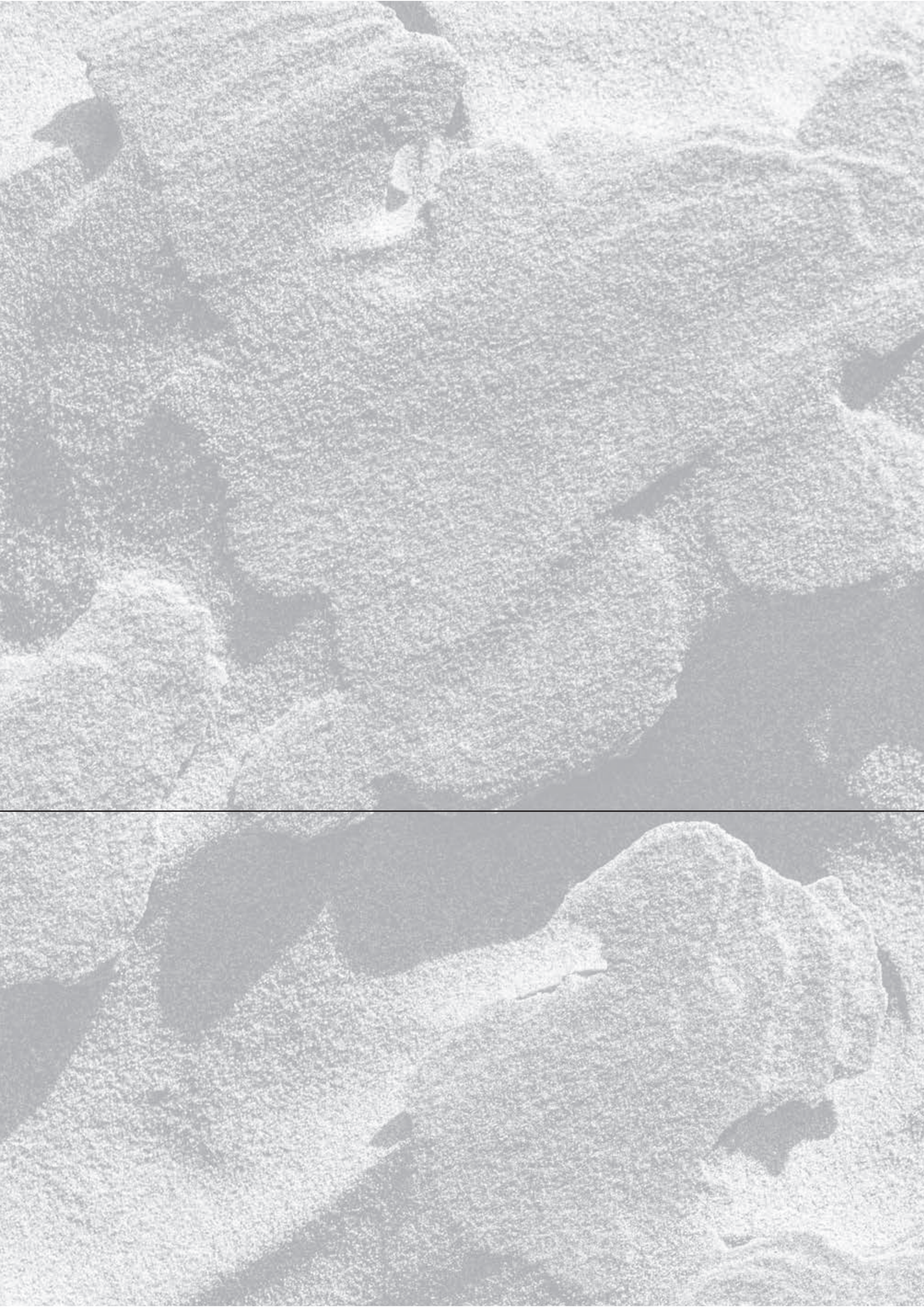
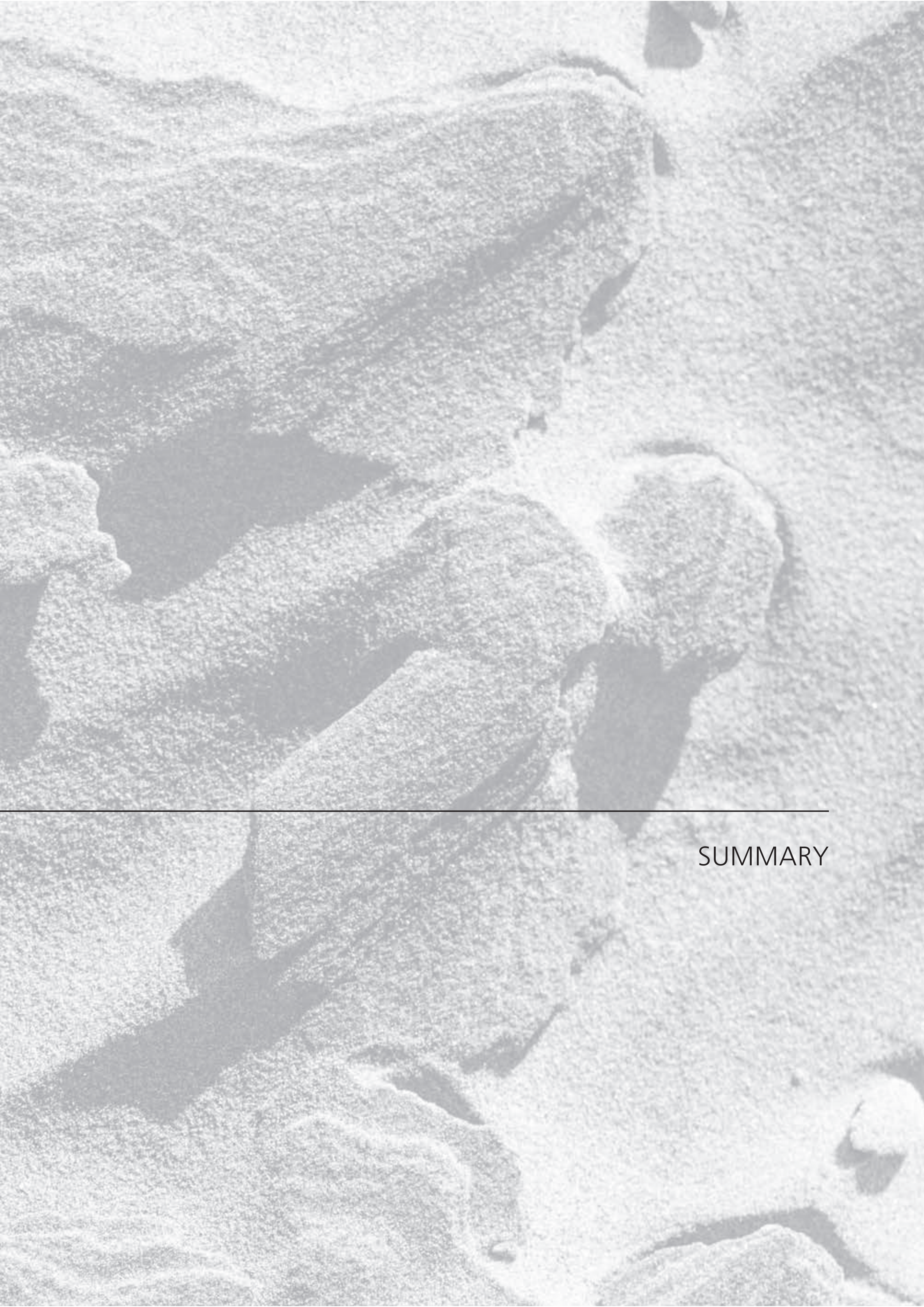




SUMMARY

Hospice care aims to optimize the quality of life of patients with a life-limiting illness and their families. Hospice care in the Netherlands has a relatively short history. Hospices were initiated by the gradually increasing belief over the years that care for the dying should be improved and de-medicalized. Two organizational structures can be distinguished: volunteer-driven hospices and professional-driven hospices, the latter being either stand-alone hospices or hospice-units in a nursing home. Referral to a hospice is usually based on availability and location. However, the type of hospice was found to make a difference for the treatment and interventions provided. Appropriate care is a fit between the needs and preferences of patients and the care and treatment provided. Patients with a life expectancy of <3 months have access to hospice care, and thus there is a large and heterogenic population. The differences in hospice care should fit the needs of patients admitted. There is little insight into hospice care and patients and their symptoms and preferences.

The aim of this thesis is twofold: to explore hospice care in the Netherlands and to gain insight into hospice patients' symptoms and well-being.

The following research questions were formulated:

Part I. Exploration of hospice care in the Netherlands

1 What are the main characteristics of hospice care in the Netherlands, and how are these characteristics operationalized in daily practice?

2 How is multidimensional care provided for hospice inpatients by the multidisciplinary hospice team?

  a How are the physical, psychological, social, and spiritual dimensions described in the patient notes by nurses, physicians, and other caregivers and in the minutes of the multi-professional team meetings?

  b How do members of the multi-professional team reflect on the multidimensional hospice care described and provided?

3 Does hospice assistance at home empower patients in the last year of their life and their relatives at home to express end-of-life preferences and to die in their preferred location? Second, what are the symptom burden and (in)stability of these patients and how can they be identified?

Part II. Symptom burden and well-being of hospice patients

4 What is the symptom burden of hospice patients and how does age influence symptom prevalence and intensity?

5 Which symptoms predict the state of well-being of cancer patients admitted to a hospice?

6 What is the concordance between patients' and nurses' assessments of symptom intensity and does it improve over time after admission?

Part I. Exploration of hospice care in the Netherlands

Chapter 2 describes the exploration of hospice care from a provider perspective. A survey was sent to the 42 members of the Dutch Association of Hospice Care (DAHC), of which 36 responded. These hospices had an average of 7.5 beds and almost 11.5 years of experience. Six core characteristics were identified:

1. Patients with an estimated life expectancy of <3 months have access to hospice care. Hospices described their patients in terms of "being in the terminal (palliative) phase" and/or as "patients with advanced illness".
2. In addition to patients, their families were explicitly described as a unit of care.
3. All hospices provided inpatient care. Admitted patients usually stayed until death (last resort care). Respite care and unplanned admissions for crises were provided by 25/36 (70%) and 16/36 hospices (44%), respectively. Three hospices (8%) provided day-care and extended home care was provided by 11/36 hospices (31%).
4. Care was provided by a multi-professional team consisting of professionals (nurses and physicians) and trained volunteers. Chaplains were included in the core team in 28/36 (78%) hospices; three hospices made use of psychologists and two hospices had a social worker instead of a chaplain.
5. Hospice care was described as multidimensional, addressing the physical as well as the psychological, social and spiritual dimensions, and as personalized care, based on the needs and wishes of patients and their families. The multidimensional assessment of patient needs was based predominantly on expert opinion, supported by tools in 18/36 hospices (50%). Eleven hospices (31%) used tools to assess the burden of care on family caregivers.
6. Atmosphere and attitude were major themes in the mission statements. The atmosphere was described as home-like, welcoming, and comfortable. Professionals and volunteers were expected to respect all patients, regardless of their social, cultural or spiritual background. Patients were treated as equals and staff had to respect the patients' privacy.

