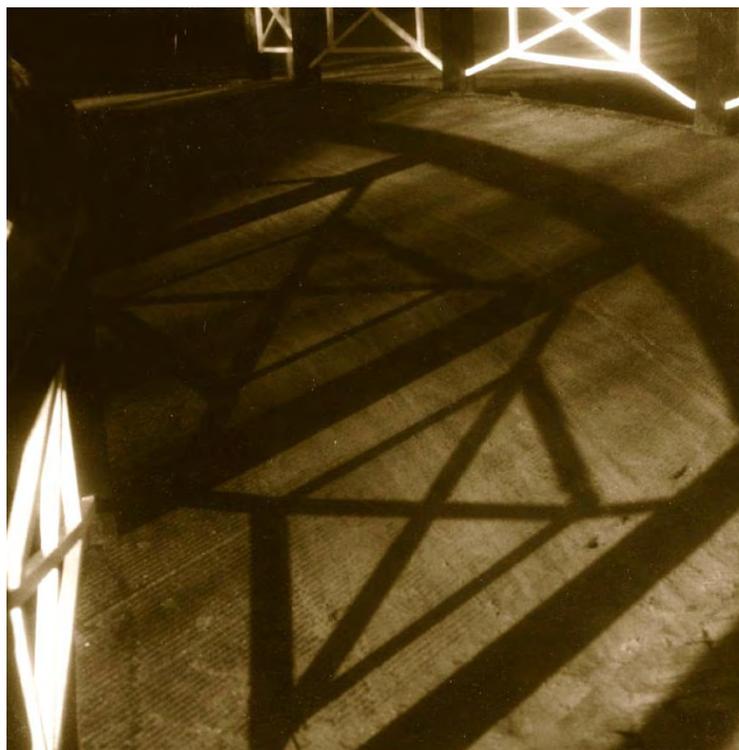


Learning Spiritual Care in Dutch Hospitals

The impact on healthcare of patients in palliative trajectories

Joep van de Geer



The research presented in this thesis was conducted at the MCL-Academy, Medical Centre Leeuwarden and the Faculty of Theology and Religious Studies, University of Groningen, Netherlands.

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The impact on healthcare of patients in palliative trajectories

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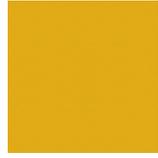
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Prologue. Travelling companion and journeyman



Prologue. Travelling companion and journeyman

*Al dat hout
bij de haard
voor één vuur*

*warmte vergt
jaren groei*

willem hussem¹

When I moved into my office in the newest section of the Leeuwarden Medical Centre in 2005 I gave this poem a prominent and permanent place. It can be interpreted in many ways, depending on the reader's situation in life. In this office I was going to receive patients and their families, if I was not going to meet them on the wards. But it was also going to be a space to meet and work with colleagues: nurses, doctors, paramedics, fellow healthcare chaplains, ministers and pastors. I was looking for a balance between professionalism, art, poetry and symbols. I placed the poem so that it could be one of the first things that struck a visitor – for one it was a greeting, for another a confirmation of an insight gained, for a third it might be an encouragement not to give up.

For myself it also referred to the spiritual baggage I was carrying at the moment when I chose this new path: healthcare chaplain in an ambitious, top-tier clinical center. Trained as a theologian I was aware of the richness and fragility of the Judeo-Christian tradition as

¹ Translation: all that wood/near the fireplace/for just one fire/warmth takes/years of growth.
From: *Schaduw van de hand*, Amsterdam 1965.

an almost limitless storeroom of wisdom and understanding. My experience as a preacher and spiritual caregiver in geriatric care had made me familiar with people's search for meaning, significance, inspiration and faith when faced with life's great challenges. That expertise, including the practical and philosophical wisdom of my tradition were like a pile of firewood, waiting for the challenge to make a difference by serving as health care chaplain in this temple of modern health care. I saw myself as a professional, equipped with the language of one of the great spiritual traditions, ready to contribute to keeping the fires burning, in a temple where the priests and priestesses wear white coats and preach a great confidence in evidence-based medicine.

As a health care chaplain in geriatric care and psycho-geriatrics I had amassed enough self-confidence to meet that challenge. I had become impressed on the one hand by the effects I could have as a health care chaplain on the quality of care for and the well-being of residents and clients, but also on the other hand by the hard effort it took in conversations with management or other disciplines to express clearly what it was exactly that I did differently from the social worker or the psychologist. The four-dimensional definition of palliative care offered me a substantive concept of care that via the term 'spirituality/spiritual' presented a framework that united the specific contribution of my area of expertise with the implicit dimension of our work in health care. A year later I was given the formal assignment to explore ways to improve palliative care in the hospital as a project manager.

The year 2006 proved crucial. First, in January my new role took me to the Galgenwaard stadium in Utrecht, to attend the presentation of Palliatieve zorg, Richtlijnen voor de praktijk (Palliative Care, Guidelines for daily practice), the first national document combining directives for the practice of palliative care. A quick glance at the table of contents caused some disappointment: apparently there was no national consensus yet about what caregivers might understand by 'spirituality in palliative care'. On the spot it

turned out that I shared this disappointment with Marijke Wulp from Agora. Then in May of that year, during the Teaching the teachers palliative care course offered by the Leerhuizen Palliatieve zorg Rotterdam, I met Ruthmarijke Smeding. Her enthusiasm and international experience in palliative care made me confide 'I wish I could take such a course exclusively with spiritual caregivers, to search for a consensus on the concept 'spirituality in palliative care'. Her willingness, together with Erhard Weiher's, to share their years of experience with exactly that type of course in Germany resulted in the masterclass 'Spirituality and spiritual care in palliative care'. That first masterclass, in 2007, brought me together with others who apparently shared the same questions, for instance my colleague Marinus van den Berg, who had written about the search for meaning in palliative care. I renewed my friendship with Carlo Leget, who in that first masterclass taught us about his *Ars Moriendi*. As it turned out, in that same year the foundation was also laid for Agora's initiative to set up a taskforce 'Guideline for spirituality (later: spiritual care)', to which I received an invitation.

Challenged at the start of that first masterclass to sketch the then current situation regarding spiritual care, I chose two metaphors, 'reisgezel' (travelling companion) and 'meesterknecht' (journeyman), by which to position our expertise within palliative care. In my function I see myself essentially as a travelling companion to patients (and their loved ones) on a unique stretch of their journey, with the patient on the one hand teaching me very concretely how an individual can react to the challenges posed by life and its approaching end, and on the other playing the pupil asking for and receiving care; here, the spiritual caregiver can at most try to facilitate the patient's learning process, or growth, from a modest position as journeyman (an advanced apprentice).