In **chapter 3**, multidimensional care, provided to hospice inpatients by a multi-professional team was explored, and facilitators were identified, by means of a convenience sample of 12 hospices, all members of the Dutch Association of Hospice Care.

A quantitative study of 36 patient records (3 patient records per hospice) was carried out first. The outcomes were 1) multidimensional care (MC), assessed on the basis of the frequency of the descriptions of the physical, psychological, social, and spiritual dimensions in patient records, 2) the description of the steps of clinical reasoning: assessment, pharmacological and non-pharmacological interventions, monitoring and evaluation, and 3) the use of assessment tools used during hospice stay. Second, MC was qualitatively explored using semi-structured focus group interviews with multi-professional hospice teams.

In total, the records of 36 patients (64% male, mean age 71, and admitted for 43 days on average) were included. Nurses were responsible for 76% of the descriptions in the records. The majority of the notes dealt with physical problems (70% of the notes by physicians and 62% of the notes by nurses). Participating nurses and physicians specified that physical symptoms were easy to spot and to discuss and that they were trained primarily to address physical problems. Of the minutes from the multi-professional team meetings (MTM), 49% dealt with the physical, 20% with the psychological, 15% with the social, and 16% with the spiritual dimension. The lack of documentation on spiritual issues was influenced by chaplains who felt that documentation would interfere with their position as the patients' confidential refuge. Furthermore, nurses explained that they lacked the vocabulary to report on spiritual issues in the patient records.

The steps of clinical reasoning were recognized in the patients' records. Nurses devoted most of their notes to monitoring symptoms and problems. Of all parts of clinical reasoning, the evaluation of interventions was described the least in the records. Participants in the focus groups explained that evaluation was easily forgotten or overlooked during busy shifts. In addition, evaluations were underreported since many evaluations took place verbally and were not documented.
Assessment tools were used in 10/12 hospices, 4/10 systematically and 6/10 ad hoc. Tools used in daily care were the distress thermometer (N=2), the Utrecht Symptom Diary (USD), a Dutch adapted translation of the Edmonton Symptom Assessment Scale (N=4), and the Liverpool Care Pathway for the Dying (N=2). Other tools were used to support a further exploration of specific problems, such as delirium, mouth problems, and pain. Professionals who used tools felt that tools supported both conversations with patients and communication with other professionals.

Participants in the focus group interviews indicated that the adoption of the steps of clinical reasoning, supported by structure in care plans, and the use of assessment tools resulted in better communication, better interdisciplinary collaboration and higher levels of multi-dimensional care provided by all members of the multi-professional team.

In **chapter 4**, an innovative combined outpatient and consultation initiative for home-dwelling palliative care patients was evaluated. The hypothesis was that this hospice assist at home (HaHo) service, which integrates specialized palliative care with general palliative care in primary care, would empower patients and their loved ones and allow patients to die at their preferred location. The HaHo service is a collaboration between GPs, district nurses, trained volunteers, and a hospice team. The HaHo service consisted of 1) a GP-initiated consultation by hospice nurses, 2) interdisciplinary consultations every two weeks, 3) a 24/7 hospice backup for patients, caregivers, and professionals, and 4) a central caregiver responsible for coordinating the care for each patient. The HaHo service was retrospectively evaluated, using documentation developed specifically for this service. The primary outcome was death at the preferred location; secondary outcomes were stability, symptom burden, and early identification.

Between June 2012 and December 2014, 130 home-dwelling patients with an estimated life expectancy of <1 year were registered for the HaHo service (62 (48%) men, mean age 72). During the study period, 107/130 died, and 5 patients dropped out. The average survival from the time of registration was 59.5 days (range 0-671).

The preferred place of death was known for 122/130 patients, and 91% of these patients died in their preferred location. On referral, patients suffered from six symptoms concurrently, of which four were clinically relevant, scoring >3 on the USD. Fatigue was the most prevalent symptom in 94% of patients. Other highly prevalent symptoms were anorexia (74%) and pain (70%). The most severe symptoms were fatigue, anorexia, and dry mouth. Scores for unwell-being were high (mean score 4.97 (SD: 2.429)), indicating a poor quality of life. 11 patients were in crisis when they were referred to HaHo. Only 18 patients (14%) were in a stable condition.

The HaHo service was able to support patients to be able to die at their preferred location. Collaboration of hospices in their local community may optimize palliative care provided at home.

Part II. The symptom burden and well-being of hospice patients

In the second part of this thesis, symptoms and well-being of hospice patients are described. For these studies symptom diaries were completed by hospice patients. The Utrecht Symptom Diary (USD) is an adapted Dutch translation of the Edmonton Symptom Assessment System (ESAS), a frequently used and validated international questionnaire. The USD contains 11 symptoms, and one item on well-being, scored on a range of 0=no symptom/highest degree of well-being to 10=worst possible symptom/lowest degree of well-being. Patients usually complete the USD twice a week, but sometimes more often, if necessary. Completing the USD is considered standard care.

For the first study on the symptom burden of hospice patients (**chapter 5**), differences between age groups were analyzed. A retrospective observational study was performed of patients who were admitted to an inpatient hospice facility between June 2007 and June 2013, using prospectively collected data from symptom diaries. The first USD, collected in the first week after admission in 227/342 patients admitted from June 2007 to December 2013, was used for this analysis. Four age groups were created (<65, 65-74, 75-84 and ≥85 years) to enable comparison. In the first week after admission, patients suffered from six symptoms concurrently. The scores for unwell-being were high (mean score 4.3) reflecting a poor quality of life. Fatigue, dry mouths, and anorexia were the most prevalent and intense symptoms. Pain had a significant higher prevalence in patients younger than 65 years and their pain was more severe than that of older patients. In contrast, anorexia occurred most often in patients ≥85 years. The scores for (un)well-being did not differ significantly between the age groups. The study demonstrated the high symptom burden of hospice patients. For most symptoms, there were no significant differences related to age.

In **chapter 6**, we analyzed which symptoms predict the quality of life (defined as the degree of well-being as measured in the USD) of cancer patients at admission to a hospice and during their stay. We used a retrospective multimethod approach, consisting of 1) a cross-sectional analysis using linear regression analysis and 2) a longitudinal analysis using a generalized estimated equation analysis. We adjusted for age, gender, marital status and survival since these are known confounders. At admission, an increasing severity of fatigue, depressed mood, and anorexia led to the worsening of well-being. These symptoms together predicted almost half of the variance of well-being. The longitudinal analysis showed that four physical symptoms (fatigue, pain, anorexia and dyspnea) and two psychological symptoms (depressed mood and anxiety), were independent predictors of well-being. A higher intensity of fatigue, depressed mood, anorexia, pain, and dyspnea were associated with lower degrees of well-being. For anxiety, the relation was reversed: higher degrees of anxiety were related to a higher degree of well-being. The study showed that fatigue was the most important predictor for well-being, followed by anorexia, pain, dyspnea, depressed mood, and anxiety. The reverse relation between anxiety and well-being is difficult to explain. The large floor effect of the anxiety scores, with most patients scoring very low, may be an explanation.

Although the patient's self-report is the gold standard for assessing symptom prevalence and intensity, not all hospice patients are able or willing to complete a symptom diary. In those cases, nurses may be a practical proxy for symptom monitoring. In **chapter 7**, we studied the concordance between hospice patients' and nurses' assessments of symptom intensity, using dyads of patients and nurses' symptom intensity scores. An adapted version of the USD was developed in collaboration with hospice nurses, the USD professional (USD-P). The USD-P entails the original USD items, assessed on a 5-point verbal rating scale (0=no symptom to 4=overwhelming symptoms). Well-being is measured on a 0 – 10 numerical scale (0=best possible to 10=worst possible) in accordance with the USD. For each patient, the first dyad of paired USD and USD-P measures per week for the first three weeks after admission was selected. In total 147 patients were included, of whom 45 had dyads for all three weeks. A USD-P was completed by 21 nurses during daily care. Fatigue, dry mouth, and anorexia were the most prevalent and severe symptoms, according to both patients and nurses. Nurses predominantly underestimated symptom intensity. The complete concordance was over 60% on average for nausea, anxiety, and dysphagia. For dyspnea and depressed mood, complete concordance was between 50% and 60%. Concordance was lowest for dry mouth, constipation, and anorexia. The least severe symptoms (nausea, anxiety and dysphagia) showed the highest complete concordance. Complete concordance did not improve over time during admission. Agreement beyond chance (concordance corrected to account for chance) was moderate for dyspnea, fair for anorexia, fatigue, nausea, and pain, and low for anxiety. Agreement beyond chance did not improve over time. The agreement beyond chance of well-being was poor and stable over time.

At the start of the study we hypothesized that nurses would be able to learn from the patients' experience and that concordance would improve over time, but the study showed that they tend to underestimate the patient's symptom intensity of patients and that this does not improve over time.

CONCLUSION

We found that the implementation of the concept of hospice care is still work in progress. Our results show the importance of further development of services, staffing and competencies in order to deliver solid multidimensional care with balanced and structured attention for physical, psychological, social and spiritual needs and priorities of patients and their families.

The use of the Utrecht Symptom Diary questionnaire as a patient reported outcome measure, supports vulnerable patients of all ages receiving hospice care in a hospice or at home. Implementation of a stepwise approach for systematic assessment and monitoring creates opportunities to ameliorate the quality of multidimensional hospice care. The results of a multidimensional assessment of symptoms should structurally be discussed with patients to explore their meaning, and identify the priority of patients, to provide optimal patient directed care. Caregivers should be aware of the likelihood of their underestimation of symptom intensity, in particular for symptoms that are difficult to observe.

To ensure high quality hospice care in a hospice or at home, more insight is needed into patient characteristics, patient profiles of symptoms, needs and wishes as well as into the effects of the multidimensional approach and implementation of palliative reasoning and evidence based guidelines. The collection of routine care data could be of tremendous help as well as a structural participation of patient delegates in the design of research projects. The long way ahead asks for national collaborative studies and a shared responsibility for further development of the concept and practice of hospice care.

NEDERLANDSE SAMENVATTING

Hospice zorg heeft als doel het optimaliseren van de kwaliteit van leven van patiënten met een levensbedreigende ziekte en hun naasten. In Nederland heeft hospicezorg een betrekkelijk jonge historie. Hospices werden geïnitieerd door mensen die overtuigd waren dat de zorg aan stervenden beter moest en gedemedicaliseerd moest worden.

Er wordt onderscheid gemaakt tussen bijna-thuis-huizen en hospices. In bijna-thuis-huizen werken hoofdzakelijk vrijwilligers. Wanneer nodig, verleent de huisarts en de wijkverpleegkundige professionele ondersteuning. Daarnaast zijn er hospices waar verpleegkundigen continu aanwezig zijn. Het gaat daarbij meestal om zelfstandige hospices met een eigen verpleegkundige staf (de high care hospices) of soms om hospice-units, die onderdeel zijn van een verpleeg- of verzorgingshuis. De keuze voor een hospice is meestal gebaseerd op basis van beschikbaarheid en locatie. Echter, onderzoek laat zien dat er verschillen zijn in behandeling tussen bijna-thuis-huizen, high care hospices en hospice-units. Patiënten met een levensverwachting van minder dan drie maanden komen in aanmerking voor hospicezorg. Hospicezorg moet passen bij de klachten en behoeften van patiënten. Inzicht in de zorg die geboden wordt aan hospice-patiënten en hun symptomen en behoeften ontbreekt.

Het doel van dit proefschrift is tweeledig: het exploreren van hospicezorg in Nederland en inzicht krijgen in de symptomen en het welbevinden van hospice-patiënten. In dit proefschrift staan zes onderzoeksvragen centraal:

Deel I. Verkenning van de hospicezorg in Nederland

1 Wat zijn de hoofdkenmerken van hospicezorg in Nederland, en hoe zijn deze geoperationaliseerd in de dagelijkse praktijk?

2 Hoe wordt multidimensionele zorg verleend aan hospice-patiënten door multidisciplinair teams?
  - Hoe zijn de fysieke, psychologische, sociale en spirituele dimensies beschreven in de rapportage van verpleegkundigen, artsen, geestelijk verzorgers en andere zorgverleners en in de rapportage van het multidisciplinair overleg?
  - Hoe reflecteren leden van het multidisciplinaire team op de multidimensionele zorg zoals die beschreven wordt in de patiëntendossiers en verleend wordt in hospices?

3 Draagt de integratie van hospicezorg in de eerste lijn bij aan het ondersteunen van patiënten met een levensverwachting van minder dan een jaar en hun naasten, aan het uiten van de voorkeurslokatie van overlijden en aan het overlijden op die locatie van hun voorkeur? En verder: wat is hun symptoomlast en de stabiliteit en hoe kunnen zij geïdentificeerd worden?

Deel II. Symptoomlijden, welbevinden en behoeften van hospice-patiënten

4 Wat is de symptoomlast van hospice-patiënten en hoe beïnvloedt leeftijd de prevalentie (het voorkomen) en de intensiteit van hun symptomen?

5 Welke symptomen zijn voorspellend voor de mate van welbevinden van patiënten met kanker in een hospice?

6 Wat is de overeenkomst tussen de ernst van symptomen, ervaren door hospice-patiënten, en de ernst, geschat door verpleegkundigen werkzaam in een hospice, in de eerste week na opname en verbetert het in de loop van de tijd?

Deel I. Verkenning van de hospicezorg in Nederland

Hoofdstuk 2 beschrijft de verkenning van de hospicezorg vanuit het perspectief van de aanbieders er. Een enquête werd gemaild naar 42 leden van de Associatie Hospicezorg Nederland (AHzN), van wie er 36 reageerden. Deze hospices hadden gemiddeld 7,5 bedden en bijna 11,5 jaar ervaring in het verlenen van hospicezorg.

Zes kernkenmerken werden geïdentificeerd:

1 Hospicezorg wordt geboden aan patiënten met een levensverwachting van minder dan 3 maanden. Hospices beschrijven hun patiënten in termen van: ‘in de (palliatief) terminale fase’ of als ‘patiënten met ver voortgeschreden ziekte’

2 Zorg wordt niet alleen geboden aan patiënten, maar ook aan hun naasten.

3 Patiënten worden meestal opgenomen om tot het overlijden in het hospice te blijven. De hospices verlenen echter ook respijtzorg (70% van de hospices), korte opnames voor crisismanagement (44%), dagzorg (8%) en thuiszorg (31%).

4 Zorg wordt geboden door een multidisciplinair team van professionals (verpleegkundigen en artsen) en geschoolde vrijwilligers. Geestelijk verzorgers maakten deel uit van het kernteam in 28 hospices (78%); drie hospices hebben gekozen voor een psycholoog en twee anderen voor maatschappelijk werkers in plaats van een geestelijk verzorger.

5 Hospicezorg werd beschreven als multidimensionele zorg, met aandacht voor zowel de lichamelijke als voor de psychische, sociale en spirituele dimensie, en als gepersonaliseerde zorg, gebaseerd op de behoeften en wensen van patiënten en hun naasten. Om inzicht te krijgen in de multidimensionele behoeften en klachten van patiënten, vertrouwen zorgverleners veelal op de eigen inschatting. In 18 hospices (50%) werd gebruik gemaakt van meetinstrumenten. Elf hospices (31%) gebruikten instrumenten om de belasting van mantelzorgers inzichtelijk te maken.

6 Atmosfeer en attitude werden als belangrijke kernwaarden genoemd. De atmosfeer in een hospice werd beschreven als huiselijk, gastvrij en comfortabel. Zorgverleners werden geacht om alle patiënten te respecteren, onafhankelijk van hun sociale, culturele of spirituele achtergrond. Patiënten werden behandeld als gelijken, met respect voor hun privacy.

In **hoofdstuk 3** werd multidimensionele zorg onderzocht, zoals die verleend aan hospice patiënten door een multidisciplinair team, en werden beïnvloedende factoren geïdentificeerd. Hierbij werd gebruik gemaakt van een steekproef van 12 hospices, allen leden van de Associatie Hospicezorg Nederland.

Eerste werd een kwantitatief dossieronderzoek uitgevoerd De primaire uitkomsten waren 1) multidimensionele zorg, geoperationaliseerd als de frequentie waarin de fysieke, psychologische, sociale en spirituele dimensies werden beschreven in het patiëntendossier, 2) de stappen van klinisch redeneren: beoordeling van de problematiek, medicamenteuze en niet-medicamenteuze behandeling, vervolgen en evalueren en 3) het gebruik van meetinstrumenten gedurende de opname in het hospice. Vervolgens werd multidimensionele zorg kwalitatief onderzocht in semigestructureerde focusgroep interviews met multidisciplinaire hospice-teams.

In totaal werden de dossiers van 36 patiënten (64% man, gemiddeld 71 jaar) bestudeerd (drie per hospice), die gemiddeld 43 dagen waren opgenomen in het hospice. Verpleegkundigen waren verantwoordelijk voor 76% van de notities in de patiëntendossiers. De meerderheid van de notities beschreven lichamelijke problemen (70% van de notities van de artsen en 62% van die van de verpleegkundigen). Verpleegkundigen en artsen gaven aan dat lichamelijke symptomen eenvoudig te identificeren en te bespreken zijn en dat zij primair opgeleid zijn om om te gaan met lichamelijke problemen. De verslagen van het multidisciplinair overleg gingen voor 49% over de lichamelijke dimensie, 20% over de psychologische dimensie, 15% over de sociale dimensie en 16% over de spirituele dimensie. Het gebruik aan documentatie van problemen op spiritueel gebied werd gedeeltelijk verklaard doordat geestelijk verzorgers aangaven dat het ging om vertrouwelijke informatie die niet in het dossier kon worden vermeld. Daarnaast gaven verpleegkundigen aan dat zij moeite hebben met het vinden van de juiste woorden om dit te beschrijven.

De stappen van klinisch redeneren waren herkenbaar in de dossiers. Verpleegkundigen beschrijven vooral over het beloop van klachten en problemen. Van alle stappen van klinisch redeneren, werd het minst geschreven over het evalueren. Deelnemers aan focusgroepen gaven aan dat evaluatie er nogal eens bij inschoot in de drukte van alledag. Daarnaast vonden evaluaties wel degelijk plaats, maar werden niet gedocumenteerd..

Meetinstrumenten werden in 10 van de 12 hospices, waarbij maar vier hospices deze systematisch toepasten in de zorgverlening. Het Utrecht Symptoom Dagboek (vier hospices), een aangepaste Nederlandse vertaling van de Edmonton Symptom Assessment System (ESAS), de lastmeter (twee hospices) en het Zorgpad Stervensfase (2 hospices) werden structureel gebruikt. Andere meetinstrumenten werden in voorkomende gevallen bij specifieke problemen gebruikt, zoals een delier, mondproblemen of pijn. Professionals die meetinstrumenten gebruiken gaven aan dat meetinstrumenten hen ondersteunden in de communicatie met patiënten en zorgverleners.

Deelnemers aan de focusgroepen gaven aan dat de methode van het klinisch redeneren, ondersteund door de structuur van zorgplannen en het gebruik van meetinstrumenten bijdroeg aan een betere communicatie en interdisciplinaire samenwerking en aan de integratie van multidimensionele zorg, verleend door alle leden van het multidisciplinaire team.

In **hoofdstuk 4** wordt een innovatieve vorm van samenwerking (HospiceThuis) tussen een hospice en zorgverleners in de eerste lijn geëvalueerd. De veronderstelling was dat een integratie van specialistische en generalistische palliatieve zorg in de thuissituatie patiënten en hun naasten in staat zou stellen om hun voorkeurslocatie van overlijden duidelijk te maken en daar te overlijden. Het HospiceThuis initiatief bestond uit 1) consultatie van de huisarts door een senior hospiceverpleegkundige, 2) interdisciplinaire overleg in de eerste lijn (in aanwezigheid van huisartsen, wijkverpleegkundigen, geschoolde vrijwilligers en senior hospiceverpleegkundige) elke twee weken, 3) 24/7 back-up vanuit het hospice voor patiënten, naasten en zorgverleners en 4) een centrale zorgverlener, door de patiënt en naasten bepaald, die de coördinatie van zorg op zicht nam. HospiceThuis werd retrospectief geëvalueerd, gebruik makend van de documentatie die voor HospiceThuis werd bijgehouden. De belangrijkste uitkomst was overlijden op de voorkeurslokatie. Daarnaast werden symptoomlast, stabiliteit en vroegtijdige identificatie meegenomen als uitkomsten van de evaluatie.