Of course I also had the poem by Willem Hussem in mind: this modesty is based on the realization that warmth sometimes takes years to grow. At the same time, this advanced apprentice is an academically trained professional, familiar with one of the great spiritual

traditions, who – like the journeyman in the medieval guilds – is able to deliver masterpieces by himself: an aspiring master craftsman. The Dutch word ‘meesterknecht’ however, is also used as a metaphor in cycling for a rider who is actually good enough to win the Tour but unquestioningly serves and supports his team leader as a ‘lieutenant’ in the latter’s quest for victory. In that sense, as a lieutenant, the health care chaplain is primarily in the service of the patient (and those near to him/her) as the team leader, but secondly also serves the doctors, nurses and other caregivers in the effort to provide four-dimensional care.

The masterclass proved not to be a one-off, but it enabled me and fellow-healthcare chaplains not only to share our questions and quest, but also to offer a joint contribution to the first concepts of a guideline for spiritual care. Around the time the first version of the guideline concept, at the comment stage, was published on internet in 2009, I attended the 15th World Congress of the European Association for Palliative Care in Vienna together with Carlo Leget and Marijke Wulp. It was there that I realized that the reality of palliative care in my own hospital was not immediately going to change on the basis of one guideline. Both in my roles as a project manager, and health care chaplain I felt a lack of evidence based implementation methods for spiritual care.

We realized then and there that these questions were also relevant in other European countries, albeit in quite different cultural and spiritual constellations, but that there was no structure within which we could share expertise and experiences. The idea to start a joint initiative towards a Taskforce Spiritual Care within the EAPC from the Netherlands coincided with my realizing that in my own hospital the next steps could only be taken in the framework of academic research.

My decision to undertake this research project myself was not exactly obvious. On the contrary, people tried to dissuade me: wasn’t my preferred habitat that of daily practice rather than academic research? A correct observation, but it seemed to me that this was

the only way to bridge the gap between health care chaplains as the representatives of the great spiritual traditions and the white-clad priests and priestesses of modern health care, if together we were to keep the fires of person-centered, compassionate health care burning. If this meant entering the woods on a path I had not trodden before, so be it.

*Toe 'j klein waarn dacht ie der nooit bij nao
As 't kaold was buuten dan was 't binnen warm
Mar nou moe 'j 't zölf doen, 't blef strabenskaold
A'j zitten blieden zunder te stoken*

*A'j t nie dreuge naost de deur hebben liggen
Dan moe'j 't bos in, soms diep 't bos in
Veur holt veur op 't vuur
Veur holt veur op 't vuur*

Daniël Lohues ²

Joep van de Geer
Franeker, June 2017.

² From the lyrics of 'Holt veur op 't vuur' by Daniel Lohues, in eastern Dutch dialect:

When you were small you took it for granted:/When it was cold outside, it was warm inside. /Now, however, it is your own responsibility, it remains freezing cold, / if you just keep sitting without lighting a fire.

If you don't have a pile dried next to the door,/You'll need to go into the woods, sometimes deep into the wood,/ for wood for the fire, for wood for the fire.

From the album: Hout moet, 2011.

1

Introduction



Chapter 1. Introduction

This thesis reports the results from a multicentre action research study that was initiated in the Medical Centre Leeuwarden in which a pilot training on spiritual care in palliative care was implemented by local trained hospital chaplains in 8 Dutch teaching hospitals. This mixed methods study explored health care chaplains' potential contributions to palliative care improvement programmes in Dutch general hospitals. The primary research questions included the following. How can chaplains teach doctors and nurses to hear and see what is existentially and spiritually at stake for patients and their proxies, who are confronted with life limiting disease(s) in treatment and care? When health care professionals are trained by specialists on this dimension of care (their local hospital chaplains), does training improve their communication skills and competencies? Finally, will patients experience better care from their multidisciplinary teams when attention is given to their spiritual and existential needs?

The 'Background' section of this introductory chapter begins with (a.) an international perspective on palliative care, which is followed by (b.) a description of the development of palliative care in Dutch health care based on the definition of the World Health Organization (WHO) and the increased attention to spiritual care in palliative care. Then, (c.) we examine this development in the international context of global developments on spirituality in palliative care and describe (d.) how attention for spiritual care increased in the Netherlands, prior to (e.) summarizing the core concepts of the first Dutch multidisciplinary guidelines for spiritual care in palliative care.

In the 'Implementation of multidisciplinary spiritual care' section, we explain the factors that are critical for successfully developing spiritual care and the specific challenges of providing training for spiritual care. Next, we describe our methods, aims and research questions.

This introductory chapter concludes with a formulation of the aim of this thesis and concludes with a description of the following chapters in the ‘Thesis Outline.’

Background

a. International perspectives on palliative care

The beginning of modern palliative care is connected to the opening of the first modern hospice, St Christopher’s Hospice in London United Kingdom, and the work of dame Cicely Saunders in the early sixties of the 20th century.(1) For the first time, end-of-life care was systematically developed and was equally combined with clinical care, education, and research. Over a period of four decades, developments in the United Kingdom, the United States, Australia and Canada demonstrated an increased global understanding of palliative care; however, it primarily focused on cancer patients. In several countries, palliative medicine was recognized as a sub-specialism. International organizations, such as the European Association for Palliative Care (1988) and the International Association for Hospice and Palliative Care (1999), were formed and led to a global understanding of the primary values and multidisciplinary character of palliative care, which culminated in the World Health Organization’s definition of palliative care that was published in 2002 and has not been amended since.(2)

The WHO’s definition of palliative care provided new opportunities for exploring the importance of the spiritual dimension. The definition also created conceptual confusion, because this dimension was not defined in Engel’s model,(3,4) which defined the relations between the somatic, mental and social dimensions of modern medical care in the seventies and is often experienced dominant in health care education and practice.

Palliative care is 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.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

b. Developing palliative care in Dutch health care

In the Netherlands, palliative care has systematically developed since 1998, when subsequent policy documents revealed that the government wanted to integrate palliative care into the Dutch health care system.