Van juni 2012 tot december 2014 werden 130 thuiswonende patiënten met een levensverwachting van minder dan een jaar in het HospiceThuis register opgenomen (62 mannen (48%), gemiddeld 72 jaar). Tijdens de studieperiode overleden 107/130 patiënten en 5 patiënten werden niet vervolgd. De gemiddelde overleving vanaf het moment van registratie bedroeg 59,5 dagen (range 0-671 dagen).

De voorkeurslocatie was voor 122/130 personen bekend en 91% van deze patiënten overleed op de voorkeurslocatie. Bij verwijzing naar HospiceThuis ervoeren patiënten zes symptomen tegelijkertijd, waarvan vier symptomen hoger dan 3 werden gescoord in het USD. Vermoeidheid kwam bij de meeste patiënten (94%) voor. Andere veel voorkomende symptomen waren verminderde eetlust (74%) en pijn (70%). De ernstigste klachten waren vermoeidheid, verminderde eetlust en droge mond. Patiënten ervoeren een aanzienlijke mate van onwelbevinden dat (op een schaal van 0 tot 10) gemiddeld bijna 5 scoorde op het USD en een uiting is van een verminderde kwaliteit van leven. Wanneer patiënten werden aangemeld bij HospiceThuis was 11% in een crisis en slechts 18 patiënten (14%) werden als stabiel gekenmerkt.

Concluderend lijkt HospiceThuis mensen te ondersteunen om op hun voorkeurslocatie te overlijden. Samenwerking tussen hospices en lokale zorgverleners in de eerste lijn, lijkt bij te dragen aan de kwaliteit van de palliatieve zorg thuis..

Deel II. Symptoomlijden, welbevinden en behoeften van hospice patiënten

Het tweede deel van dit proefschrift bestaat uit onderzoeken die symptomen en welbevinden van hospice-patiënten beschrijven. Voor deze onderzoeken is gebruik gemaakt van symptoom dagboeken die door hospice-patiënten worden ingevuld. Het Utrecht Symptoom Dagboek (USD) is een aangepaste Nederlandse vertaling van de Edmonton Symptom Assessment System (ESAS), een internationaal veel gebruikte vragenlijst. Het USD bevat 11 symptomen en een item over onwelbevinden, gescoord op een 0-10 numerieke schaal (geen symptoom/geen onswelbevinden – ergst denkbare symptoom/ergste graad van onwelbevinden). Over het algemeen worden patiënten gevraagd het USD 2 keer per week in te vullen, of vaker indien dit noodzakelijk wordt geacht door het multidisciplinaire team. Het afnemen van het USD behoort tot de standaard zorg.

Het eerste onderzoek naar symptoomlijden van hospice patiënten (**hoofdstuk 5**) is gericht op de verschillen tussen leeftijdsgroepen. Een retrospectief onderzoek werd uitgevoerd met prospectief verzamelde USD's van patiënten die tussen juni 2007 en juni 2013 werden opgenomen in een hospice in De Bilt. Het eerste USD, ingevuld in de eerste week na opname in het hospice werd gebruikt voor deze analyse. In totaal hadden 227 patiënten tenminste een USD in de eerst week ingevuld. Voor de analyse werden vier leeftijdsgroepen (<65, 65-74, 75-84 en ≥85 jaar) vergeleken. In de eerste week na opname ervoeren patiënten gemiddeld zes symptomen tegelijkertijd. Onwelbevinden werd gemiddeld op 4,3 gescoord, wat aangeeft dat de kwaliteit van leven sterk was aangetast. Vermoeidheid, droge mond en verminderde eetlust kwamen het meeste voor en waren het meest ernstig. Pijn kwam significant vaker voor bij patiënten jonger dan 65 jaar; in deze werd de pijn ook hoger gescoord dan in de andere leeftijdsgroepen. De oudste patiënten (85 jaar en ouder) hadden vaker een verminderde eetlust. De mate van onwelbevinden was niet verschillend voor de leeftijdsgroepen.
Het onderzoek toonde de hoge symptoomlast aan van patiënten, opgenomen in een hospice. Voor de meeste symptomen waren er geen significante leeftijdsverschillen.

In **hoofdstuk 6** werd retrospectief de voorspellende waarde van symptomen voor de mate van onwelbevinden onderzocht van patiënten met kanker, opgenomen in het hospice. Hiervoor werd zowel een cross-sectionele (van het eerste USD dat in de eerste week van opname werd ingevuld) analyse als een longitudinale analyse (meerdere USD's van dezelfde patiënt in de loop van de tijd) uitgevoerd. Omdat leeftijd, geslacht, burgerlijke staat en aantal dagen tot overlijden van invloed zijn op onwelbevinden, is hiervoor gecorrigeerd. Wanneer de ernst van vermoeidheid, somberheid en verminderde eetlust toeneemt, leidt dit tot een afname van de mate van welbevinden. Deze symptomen verklaren samen bijna 50% van de variantie van welbevinden. In de longitudinale analyse bleken vier lichamelijke (vermoeidheid, pijn, gebrek aan eetlust, kortademigheid) symptomen en twee psychische symptomen (somberheid, en angst) onafhankelijke voorspellers te zijn voor de mate van onwelbevinden. Wanneer vermoeidheid, somberheid, pijn, verminderde eetlust en benauwdheid erger werd, nam de mate van onwelbevinden toe. Voor angst was het verband echter andersom: wanneer angst toenam, nam de mate van onwelbevinden af. Het onderzoek liet zien dat vermoeidheid de belangrijkste voorspeller is voor onwelbevinden, gevolgd door pijn, gebrek aan eetlust, kortademigheid en somberheid. Deze omgekeerde relatie tussen angst en onwelbevinden is niet goed te verklaren. Misschien heeft dit te maken met de relatieve lage scores voor angst, die werden gevonden.

Wanneer het sterven nadert, zijn patiënten in steeds minder in staat een USD in te vullen. Omdat de patiënt eigenlijk de enige is die de aanwezigheid en de ernst van zijn klachten kan aangeven, valt daarmee strikt genomen de mogelijkheid weg om symptomen te monitoren. Een praktische oplossing zou kunnen zijn om de verpleegkundige de symptomen van de patiënt te laten scoren.

In **hoofdstuk 7** wordt een onderzoek beschreven, dat de overeenkomst tussen de scores van de patiënt en de inschatting van de verpleegkundigen beschrijft, waarbij gebruik gemaakt werd van gepaarde symptoomregistratie. Hiervoor werd een aangepaste versie van het USD is ontwikkeld in samenwerking met hospice verpleegkundigen: het USD voor zorgverleners (USD-Z). Het USD-Z bevat dezelfde symptomen als het USD. Symptomen worden gemeten op een vijf-punts schaal, variërend van 0= geen symptoom tot 4= ergst denkbaar, allesoverheersend symptoom. Onwelbevinden wordt (net als in het USD) gemeten op een elf-punts numerieke schaal (=geen onwelbevinden – 10 sterkste mate van onwelbevinden). Voor dit onderzoek zijn gepaarde metingen gebruikt van USDs van patiënten en USD-Zs, ingevuld door verpleegkundigen. De USD scores zijn gecategoriseerd om een vergelijking mogelijk te maken.

Er zijn twee analyses uitgevoerd: 1) de absolute overeenkomst in procenten en 2) de mate van overeenkomst wanneer gecorrigeerd werd voor toeval. Per patiënt werd de eerste gepaarde meting per week geselecteerd, gedurende de eerste drie weken na opname. In totaal voldeden 147 patiënten aan de inclusiecriteria, waarvan 45 patiënten drie gepaarde metingen hadden. Het USD-Z was ingevuld door 21 verpleegkundigen gedurende de dagelijkse zorg. De meeste patiënten hadden last van vermoeidheid, droge mond en verminderde eetlust Deze klachten hadden ook de hoogste scores. Dit gold zowel voor het USD als voor het USD-Z. Wanneer de ernst van de symptomen werd vergeleken dan bleek dat verpleegkundigen over het algemeen de intensiteit van de symptomen onderschatten. De mate van overeenkomst was gemiddeld hoger dan 60% voor misselijkheid, angst en slikklachten. Voor benauwdheid en somberheid was het geval bij 50-60%. De mate van overeenkomst was het laagst voor droge mond, obstipatie en verminderde eetlust. De minst intense symptomen (misselijkheid, angst en slikstoornissen) hadden de hoogste mate van overeenkomst. De mate van overeenkomst verbeterde niet gedurende de eerste drie weken na opname.
Wanneer gecorrigeerd werd voor toeval, was de overeenkomst redelijk voor kortademigheid, matig voor verminderde eetlust, vermoeidheid, misselijkheid en pijn en laag voor angst. De gecorrigeerde mate van overeenkomst was laag voor angst. Ook deze gecorrigeerde mate van overeenkomst verbeterde niet in de eerst drie weken na opname. De gecorrigeerde mate van overeenkomst was matig voor welbevinden en verbeterde niet tijdens de opname.

De hypothese dat verpleegkundigen in staat zouden zijn gedurende de opname te leren van de ervaring van de patiënten, en daarmee beter in kunnen schatten wat de ernst is van de symptomen die patiënten ervaren, wordt door dit onderzoek niet ondersteund.