The principles for palliative care in the Netherlands were formulated in policy documents as follows:

- Palliative care should focus on achieving the best possible quality of life for patients, according to the WHO definition of palliative care.
- As much as possible, palliative care should remain a part of mainstream health care. General care providers should be supported by, and get advice from, specialized, multidisciplinary consultation teams.
- There should be co-operation within palliative care networks to ensure that care is organized as well as possible around the patient.
- There should be support, on a national level, from the Agora Foundation (the national support platform for palliative care), four university medical expertise centres, and, at a regional level, from the Comprehensive Cancer Centers, which were temporarily (1998-

2003) expanded with palliative care departments: *Centra voor Ontwikkeling van Palliatieve Zorg (COPZ)*.(5)

In this COPZ period, between 1998 and 2003, there was no distinction between the expertise and contributions of psychologists, social workers, and health care chaplains. Health care chaplains in the Netherlands did not step forward as specialists in the field of spiritual care in palliative care. There was only one health care chaplain who was involved in the development of palliative care in the Netherlands during this time: Marinus van den Berg.(6)

In contrast to English speaking countries, the words 'spirituality' or 'spiritual care' were hardly or not used at all. Initially, the term for spiritual care in the Netherlands was the same as the central concept in the health care chaplaincy definition: 'zinggeving' (literally: 'sense-giving or making' or 'search for meaning'). As such, health care chaplains had to explain the characteristics of their profession in multidisciplinary consultations with doctors, nurses and other disciplines, as well as in training situations, which included the spiritual aspects of care in psychosocial vocabulary terms. Thus, the name and description of 'spiritual care' was framed within a three-dimensional care model (somatic, psychological, social).

Based on this framework, the Dutch Association of Spiritual Caregivers in Health Care Institutions (*Vereniging voor Geestelijk Verzorgers in Zorginstellingen*, which recently changed its name to *Vereniging Geestelijk VerZorgers, VGVZ*)(7) was founded in 1971. Over the past 40 years, it was very useful for developing the profession by providing a conceptual and theoretical underpinning, and issuing guidelines for integration as well as professionalization (for example, organizing additional training, supervision, and clinical-pastoral education). In the first version of a professional standard for health care chaplains, in addition to core tasks that were related to patients and loved ones, there were tasks that were related to the institution.(8) However, until recently, health care chaplains have elaborated on these institution-related tasks in a very diverse manner. Contextual factors (such as the identity of the institution, the management's vision, the health

care chaplain's personal views) and a lack of national consensus in the profession contributed to a lack of clarity as to what other disciplines and organizations could expect from spiritual care.(9,10) There was also no consensus on the expectations of primary caregivers (doctors and nurses) for spiritual and religious matters.

Within the development of palliative care in the Netherlands, there was no systematic attention to the spiritual dimension in regular health care until 2005-2006. For example, the first edition of the national guidelines for palliative care(11) contained no section or chapter that described the 'spiritual dimension'. With the inauguration of the first two chairs in palliative care(12,13), the question was raised where and how to operationalize the spiritual dimension in medical practice and, specifically, in palliative care . Since then, there has been a progressive focus on and attention to the spiritual dimension in important organizations in palliative care in the Netherlands, such as Agora (at that time, they were the national platform of support for palliative care). An example of this shift in focus is that Agora adapted the mission and re-named the 'taskforce on ethics' into the 'taskforce on ethics and spiritual care'.

c. International perspectives on spirituality in palliative care

Several researchers reported a positive relationship between attention to the spiritual dimension for patients and their proxies, with a higher quality of life at end of life. (14,15,16,17) Moreover, patients valued attention to spirituality from doctors, nurses and other health care professionals.(17,18) In spiritual care and palliative care in general, based on the bio-psycho-socio-spiritual care model,(19) the patient and those closest to him/her have a central position.

For many years, the definitions of the concept of spirituality in health care were highly diverse, and impeded a common foundation for research and development. With the publication of Allen Kellehear's 'Spirituality and palliative care: a model of needs',(20) attention shifted from defining this complex concept to a functional approach that concentrated on the spiritual needs of patients and

those closest to them. Internationally, this approach attracted an increasing number of followers, which resulted in a national consensus report from the USA, where the authors also used a functional definition: 'Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.'(21) In the Netherlands, this line was followed first by Jochemsen,(22) and was later elaborated by Leget et al. in the Guideline for spiritual care(23): 'Spirituality is the functioning of people with regard to worldviews, including issues related to the search for and experience of meaning. Spirituality includes a wide range of sources of inspiration - varying from religious to the ordinary. For some people, the emphasis is on emotional experience (e.g., prayer, enjoyment of nature, literature, music, art) or on activities (meditation, performance of rituals, or commitment to a good cause); others experience spirituality more intellectually (contemplation or study). Spirituality affects one's entire existence. It is dynamic and has more to do with the source of an attitude towards life than it does with a distinguishable realm of life.'

This thesis used and implemented the working definition of the EAPC Taskforce on Spiritual Care(24), which was affirmed and reaffirmed in 2013 and 2015 and defines spirituality as follows:

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. The spiritual field encompasses:

- existential questions (concerning, for example, identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy),
- value-based considerations and attitudes (that is, the things most important to a person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself),
- religious considerations and foundations (faith, beliefs and practices, one's relationship with God or the ultimate).

This taskforce aims to stimulate the exchange of knowledge in the fields of research, training, and the implementation of spiritual care in palliative care in Europe.(25) This PhD thesis is inspired by interactions with the EAPC taskforce on spiritual care, of which myself and my promotor, Professor Carlo Leget, are co-chairs.

d. Increasing attention for spiritual care in palliative care in the Netherlands

In the Netherlands, the nursing profession was the first to react to the introduction of the four dimensional model of care by developing a nursing competency profile for spirituality.(26,27) A few years later, in 2006, I became responsible for developing palliative care in this hospital and found that there was a lack of additional, substantial training on spirituality in palliative care. With the support of the Comprehensive Cancer Centre North-East (*Integraal Kankercentrum Noord Oost*), which is currently incorporated into the Dutch Comprehensive Cancer Centre (*Integrale Kankercentra Nederland, IKNL*), the first master class in spirituality and health care chaplaincy in palliative care was offered for health care chaplains.(28)

In the same year, the Taskforce on ethics and spiritual care (*Agora Ethiek en Spirituele Zorg*)(29) convened a taskforce to explore the possibility of writing a guideline, and commissioned a pilot study to examine the competencies that are important in spiritual care.(30) In the following years, Agora organized several conferences on spiritual care, the master class was repeated several times, the programme was developed as multidisciplinary, and the participants provided feedback and input on the draft versions of the Guideline for Spiritual care(23) (*Richtlijn Spirituele Zorg*, hereafter: the Guideline), which was eventually accepted by the editorial board of the Guideline book and was included in the second edition in 2010.(31) In the same year, the VGVZ included the concept of spirituality in its professional definition of health care chaplaincy,(32) and Agora published a consensus based vision for the future of spiritual care, which

resulted from a project that was funded by the Ministry of Health and Welfare.(33)

The Dutch government presented a plan of action to further develop palliative care,(34) which included the development of spiritual care. This plan consisted of three areas: 1. organizing and financing palliative care, 2. improving the quality and transparency of palliative care, and 3. training and improving expertise.