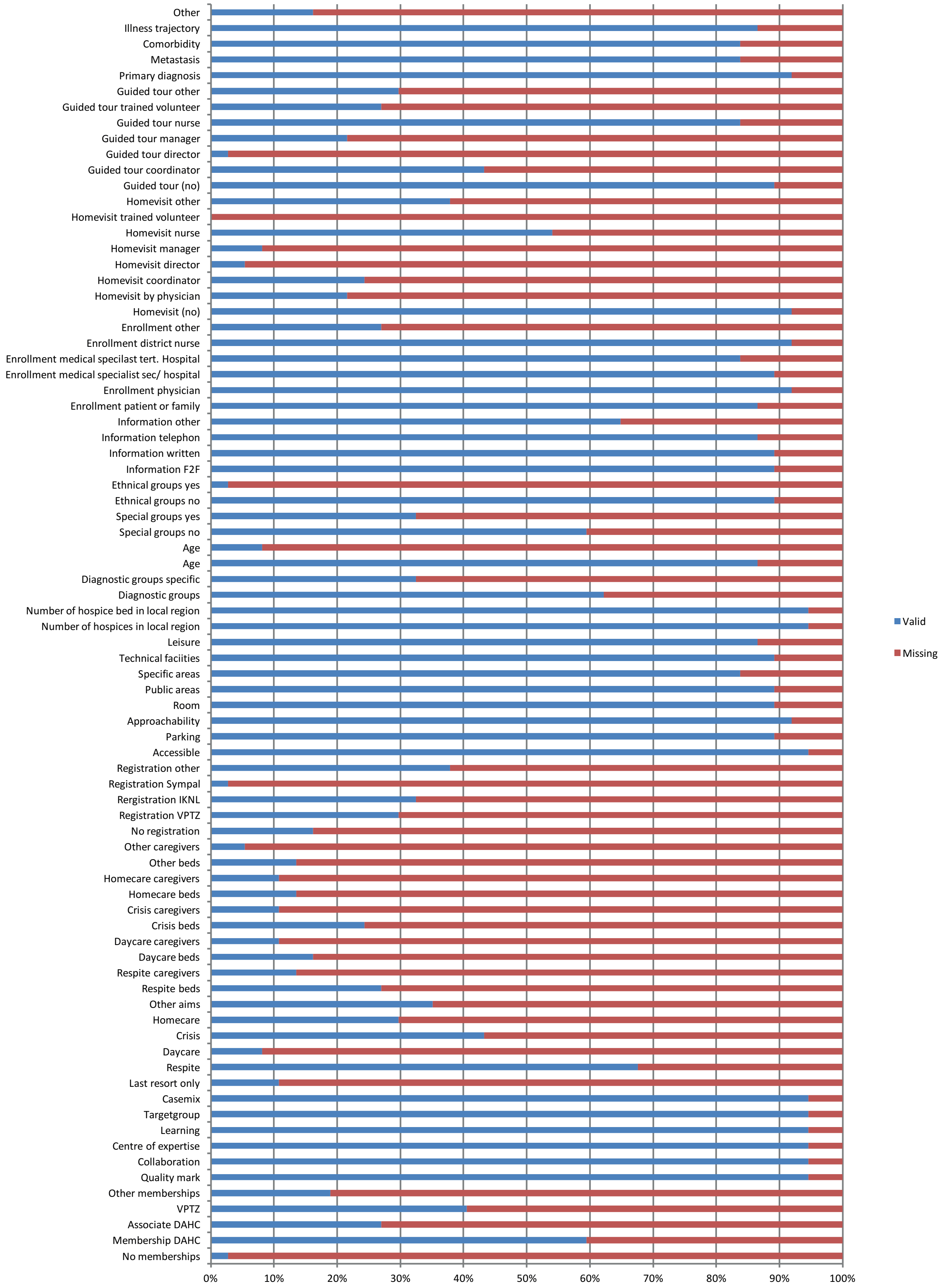
CONCLUSIE

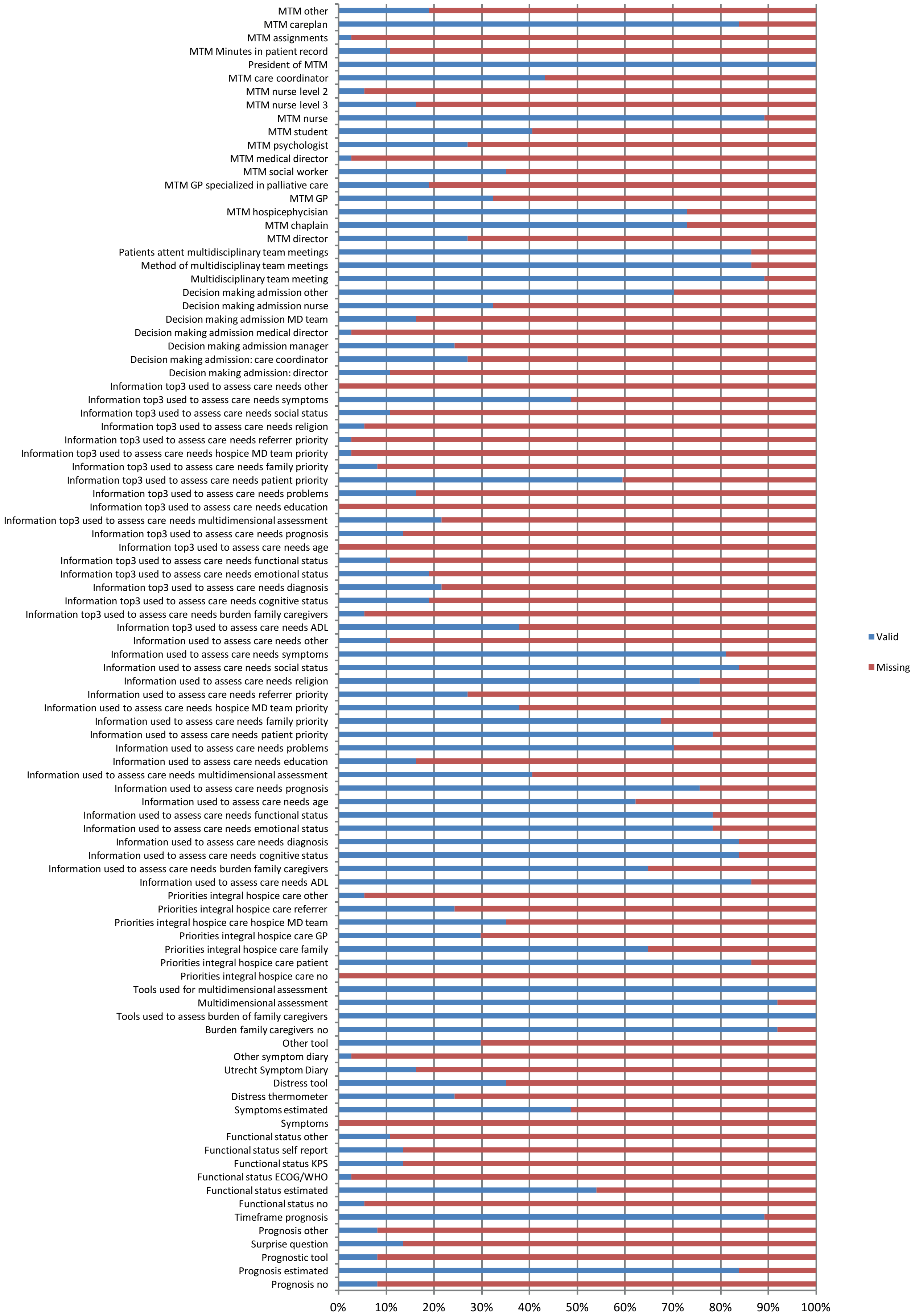
De implementatie van het hospicezorg concept is nog werk in uitvoering. Onze resultaten laten het belang van de verdere ontwikkeling van diensten en faciliteiten, personeel en de ontwikkeling van competenties om multidimensionele zorg met uitgebalanceerde en gestructureerde aandacht voor lichamelijke psychologische, sociale en spirituele behoeften en prioriteiten van patiënten en naasten. Het gebruik van het Utrecht Symptoom Dagboek, als uitkomstmaat, ondersteund kwetsbare hospice patiënten van alle leeftijden, thuis of in een hospice. De implementatie van een stapsgewijze benadering voor het systematisch signaleren en volgen van symptomen, maakt ruimte voor de verbetering van de kwaliteit van multidimensionele hospicezorg. De resultaten van multidimensionele assessments zouden structureel besproken moeten worden met de patiënt om de betekenis van een symptoom voor de patiënt te verkennen en prioriteiten vast te stellen, om optimale patiëntgerichte zorg te kunnen verlenen. Zorgverleners zouden zich bewust moeten zijn van de waarschijnlijkheid dat de eigen inschatting van de ernst van symptomen een onderschatting is van wat de patiënt ervaart, vooral voor die symptomen die moeilijk te observeren zijn.