Since 2012, there has been a change in the climate for the purpose and necessity of using the concept of spirituality/spiritual care in palliative care in the Netherlands. Skepticism and resistance led to consensus and a willingness to develop spiritual care as part of palliative care. A sort of infrastructure for spiritual care in palliative care developed,(35) that consisted of the following:

- an inventory of desired competencies in spiritual care;
- a consensus-based multidisciplinary and multi-denominational guideline for spiritual care in palliative care;
- a sufficient consensus on the importance of elaborating the concept of spirituality among health care chaplains, which resulted in incorporating the concept of spirituality into the professional definition of health care chaplaincy;
- a national document that outlined a plan for including spiritual care in palliative care.

Critical to this development was the Agora Taskforce on ethics and spiritual care's international orientation, which resulted in hosting the invitational conference that led to the initiation of the Taskforce on Spiritual Care within the European Association for Palliative Care (EAPC) in 2011.(24)

The inauguration of the first chair in 'spiritual and ethical questions in palliative care' in 2013(36) was a formal recognition of the increased attention for spiritual care in palliative care in the Netherlands.

e. Core concepts in the first Dutch multidisciplinary guideline for spiritual care in palliative care

The Dutch consensus-based Guideline aims to clarify this concept and improve the practice of palliative care. This Guideline emphasized that the nature of spiritual care is multidisciplinary by definition, and requires close cooperation between all disciplines, with each discipline having its own role and task (see diagram below).

In the diagram, there is a distinction between primary health care professionals (physicians, nurses), other disciplines, and the experts in the field: health care chaplains. Primary health care professionals are expected to recognize the spiritual needs of the patients and those closest to them, screen for their needs, follow the search process, refer, and assess (take the spiritual history). As such, the guideline provides diagnostic tools that differentiate (consistent with Puchalski 2009: 891) between *screening* (a translation of the Mount Vernon Cancer Network screening instrument(37)); and *spiritual history taking/assessing* (*spiritual history taking*) (FICA(38), SPIR(39), Ars Moriendi(40,41)).

In the first two columns of the diagram, A Attention, B Counselling (in Dutch: Begeleiding) and C Crisis intervention reflect the seriousness of a situation in an ascending order, in which there are changes in the roles of the health care professionals.

Indicating the primary focus, access and frame of reference is not meant to limit or exclusively separate professional domains, but allows for differentiation. The authors of the guideline provided the following explanation: ‘The distinctions point to the dimension of care for which a discipline bears final responsibility and possesses specialized expertise. In palliative care, multidisciplinary cooperation (with mutual consultation) or (preferably) interdisciplinary collaboration is always desirable. Every discipline evokes its own reality (‘world’) that has a different effect on the patient. That influences what a patient tells a nurse, doctor, psychologist, or health care chaplain, respectively. Each discipline also has its own discipline-bound manner of helping or counselling, its own repertoire and role with

regard to the patient. By their presence, health care chaplains evoke a different response than do doctors or nurses. They (chaplains) represent a dimension of meaning in life. Coming from a specific worldview tradition, health care chaplains can also represent other realities, such as a religious community or God. What is also characteristic of the work of health care chaplains is the dimension of connectedness (linking the unique life story with appropriate images, symbols, rituals, stories, and poems). That requires its own set of competencies along with those shared with other disciplines such as listening, supporting, recognizing, counselling, and treating. Listening and recognizing (see A in the Table) are always meaningful in themselves, but they also serve to prevent crisis.’

		Doctors and nurses	Medical social workers, psychologists	Health care chaplains	
	<i>Primary focus, access and frame of reference</i>	<i>Somatic</i>	<i>Psychosocial</i>	<i>Spiritual</i>	
A	Attention <i>(always)</i>	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening, interpreting	Representing and connecting
B	Counselling <i>(at patient's request)</i>	Following the search process, referring, assessing	Following the search process, referring (->) assessing	Following the search process (<-) referring assessing, interpreting and appraising	
C	Crisis intervention <i>(if indicated)</i>	Detecting, referring	Recognizing, counseling, treating referring (->)	Recognizing, counseling, (sometimes) treating, (<-) referring interpreting and appraising	

Figure 1 Primary focus, access, and frame of reference of the various care disciplines (Leget 2010: 652).

The remaining four columns reflect the dimension of care for which a discipline has the final responsibility, possesses specific expertise, and, thus, has its own discipline-bound method of counselling (repertoire).

The guideline describes health care chaplains as professionals who are specialized in spiritual care: first, as counsellors for more complex spiritual needs and crisis interventions, and second, as those responsible for the spiritual care policy in their institutions. For their position within institutional policy, the Guideline formulates seven tasks. Without denying the importance of the other four, we concentrate on the first three: ‘Other care providers can enlist the aid of a health care chaplain for the following reasons:

- consultation and advice for questions about spiritual care.
- training in spirituality, religion, worldviews and meaning.
- translating spiritual care into local formulations of care policies and national protocols and guidelines.’

Thus, health care chaplains are expected to train others in the methods that are advised in the Guideline. The need for training is also presented in the Agora plan for the future(33) as one of the four core aims that was formulated with the intent to develop multidisciplinary spiritual care. With the Guideline’s publication, a new aspect of the health care chaplain's professional profile emerged: that of the spiritual care consultant. As early as 2008 Vissers and van de Sande argued for further exploring and understanding this specific aspect.(42)

Implementing multidisciplinary spiritual care

An analysis of the situation that was described above revealed three critical factors for the successful development of spiritual care:

- a lack of evidence that attention to the spiritual dimension improves the quality of Dutch health care;
- the availability of validated diagnostic instruments for primary care professionals (doctors and nurses); at baseline in this study no instrument was tested on its workability within the Dutch cultural context (all instruments in the Guideline, with the exception of Leget's *Ars Moriendi*, were developed in English speaking countries and cultures);

- consensus about the responsibility of health care chaplains for structuring or organizing spiritual care and training primary health care professionals to use diagnostic instruments in spiritual care.

Given these three critical factors for success, our goal was to connect the primary actors in developing multidisciplinary spiritual care in palliative care in a common learning process. We used an action research approach that focused on health care chaplain's training of primary health care professionals to generate knowledge about the applicability of the diagnostic instruments for primary caregivers and the quality requirements for spiritual care training.

Specific challenges for training in spiritual care

The training was developed in cooperation with the participating health care chaplains, and the central target issue was the 'ABC of spiritual care' for primary health care professionals: the skills in the above diagram, which are summarized as *screening, counselling, assessing, detecting, referring*. The foundation of these skills is understanding how meaning is ascribed to life events from the perspectives of the patients and those who are closest to them. The Guideline describes the features of spiritual care as being attuned to the personal ways in which patients and those closest to them ascribe meaning to their situations, which is a sensitivity that develops from meeting patients in a concrete relationship in a specific (care) context.

In the field of spiritual care, for health care chaplains, these skills were described in the Netherlands as 'diagnostic and hermeneutic competency': 'the ability to interpret the patient's experiences with illness, suffering, invalidity, dependency and the finiteness of life in the light of the patient's life-view framework, by linking the patient's situation with his/her philosophical/ideological tradition.'⁽³²⁾ Training in spiritual care for primary health care professionals would also need to focus on developing these competencies at a basic level. As such, primary health care professionals would need to become conversant with hermeneutical diagnostics to understand the personal sense-making strategies of patients and

proxies while using the available diagnostic instruments for spiritual care. Although there is no consensus among health care chaplains on using diagnostic instruments in professional chaplaincy practice, they agree on the hermeneutical character of diagnostic competency.(43)

Diagnostic instruments can help improve spiritual care in palliative care in two ways.

In training, health care professionals can be taught to develop a sensitivity to the spiritual dimension by being introduced to, and practicing with, diagnostic instruments. In practice, these instruments function as practical tools for primary care and provide a basis for multidisciplinary communication, such as reporting. In contrast to training in medical/nursing-related diagnostic instruments, in which ambiguity creates confusion, primary health care professionals need to become familiar with ambiguity and metaphoric language to develop this hermeneutic competency for working with spiritual diagnostic instruments.

Specific challenges for implementing a spiritual care guideline

Implementing any multidisciplinary guideline to improve the practice of palliative care is a complex intervention.(44) Usually, these interventions are planned as quality improvement projects that integrate new methods into the work processes of the included professional disciplines. For implementing the multidisciplinary guideline on spiritual care(23) in the Netherlands, one challenge was introducing concepts and practical tools for a dimension of care that was not included in basic education for the most important disciplines that care for patients in a palliative trajectory. Health care professionals, specifically physicians and nurses, who are the primary caregivers, are initially educated in the bio-psycho-social model of care(3), in which spirituality is of minor interest. The WHO definition of palliative care explicitly identifies the spiritual dimension as a specific dimension of care that warrants attention, which results in a four dimensional model of care.(2) This new model of care cannot be integrated in practice by health care professionals without any specif-

ic education on the concepts and practical tools of this fourth dimension of spiritual care. At the beginning of this study, there was little research on how to train health care professionals. The only two studies were from Wasner et al.(45) and Put and Cornette,(46) who both reported multiple day courses that would not be applicable in to a hospital context.

The second challenge was that the professionals who were active in the spiritual dimension, such as health care chaplains, were often unaware of how to implement a guideline or protocol into the quality improvement programme in the health care setting. Because both the primary caregivers and the health care chaplains are not familiar with their new roles and tasks for developing spiritual care, our aim was to initiate a process that would lead to the development, implementation and improvement of spiritual care, as described in the national guideline on spiritual care in palliative care.

Action research

Since the quantitative and narrative research methods that are used by health care chaplains were not expected to sufficiently bridge the gap between these stakeholders, we employed a mixed method action research approach. Action research combines action, research and education, and the researcher intervenes in different ways in the investigated context.(47) This intervention has two goals: (1) to induce change in medical practice, and, thus, cause an effect that can be measured and (2) to generate new knowledge, theory or health care strategies. The researcher functions as a type of ‘social change expert’, and helps people who function in a certain context to change in a self-chosen direction. Rappaport’s (48) early definition suggests the following: ‘Action research aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration within a mutually acceptable ethical framework.’ In health care, Koshy, Koshy and Waterman(49) define action research as ‘an approach employed

by practitioners for improving practice as part of the process of change. The research is context-bound and participative. It is a continuous learning process in which the researcher learns and also shares the newly generated knowledge with those who may benefit from it. ... The key concepts include a better understanding, participation, improvement, reform, problem finding, problem solving, a step-by-step process, modification and theory building'

This definition implies that this PhD project should focus the study design on supporting health care professionals who want to improve their practice of palliative care, including spiritual care, following a consensus-based guideline. The study design and research questions should allow the researchers to collaborate with the participating health care chaplains as co-researchers, based on a practical(50) trial protocol that is designed to influence vision and behaviour in the self-chosen direction of evidence-based evaluations of medical and chaplaincy practice.

This multidisciplinary, practice-based action research project specifically includes and explores the needs of health care professionals using different research paradigms and methods. We believed that it was essential to combine these paradigms for the development of multidisciplinary spiritual care; therefore, we chose a mixed method study that includes both quantitative and qualitative methodologies.

Although we have highlighted that it is important to increase awareness within palliative care for spiritual care, attention to the spiritual dimension is also appropriate in acute, curative and chronic care settings. Because health care professionals who provide palliative care appeared to be more aware of the spiritual dimension and due to methodological limitations, we limited this exploratory study to one type of care trajectory and one setting: hospital care for patients in palliative trajectories. Because the coordinating researcher was working in hospital palliative care, we chose this setting at more than one site. We expanded the study to a multicentre trial in teaching hospitals, because these hospitals are often important for disseminating

new methods for practice to peripheral hospitals and other health care facilities in their catchment areas.