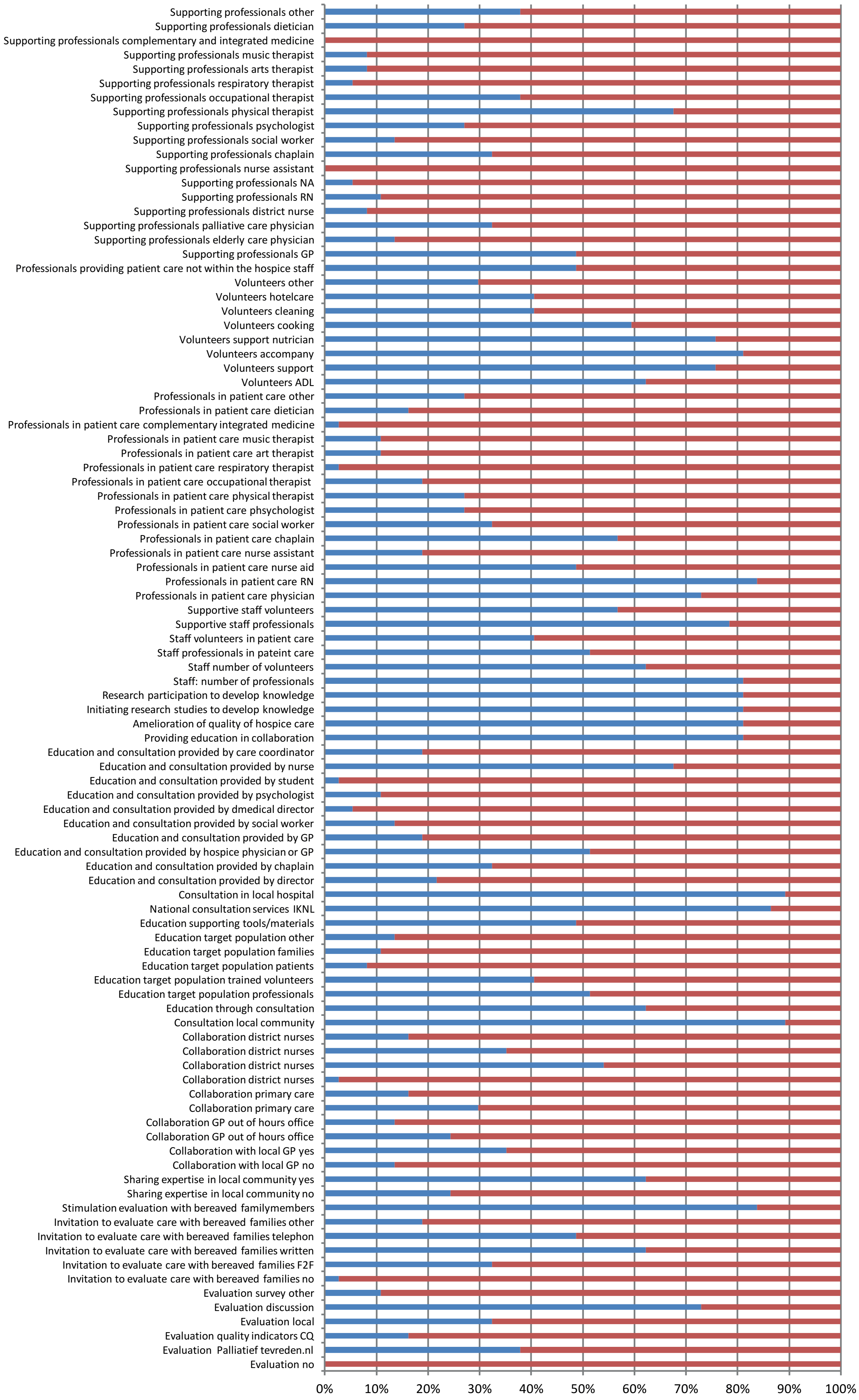
Om hoge kwaliteit van hospice zorg te kunnen garanderen, thuis en in een hospice, is meer inzicht nodig in patiënten kenmerken, symptoom profielen, behoeften en wensen, alsook in de effecten van de multidimensionele benadering en de implementatie van palliatief redeneren en evidence based richtlijnen. Het verzamelen van gegevens uit routine zorg en de samenwerking met patiëntvertegenwoordigers zou kunnen bijdragen aan het ontwerpen van nieuwe onderzoeksprojecten. De lange weg voor ons, vraagt nationale samenwerkingsinitiatieven en een gedeelde verantwoordelijkheid voor de verdere ontwikkeling van het hospicezorg concept en de uitvoering van hospicezorg van alledag.

APPENDIX 1

Items survey, missing item analysis Exploration of hospice care, 2014 (chapter 1)




MTM other
MTM careplan
MTM assignments
MTM Minutes in patient record
President of MTM
MTM care coordinator
MTM nurse level 2
MTM nurse level 3
MTM nurse
MTM student
MTM psychologist
MTM medical director
MTM social worker
MTM GP specialized in palliative care
MTM GP
MTM hospicephycisian
MTM chaplain
MTM director
Patients attent multidisciplinary team meetings
Method of multidisciplinay team meetings
Multidisciplinary team meeting
Decision making admission other
Decision making admission nurse
Decision making admission MD team
Decision making admission medical director
Decision making admission manager
Decision making admission: care coordinator
Decision making admission: director
Information top3 used to assess care needs other
Information top3 used to assess care needs symptoms
Information top3 used to assess care needs social status
Information top3 used to assess care needs religion
Information top3 used to assess care needs referrer priority
Information top3 used to assess care needs hospice MD team priority
Information top3 used to assess care needs family priority
Information top3 used to assess care needs patient priority
Information top3 used to assess care needs problems
Information top3 used to assess care needs education
Information top3 used to assess care needs multidimensional assessment
Information top3 used to assess care needs prognosis
Information top3 used to assess care needs age
Information top3 used to assess care needs functional status
Information top3 used to assess care needs emotional status
Information top3 used to assess care needs diagnosis
Information top3 used to assess care needs cognitive status
Information top3 used to assess care needs burden family caregivers
Information top3 used to assess care needs ADL
Information used to assess care needs other
Information used to assess care needs symptoms
Information used to assess care needs social status
Information used to assess care needs religion
Information used to assess care needs referrer priority
Information used to assess care needs hospice MD team priority
Information used to assess care needs family priority
Information used to assess care needs patient priority
Information used to assess care needs problems
Information used to assess care needs education
Information used to assess care needs multidimensional assessment
Information used to assess care needs prognosis
Information used to assess care needs age
Information used to assess care needs functional status
Information used to assess care needs emotional status
Information used to assess care needs diagnosis
Information used to assess care needs cognitive status
Information used to assess care needs burden family caregivers
Information used to assess care needs ADL
Priorities integral hospice care other
Priorities integral hospice care referrer
Priorities integral hospice care hospice MD team
Priorities integral hospice care GP
Priorities integral hospice care family
Priorities integral hospice care patient
Priorities integral hospice care no
Tools used for multidimensional assessment
Multidimensional assessment
Tools used to assess burden of family caregivers
Burden family caregivers no
Other tool
Other symptom diary
Utrecht Symptom Diary
Distress tool
Distress thermometer
Symptoms estimated
Symptoms
Functional status other
Functional status self report
Functional status KPS
Functional status ECOG/WHO
Functional status estimated
Functional status no
Timeframe prognosis
Prognosis other
Surprise question
Prognostic tool
Prognosis estimated
Prognosis no
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Valid
Missing


Supporting professionals other
Supporting professionals dietician
Supporting professionals complementary and integrated medicine
Supporting professionals music therapist
Supporting professionals arts therapist
Supporting professionals respiratory therapist
Supporting professionals occupational therapist
Supporting professionals physical therapist
Supporting professionals psychologist
Supporting professionals social worker
Supporting professionals chaplain
Supporting professionals nurse assistant
Supporting professionals NA
Supporting professionals RN
Supporting professionals district nurse
Supporting professionals palliative care physician
Supporting professionals elderly care physician
Supporting professionals GP
Professionals providing patient care not within the hospice staff
Volunteers other
Volunteers hotelcare
Volunteers cleaning
Volunteers cooking
Volunteers support nutrician
Volunteers accompany
Volunteers support
Volunteers ADL
Professionals in patient care other
Professionals in patient care dietician
Professionals in patient care complementary integrated medicine
Professionals in patient care music therapist
Professionals in patient care art therapist
Professionals in patient care respiratory therapist
Professionals in patient care occupational therapist
Professionals in patient care physical therapist
Professionals in patient care phsychologist
Professionals in patient care social worker
Professionals in patient care chaplain
Professionals in patient care nurse assistant
Professionals in patient care nurse aid
Professionals in patient care RN
Professionals in patient care physician
Supportive staff volunteers
Supportive staff professionals
Staff volunteers in patient care
Staff professionals in pateint care
Staff number of volunteers
Staff: number of professionals
Research participation to develop knowledge
Initiating research studies to develop knowledge
Amelioration of quality of hospice care
Providing education in collaboration
Education and consultation provided by care coordinator
Education and consultation provided by nurse
Education and consultation provided by student
Education and consultation provided by psychologist
Education and consultation provided by dmedical director
Education and consultation provided by social worker
Education and consultation provided by GP
Education and consultation provided by hospice physician or GP
Education and consultation provided by chaplain
Education and consultation provided by director
Consultation in local hospital
National consultation services IKNL
Education supporting tools/materials
Education target population other
Education target population families
Education target population patients
Education target population trained volunteers
Education target population professionals
Education through consultation
Consultation local community
Collaboration district nurses
Collaboration district nurses
Collaboration district nurses
Collaboration district nurses
Collaboration primary care
Collaboration primary care
Collaboration GP out of hours office
Collaboration GP out of hours office
Collaboration with local GP yes
Collaboration with local GP no
Sharing expertise in local community yes
Sharing expertise in local community no
Stimulation evaluation with bereaved familymembers
Invitation to evaluate care with bereaved families other
Invitation to evaluate care with bereaved families telephon
Invitation to evaluate care with bereaved families written
Invitation to evaluate care with bereaved families F2F
Invitation to evaluate care with bereaved families no
Evaluation survey other
Evaluation discussion
Evaluation local
Evaluation quality indicators CQ
Evaluation Palliatief tevreden.nl
Evaluation no
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

APPENDIX 2

Data collection tool: Multidimensional hospice care, 2014 (chapter 3)

		Physical		**Psychological**		**Social**		**Spiritual**	
		Disease related	Functional	Emotional	Cognitive	Role patiënt	Presence caregivers	Active participation religion	Existential questions
Nurse	Assessment								
	Monitor								
	Intervention pharmaceutical								
	Intervention non-pharmaceutical								
	Evaluation								
Physician	Assessment								
	Monitor								
	Intervention pharmaceutical								
	Intervention non-pharmaceutical								
	Evaluation								
Spiritual counseler	Assessment								
	Monitor								
	Intervention pharmaceutical								
	Intervention non-pharmaceutical								
	Evaluation								
Others	Assessment								
	Monitor								
	Intervention pharmaceutical								
	Intervention non-pharmaceutical								
	Evaluation								
MDC	Assessment								
	Monitor								
	Intervention pharmaceutical								
	Intervention non-pharmaceutical								
	Evaluation								
Instruments									