Facilitated with a grant from the Dutch Comprehensive Cancer Centre, the lack of knowledge related to implementing the multidisciplinary guideline on spiritual care in palliative care was developed into an elaborate action research project that led to this thesis.

Aim of the thesis

The aim of this thesis is to improve multidisciplinary spiritual care, using an action research design, investigating the application of spiritual care diagnostic tools in training (and practice) for primary health care professionals by health care chaplains.

As such, primary health care professionals and health care chaplains collaborate in a joint learning process to generate knowledge about the practical application of diagnostic tools for spiritual care and quality indicators for spiritual care training in palliative care. This joint learning process seeks to develop new actionable methods for and in cooperation with primary health care professionals and health care chaplains.

In sum, we conclude the following. (1) The diagnostic tools that are recommended in the multidisciplinary guideline for spiritual care in palliative care have not been sufficiently tested in Dutch health care. (2) Physicians and nurses, who often work under time constraints, use diagnostic tools for spiritual care, increasing the risk of a tick-box approach; therefore, training should target the hermeneutical use of diagnostic tools and support patients in exploring or affirming their personal spiritual resources. (3) Health care chaplains' knowledge of health care professionals' use of and training in these tools is too limited to formulate quality indicators for multidisciplinary spiritual care training in palliative care.

Research questions

Our primary research question was ‘What training do primary health care professionals (physicians, nurses) need to use hermeneutical diagnostic tools for multidisciplinary spiritual care and to integrate these tools in their professional practice, with the expert support of health care chaplains?’ This primary research question will be addressed in the general discussion in Chapter 8.

Secondary research questions included the following:

1. What is the baseline situation for the development of multidisciplinary spiritual care in palliative care in the Netherlands in the year 2012?
2. How have teaching hospitals in the Netherlands structured and organized inpatient palliative and spiritual care?
3. What diagnostic tools for spiritual care:
 - a. theoretically correspond to the multidisciplinary guideline,
 - b. correspond with the needs of patients and proxies,
 - c. correspond with the needs of health care professionals and their professional tasks and standards,
 - d. from primary health care professionals’ perspective, are suitable for practical application?
4. How do chaplains concretise spiritual care training for primary caregivers in clinical practice?
5. What is the effect of this training on:
 - a. patients?
 - b. participating health care professionals?
 - c. chaplains?

Method: improving multidisciplinary spiritual care in palliative care by training primary caregivers

To answer these research questions, we initiated a multicentre action research study that was coordinated at the Medical Centre Leeuwarden to test the method and content of a pilot training on spiritual care in palliative care for physicians and nurses. The content, meth-

ods and requirements for this intervention were based on the literature review and expert opinion, and were administered by accredited, local, hospital chaplains in 8 Dutch teaching hospitals.

The effects of this training on the barriers to spiritual care and the primary caregiver's spiritual care competences were measured one month before, and one and six months after the training. We used quantitative methods to measure the effects on patients and primary health care professionals, and qualitative methods to evaluate the effect on health care chaplains.

Patients' in palliative trajectories were identified from intervention and control wards one month before and one month after the training. After being informed about the study and providing consent, these patients completed questionnaires that evaluated their physical, psychosocial and spiritual wellbeing. We measured and compared patients' spiritual needs and their perceived caregivers' focus on their spiritual needs, their quest for meaning and existential questions.

The chaplains were interviewed before and after the training given their roles as trainers and co-researchers.

We present the outline of our study in the following chapters.

Thesis Outline

In **Chapter 2**, 'How spirituality is integrated system-wide in the Netherlands Palliative Care National Programme', we address research question 1: 'What is the baseline for developing multidisciplinary spiritual care in palliative care in the Netherlands in 2012?' This chapter presents the national and international background for this study and describes characteristics of the Dutch context for chaplaincy, spirituality, spiritual care, and palliative care. We also refer to the beginning of the Taskforce on Spiritual Care in the European Association for Palliative Care, and use the EAPC definition of spirituality as the basis for our intervention in combination with the multidisciplinary guideline for spiritual care in palliative care.

In **Chapter 3**, ‘Effects of spiritual care training on patients and health care professionals: a systematic review’, we present 16 selected articles in English, variable in study design and outcomes, concluding that practice and theory of training spiritual care are still developing, showing a tendency towards competency-based education. In the identified best practices, training is part of a quality improvement project, identifying barriers, formulating policy, implementing training aimed at provision of spiritual care as formulated in the policy, and evaluating the effects of the training and the policies.

In **Chapter 4**, ‘Training Spiritual Care in Palliative Care in Teaching Hospitals in the Netherlands: A Multicentre Trial’, we present the study protocol, which includes the methods and measures. This chapter also addresses research question 3a: ‘What diagnostic tools for spiritual care theoretically correspond to the multidisciplinary guideline?’

In **Chapter 5**, ‘Training hospital staff on spiritual care in palliative care influences patient-reported outcomes: Results of a quasi-experimental study’, we address research question 5a: ‘What is the effect of this training on patients?’ This chapter presents the effects of the training on spiritual care with quantitative data based on patient-reported outcomes. Patients in palliative trajectories were identified from the intervention and control wards 1 month before and 1 month after the training, were informed about and provided written consent to participate in the study and completed questionnaires.

In **Chapter 6**, ‘Multidisciplinary training on spiritual care for patients in palliative care trajectories improves the attitudes and competencies of hospital medical staff: Results of a quasi-experimental study’, we address research question 5b: ‘What is the effect of this training on participating health care professionals?’ This chapter presents the results from our second quantitative study. Health care professionals (nurses and physicians) from the participating wards were scheduled for the training, and completed questionnaires 1 month before, as well as 1 and 6 months after the training,

which included self-assessment instruments on barriers to spiritual care and spiritual care competencies.

In **Chapter 7**, ‘Improving Spiritual Care in Hospitals in the Netherlands: What Do Health Care Chaplains Involved in an Action-Research Study Report?’, we address the following research questions: (2) ‘How do second line teaching hospitals in the Netherlands have structured and organized inpatient PC and SC?’; (3) ‘What diagnostic tools for spiritual care correspond with (b) the needs of patients and proxies, (c) the needs of health care professionals and their professional tasks and standards?, (d) from the primary health care professionals’ perspective, are acceptable for practical application?’ (4) ‘How do chaplains concretise training spiritual care to primary caregivers in clinical practice?’; and (5c) ‘What is the effect of this training on chaplains?’ This chapter describes the findings from our qualitative study that is based on pre- and post-intervention interviews with health care chaplains in their role as co-researchers and trainers of spiritual care.