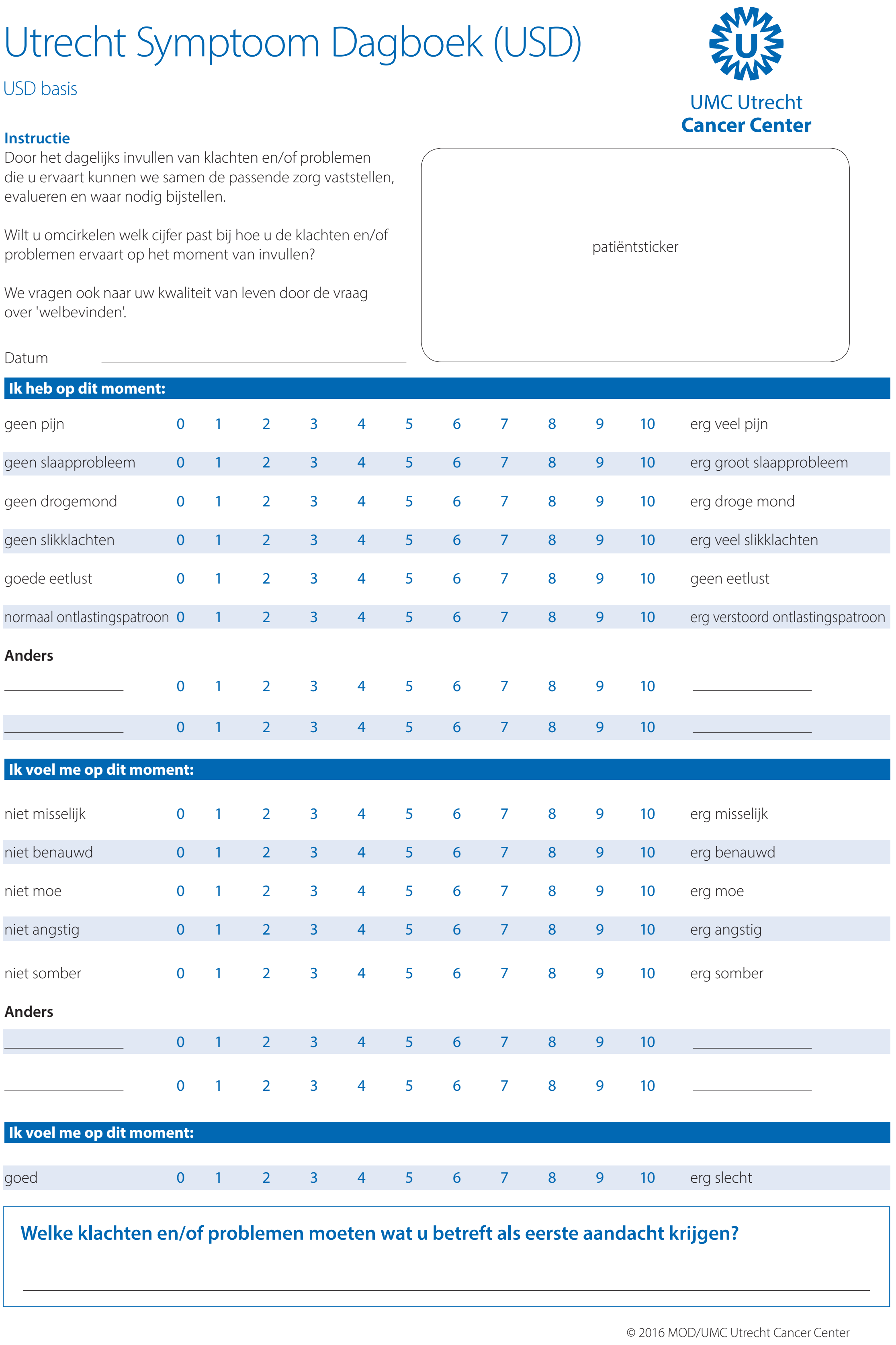
APPENDIX 3

Case Report File (CRF) HaHo service evaluation, 2014 (chapter 4)

Patient code	
Date first consult CHN	
Referral date HaHo	
Date first contact HaHo	
Name	
Gender	
Age in years	
GP (name)	
Preferred place of death	Home Hospice Hospital Nursing Home Other
Died	Yes / No
Stability	Stable, vulnerable, instable, in crisis
Phase of palliation	Illness directed,symptom directed, terminal care
End date	
Date of death	
Place of death	Home, hospice, hospital, nursing home other
Concordance actual and preferred place of death	Yes / No
Period CHN– Death days	
Periode MTM – death days	
Diagnosis	
Primary cancer site	
Primary cancer site specific	
Date of diagnosis	
Date start palliative phase	
Comorbidity	
Period start – death in days	
Period start – end project in days	
Upload Utrecht Symptom Diaries	

APPENDIX 4

Utrecht Symptom Diary, Dutch version 2016 (chapter 4,5,6,7)



Utrecht Symptoom Dagboek (USD)

USD basis

UMC Utrecht
Cancer Center

Instructie
Door het dagelijks invullen van klachten en/of problemen die u ervaart kunnen we samen de passende zorg vaststellen, evalueren en waar nodig bijstellen.

Wilt u omcirkelen welk cijfer past bij hoe u de klachten en/of problemen ervaart op het moment van invullen?

We vragen ook naar uw kwaliteit van leven door de vraag over 'welbevinden'.

patiëntsticker

Datum ______________________________

Ik heb op dit moment:

geen pijn	0	1	2	3	4	5	6	7	8	9	10	erg veel pijn
geen slaapprobleem	0	1	2	3	4	5	6	7	8	9	10	erg groot slaapprobleem
geen drogemond	0	1	2	3	4	5	6	7	8	9	10	erg droge mond
geen slikklachten	0	1	2	3	4	5	6	7	8	9	10	erg veel slikklachten
goede eetlust	0	1	2	3	4	5	6	7	8	9	10	geen eetlust
normaal ontlastingspatroon	0	1	2	3	4	5	6	7	8	9	10	erg verstoord ontlastingspatroon
Anders												
__________	0	1	2	3	4	5	6	7	8	9	10	__________
__________	0	1	2	3	4	5	6	7	8	9	10	__________

Ik voel me op dit moment:

niet misselijk	0	1	2	3	4	5	6	7	8	9	10	erg misselijk
niet benauwd	0	1	2	3	4	5	6	7	8	9	10	erg benauwd
niet moe	0	1	2	3	4	5	6	7	8	9	10	erg moe
niet angstig	0	1	2	3	4	5	6	7	8	9	10	erg angstig
niet somber	0	1	2	3	4	5	6	7	8	9	10	erg somber
Anders												
__________	0	1	2	3	4	5	6	7	8	9	10	__________
__________	0	1	2	3	4	5	6	7	8	9	10	__________

Ik voel me op dit moment:

goed	0	1	2	3	4	5	6	7	8	9	10	erg slecht

Welke klachten en/of problemen moeten wat u betreft als eerste aandacht krijgen?

____

APPENDIX 5

Utrecht Symptom Diary (USD) Core instrument, 2006 (chapter 4, 5, 6, 7)

Name ……………………..

Date ……./….…./………

Time ……………………..

I have												
no pain	0	1	2	3	4	5	6	7	8	9	10	worst possible pain
no sleeping problems	0	1	2	3	4	5	6	7	8	9	10	worst possible sleeping problems
no dry mouth	0	1	2	3	4	5	6	7	8	9	10	worst possible dry mouth
no dysphagia	0	1	2	3	4	5	6	7	8	9	10	worst possible dysphagia
no lack of appetite	0	1	2	3	4	5	6	7	8	9	10	worst possible lack of appetite
no constipation	0	1	2	3	4	5	6	7	8	9	10	worst possible constipation
Other												
…………………………………….	0	1	2	3	4	5	6	7	8	9	10	………………………………
…………………………………….	0	1	2	3	4	5	6	7	8	9	10	………………………………
I feel												
no nausea	0	1	2	3	4	5	6	7	8	9	10	worst possible nausea
no shortness of breath	0	1	2	3	4	5	6	7	8	9	10	worst possible shortness of breath
no fatigue	0	1	2	3	4	5	6	7	8	9	10	worst possible fatigue
no anxiety	0	1	2	3	4	5	6	7	8	9	10	worst possible anxiety
no depressed mood	0	1	2	3	4	5	6	7	8	9	10	worst possible depressed mood
Other												
…………………………………….	0	1	2	3	4	5	6	7	8	9	10	………………………………
…………………………………….	0	1	2	3	4	5	6	7	8	9	10	………………………………
best feeling of well-being	0	1	2	3	4	5	6	7	8	9	10	worst possible feeling of well-being
Which symptom or feeling bothers you the most and is your priority for support?												

APPENDIX 6

Utrecht Symptom Diary Professional (USD-P) 2012 (chapter 7)

Instruction

0	*USD score 0*	Not at all, no symptom;
1	*USD score 1-3*[2]	Slightly - but not bothered to be rid of it;
2	*USD score 4-6*[2]	Moderately - pain limits some activity;
3	*USD score 7-9*[2]	Severely - activities or concentration markedly affected;
4	*USD score 10*	Overwhelmingly - unable to think of anything else.

Patient Name	**Room number**
Date	**Time**

The patient has according to the caregiver

Pain	0	1	2	3	4
Sleeping problems	0	1	2	3	4
Dry mouth	0	1	2	3	4
Dysphagia	0	1	2	3	4
Lack of appetite	0	1	2	3	4
Constipation	0	1	2	3	4
Other	0	1	2	3	4
	0	1	2	3	4

The patient feels according to the caregiver

Nausea	0	1	2	3	4
Shortness of breath	0	1	2	3	4
Fatigue	0	1	2	3	4
Anxiety	0	1	2	3	4
Depressed mood	0	1	2	3	4
Constipation	0	1	2	3	4
Other	0	1	2	3	4
	0	1	2	3	4

The feeling of well-being of the patient is:

Best feeling of well-being	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of well-being

Which symptom or feeling bothers the patient most?

Which symptom or feeling is the patients priority for support?