In **Chapter 8**, the ‘General discussion’, we summarize and integrate our findings and present recommendations for the research, education and implementation of spiritual care in palliative care, as well as health care in general.

In an **Epilogue**, ‘Traveling companions and foremen’, we present a theological reflection on this research project with a personal, spiritual elaboration of the first topic in Legets Ars Moriendi:(40,41) autonomy, the dynamic tension between oneself and the others, and/or the Other.

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2

How spirituality is integrated system-wide in the Netherlands Palliative Care National Programme



Chapter 2. How spirituality is integrated system-wide in the Netherlands Palliative Care National Programme

Joep van de Geer¹, Carlo Leget²

¹Medical Centre Leeuwarden, Chaplaincy Department, Leeuwarden, The Netherlands,

²Department of Culture Studies, Tilburg University, Tilburg, The Netherlands.

Abstract

After the decline of the compartmentalisation of Dutch society, where healthcare was being organized along confessional / denominational lines, spirituality became neglected or implicit for decades in The Netherlands healthcare system. During the modernisation of healthcare in the 1960s, the development of professional language concerning chaplaincy and psychosocial care in a secularising society created a blind spot for this fundamental dimension of care. From the moment palliative care in the Netherlands became part of a national programme, healthcare providers, policymakers and researchers were presented with the challenge of reassessing this complex concept. National policy and personal initiatives on research and education connected in an inspiring process that led to a Dutch, consensus-based national guideline for multidisciplinary spiritual care as part of palliative care, the adjustment of the professional standard of healthcare chaplaincy in the Netherlands and the initiative for a European Taskforce on Spiritual Care. In the appendices of this paper the first English-language summary of the Dutch guideline on spiritual care and the European Association for Palliative Care (EAPC) definition of spirituality are presented.

Keywords: Chaplaincy, Healthcare system, Multidisciplinary guideline, Palliative care, Spiritual care

Introduction

In Dutch healthcare organisations, ‘spirituality’ or ‘spiritual care’ were not frequently used concepts until recent palliative care developments (referring to the WHO definition of palliative care) reintroduced these words. The word ‘spirituality’ (NL: *spiritualiteit*) is a familiar word in Dutch language in some Christian traditions, and the concept is used in contemporary esoteric and new age publications. It has never been used, however, to refer to the practice of healthcare chaplains, nor to the spiritual dimension of nursing or medicine. It was only after 2001 – the year in which the Dutch government placed the integration of modern hospice and palliative care on the agenda of regular healthcare organisations(1) that healthcare providers and administrators were confronted with spirituality as a concept. Its prominent place in the WHO definition of palliative care challenged healthcare chaplains and researchers to explain how this rather vague concept, which is often used outside of the context of healthcare, related to the developments in the Dutch healthcare system.

In this paper we will describe how spiritual care was incorporated into the Dutch healthcare system and how the answer to the challenges this posed laid the foundation for a Dutch multidisciplinary consensus-based guideline on spiritual care in palliative care. Finally, the paper also explores how this resulted in the Dutch initiative known as the ‘Taskforce on Spiritual Care in the European Association of Palliative Care’.

Characteristics of the Dutch context

In trying to establish a new role during the modernisation of healthcare in the 1960s and 1970s, healthcare chaplains in the Netherlands organised themselves into a multidenominational professional organisation.(2) Prior to this point, Catholic and Protestant clergy had held respected positions in healthcare institutions. In non-denominational settings, local churches offered chaplaincy, and this

service was mostly restricted to the members of these churches. The title or name of the spiritual caregiver's profession and function reflected the denominational preferences.

From the foundation of the Dutch Association of Spiritual Caregivers in Healthcare Institutions (VGVZ)(3) in 1971, healthcare professionals from another influential denomination, the humanistic counsellors, applied and were welcomed as members. The association organised itself in denominational sectors and later also in working fields (hospitals, nursing homes, psychiatry, care of the mentally handicapped, etc.). Although the word 'spiritual' has a central place in the English translation of the profession of 'spiritual caregiver', in Dutch the new organisation did not choose the Dutch term 'spiritueel', but rather the more neutral or broader 'geestelijk'. (In Dutch the words 'spiritueel' and 'geestelijk' are synonyms. Both can be translated in English as *spiritual*. In Dutch 'geestelijk' refers also to the intellectual and mental capacities of a person and 'spiritueel' also refers to the immaterial world.) In fact, the foundation of this multid denominational professional organisation created a new word in Dutch healthcare in order to define 'the professional assistance and guidance to people in fundamental questions of life, sickness and death, given from and based on faith and philosophy of life'.(2) To a certain extent, this definition reflects the period in which the Netherlands seemed to take the lead in secularization in north-west Europe. At that time, the concept of spirituality was probably too associated with traditional belief systems, and insufficiently rooted in the new professional multidisciplinary language in modern Dutch healthcare, to be used without negative traditionalist associations. In search of its identity, the Association was a place of intense debate and this definition of healthcare chaplaincy was eventually amended in 2002 to 'the professional and official guidance of and caregiving to people in the process of seeking meaning for their existence, from and on the basis of religious and existential convictions, and professional consultation in ethical and philosophical aspects of healthcare and management'.(4) Note that even in this definition spirituality

was not explicitly mentioned, although concepts such as ‘seeking meaning’, ‘existence’ and ‘existential convictions’ could be seen as referring to spirituality, as reflected in recent literature.(5)

This linguistically peculiar situation was one of the reasons why spirituality was often neglected or implicitly implemented in psychosocial care. As a result, healthcare chaplains had to establish their role within a bio-psycho-social model of healthcare, without using an important part of their specific expertise: the language of spiritual care. Because of this, the healthcare chaplaincy professionalised and integrated into modern healthcare with a professional profile, handbook and requirements for further professionalization, including clinical pastoral education. This tension led to an ongoing, internal professional debate on how to integrate a multid denominational chaplaincy in healthcare without the loss of its common identity, which was based on its specific expertise and approach. The need for integration was generally felt, but, where the specific approach was at stake, healthcare chaplains often referred to their extraordinary sanctuary function. Healthcare chaplains were not eager to share information about their patients, as they tended to treat all communication with patients as belonging to the secret of the confession. Healthcare chaplains and spiritual caregivers had to interpret and explain their professional activities within the dominant bio-psycho-social model of care.