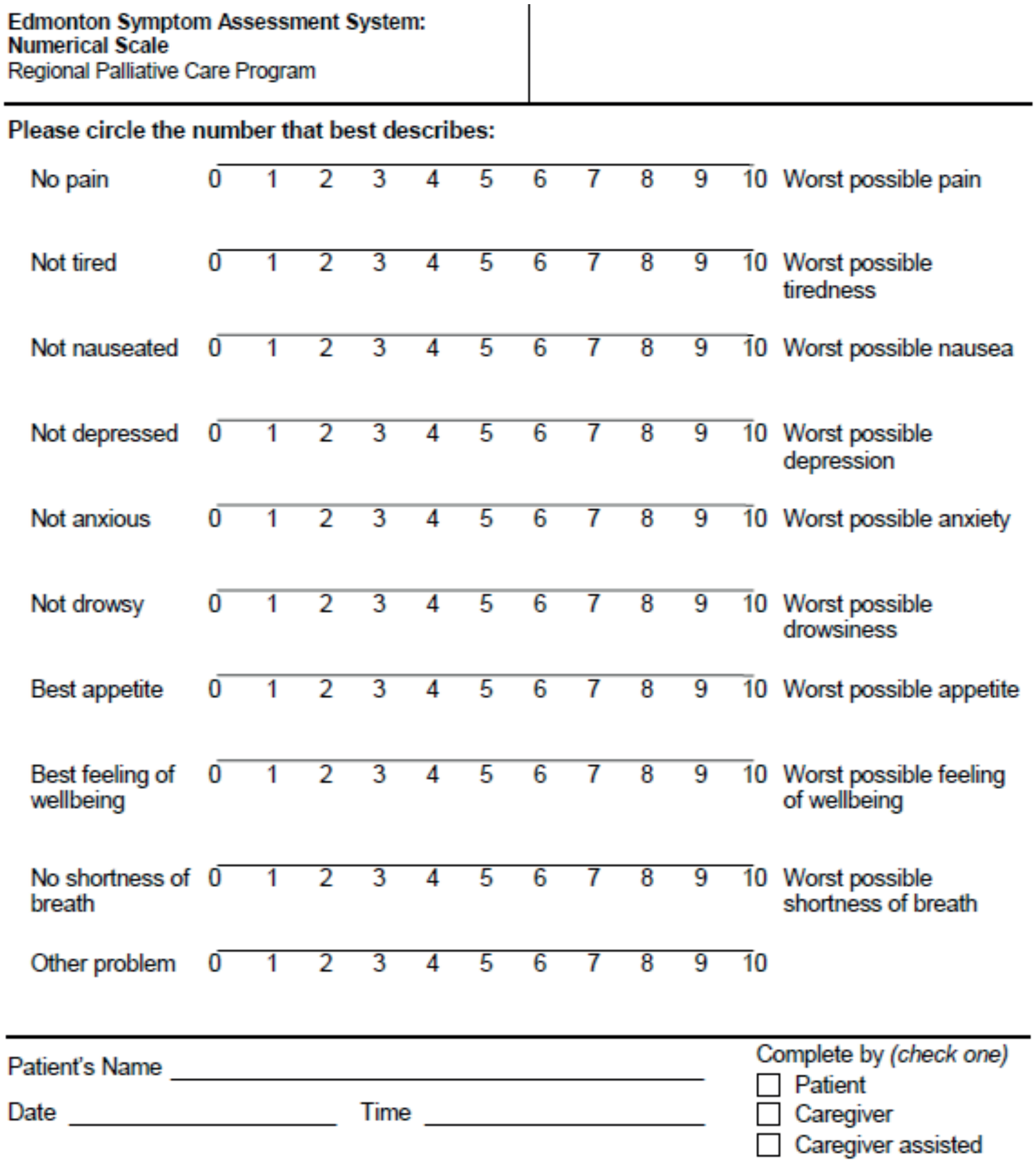
---

[1] USD-P based on W.Bloemink, STAS en POS. September 2011 De Graaf & Teunissen

[2] Cutoffs based on : Van der Wel et al (2011) en Oldenmenger et al (2012)

APPENDIX 7

Edmonton Symptom Assessment System, 1991 (chapter 8)



Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

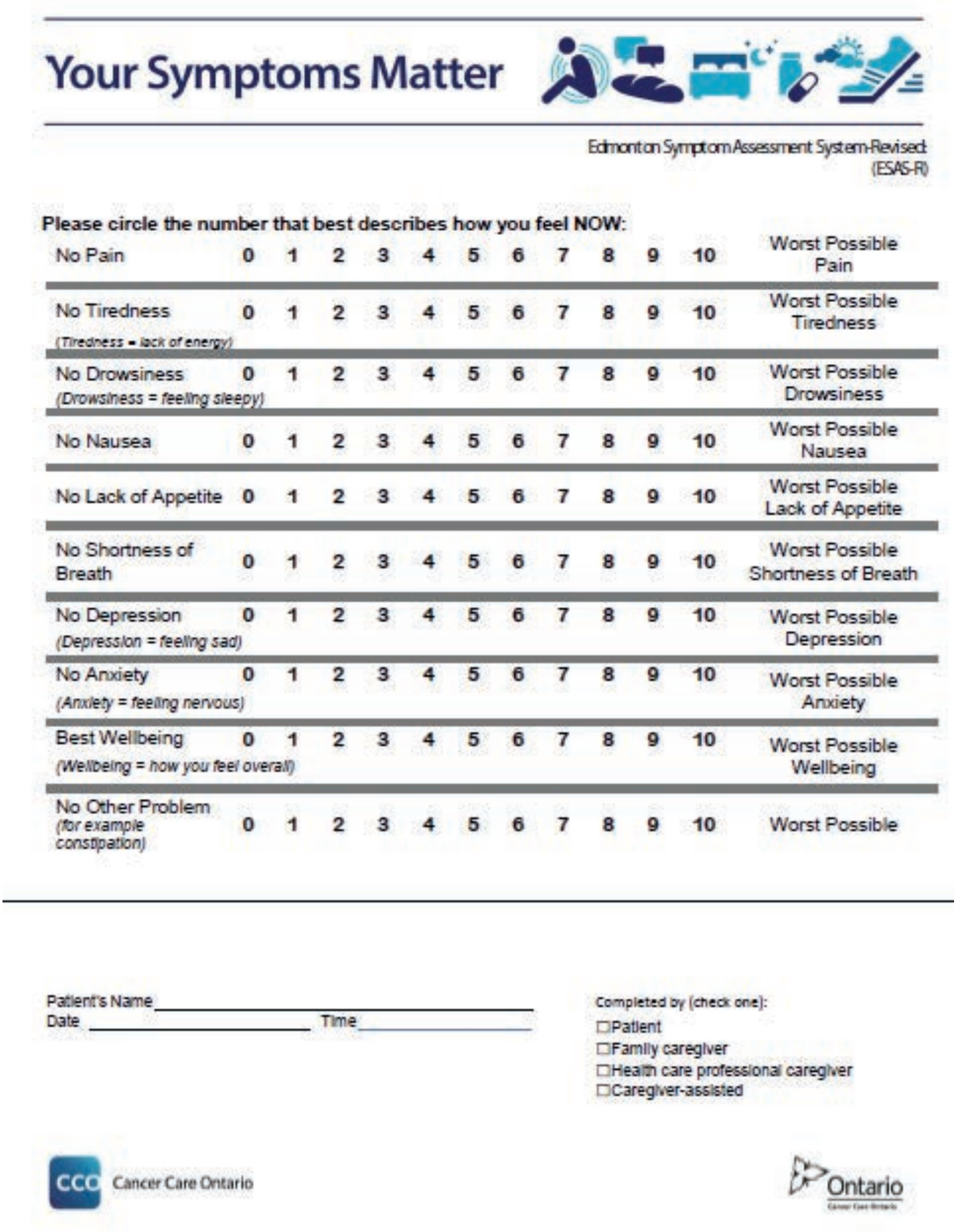
Patient's Name ______________________________

Date ____________________ Time ____________________

Complete by *(check one)*
☐ Patient
☐ Caregiver
☐ Caregiver assisted

APPENDIX 8

Edmonton Symptom Assessment System Revised, 2011 (chapter 8)



Your Symptoms Matter

Edmonton Symptom Assessment System-Revised:
(ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No Other Problem *(for example constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible

Patient's Name ____________________

Date ____________ Time ____________

Completed by (check one):
☐ Patient
☐ Family caregiver
☐ Health care professional caregiver
☐ Caregiver-assisted

CCO Cancer Care Ontario

Ontario

DANKWOORD

Er zijn zoveel mensen die een bijdrage hebben geleverd aan de totstandkoming van de studies beschreven in dit proefschrift en al evenzoveel mensen die hebben bijgedragen door er te zijn, te steunen waar nodig en te jubelen waar mogelijk.

Allereerst wil ik mijn promotor Saskia Teunissen bedanken. Saskia, dank voor de kansen, het vertrouwen en de steun die je de afgelopen jaren hebt geboden. De wereld van de academie was compleet nieuw voor mij en niet altijd eenvoudig. Ik moest mijn weg vinden en wilde mijn eigenheid behouden. Samen hebben we wegen gezocht, en waar nodig wegen geplaveid. Dat waren niet altijd de gemakkelijkste wegen, maar je hebt me altijd op het juiste pad gehouden, en ik heb genoten van de weg. De denksessies waarin je me uitdaagde ‘out of the box’ te denken en we samen associeerden, leverden vaak nieuwe ideeën op en altijd nieuwe energie, inspiratie en mooie tekeningen. Je stimuleerde mij de keuzes te maken en mezelf te ontwikkelen als onderzoeker en als mens. De laatste jaren bood je nieuwe perspectieven met plannen voor de toekomst en nieuwe projecten, daar kijk ik naar uit.

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CURRICULUM VITAE

Everlien de Graaf was born in Nijkerk, the Netherlands July 5th 1976. After graduating the secondary school at the Farel College in Amersfoort, she obtained her nursing education at the Hogeschool Utrecht in 1998. After working in several fields of nursing, her interest in palliative care was aroused during her work as a district nurse (2004-2010). Besides her work as a district nurse, she started as a member if the Palliative Care Consultation Service Northwest Veluwe. During these years (2008-2011), she specialized in palliative care of patients at home coordinating the nursing care for palliative patients at home and providing support at home. In 2007, she continued her education at the Utrecht University, obtaining a Master of Science degree with judicium Cum Laude in Nursing Science in 2010. From 2008-2010 she performed her first studies in palliative care, inspired by the everyday problems experienced and witnessed in daily care. Concurrently, she started quality improvement projects at Icare, a large home care organization, first in her team of district nurses and nursing aides, later in expert panels across the home care organization (2007-2010). During this period, Everlien was actively involved in the development of the multidisciplinary guideline Anticipating Decision Making about Resuscitation of Frail Elderly which was published in 2013 (richtlijn Anticiperende Besluitvorming over Reanimatie bij Kwetsbare Ouderen). After completing her Master of Science, she worked as a project leader of Excellente Zorg at Icare 2010 to 2011, which aimed to ameliorate work satisfaction and the quality of care provided. In 2011, Everlien started working as a researcher at hospice Demeter in De Bilt, performing studies in hospice care and at home. Since 2015, Everlien works at the Julius Center, in the department of General Practice of the University Medical Center Utrecht as a PhD student. She combines the doctoral research described in this thesis with working as a lecturer at Clinical Health Sciences at the Utrecht University (2012-currently). From 2011 Everlien yearly contributes to national and international conferences on palliative care and actively participated in seminars of the European Association of Palliative Care in 2014 and 2016. Everlien is since 2012 member of the core team of Science in Practice, a platform of the Dutch professional Association of Nurses and Care workers (Platform Wetenschap in Praktijk van Verpleegkundigen en Verzorgenden Nederland, V&VN).

From January, Everlien will continue her research at the Julius Center to further explore and develop hospice care as team member of, the HOPEVOL- project (ZonMw) and the INZICHT project (ZonMw) concerning the development and validation of the multidimensional Utrecht Symptom Diary (USD-4D).

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