Consequently, the translation and implementation of the WHO definition of palliative care and its four dimensions, including spirituality, created confusion among healthcare providers and chaplains. In the first place, there was no consensus about what this concept of ‘spirituality’ might mean. Moreover, the concept hardly seemed to be necessary since spiritual care had until then been seen as a specific part of psychosocial care. The first translations of the WHO definition of palliative care reflected this situation by changing the phrase ‘spiritual’ into ‘existential’. And in the first Dutch Master Class on Spirituality and Healthcare Chaplaincy in Palliative Care (2007),(6) chaplains were reluctant to adopt the concept of spiritual-

ity. A fierce, fundamental discussion showed that there were individual preferences for other central concepts (seeking meaning, existential, fundamental life questions), and that there was a fear of being taken less seriously by other professionals and being seen as associated with representatives of trendy, popular or vague spiritual movements. But this discussion did not last long. In the third group of this master class (2008), resistance to the use of the concept of spirituality had disappeared. The awareness that active participation in the development of palliative care in the Netherlands created new opportunities grew rapidly. This active participation contributed to a new multidisciplinary understanding of spiritual care, as described in this paper, which might lead to a renewed integration of healthcare chaplaincy in the Netherlands.

As a result of the prior conceptual and linguistic confusion it was hard to engage in or make use of international discourse and research on spiritual care. Nevertheless, the Dutch National Palliative Care Programme challenged healthcare providers to improve palliative care for all patients in all four dimensions. What were the characteristics of this programme?

Main goals and characteristics of the Dutch Palliative Care Programme

Until the 1990s, palliative care in the Netherlands was hardly stimulated by the government in any national programme. In the public debate about euthanasia, palliative care pioneers acted as the opponents of the practice's regulation. And it was only after this debate was 'settled' – a typically Dutch phenomenon meaning that a discussion is considered to be over and done with – that palliative care could be further developed and stimulated in the healthcare system. At that time most people with severe illness were treated in hospitals and nursing homes. Without explicitly using the modern concept of palliative care, the quality of care in nursing homes had been developed in a comparable way to palliative care (multidisciplinary and patient centred). One of the key factors in this process was the de-

velopment of a new medical specialty, an ‘elderly care physician’, which at that time was called ‘nursing home medicine’ in Dutch. Being confronted with the definition and methods of palliative care, the reaction of many nursing home physicians and nurses was one of recognition and familiarity.

In the 1980s and early 1990s, palliative care in the Netherlands was still a pioneer movement, with a few ‘nearly-home facilities’ and ‘high-care’ hospices. A national organisation to stimulate and develop palliative care for terminally ill patients in the Netherlands was founded in 1996. In 2009, in a new section of the European Journal of Palliative Care, Arianne Brinkman(7) gives a brief summary of the two-decade development of palliative care in the Netherlands:

at the end of the 1990s the Dutch government began to take an interest in palliative care and started a national programme to stimulate service development and improvement in the quality of palliative care. ‘Palliative Care in the Terminal Phase’ by ZonMw the Netherlands Organisation for Health Research and Development was the first programme. It focused on promotion of expertise, needs planning and structural change. After that the government initiated centres for the development of palliative care (departments of regional Comprehensive Cancer Centres). The Hospice Care Integration Project group focused on integration of hospice facilities into mainstream healthcare. Based on the results government guidelines were drawn up, which stated that:

- *palliative care should focus on achieving the best possible quality of life for patients, according to the WHO definition,*
- *palliative care should remain, as much as possible, part of mainstream healthcare; general care providers should be supported by, and get advice from, specialised, multidisciplinary consultation teams,*
- *there should be co-operation within palliative care networks to ensure that care is organised as well as possible*
- *there should be support, on a national level, by the Agora Foundation (National Platform for Palliative Care) and by the palliative care departments in the Comprehensive Cancer Centres.*

Palliative care became an important point of focus for government policy at the beginning of the 21st century. Funding for network development, for volunteer coordination and structural financing for palliative units in nursing and care centres became available.

In 2006 the Comprehensive Cancer Centres in the Netherlands published their second practice-based and practice-oriented multidisciplinary guidelines for the practice of palliative care.(8) In the 768 pages of this book, the word 'spiritual' was only mentioned twice in the index, and referred only to the guideline on existential crisis. This guideline was written from a more psychological perspective, and hardly dealt with the broader practice of spiritual caregivers.

The National Programme for Palliative Care 2008–2010 included three themes: 1) the organisation and financing of palliative care, 2) the improvement of quality of palliative care and transparency, and 3) education and advancement of professionalism. The new government has ordered ZonMw to elaborate a new Improvement Programme, which is to come out in 2012.

Spirituality emerging as a theme: initiatives and choices.

In 2006 both new professors on palliative care in the Netherlands Zuurmond and Vissers articulated the need to integrate spiritual care in clinical practice, research and education.(9,10) In the same year, the Agora Foundation appeared to be a very strong supporter for the development of spiritual care in the Dutch healthcare system. Its working group on ethics had extended its name to ethics *and* spiritual care, and called attention to the fact that there was an important omission in the 2006 publication of the multidisciplinary guidelines. This group decided to develop a multidisciplinary guideline on spiritual care in order to establish the fourth dimension of palliative care more firmly, and they consequently contacted the editors of the national guidelines. The editors were positive about this initiative and challenged the group to integrate the existing guideline on existential crisis(11) into the new guideline on spiritual care.

In the same year, healthcare chaplains who were looking for postgraduate education on spiritual care in palliative care discovered that there was no such course available in the Netherlands. In Rotterdam there was a course in 'Teaching the Teachers' in palliative care, based on an international concept of developing an international community of teachers in palliative care.⁽¹²⁾ This course included a focus on spiritual care within palliative care, and the course's organisers expected healthcare chaplains to engage in its development. During the course, the need was stated for monodisciplinary training for healthcare chaplains on spirituality and palliative care. The internationally experienced educators made a connection between Dutch experts and a German expert⁽¹³⁾ who already had years of experience in mono- and multidisciplinary courses on spiritual care in palliative care in Germany. As a result of these connections, a programme for healthcare chaplains with international and national experts, entitled 'Master class spirituality and chaplaincy in palliative care', was established. Both the Comprehensive Cancer Centre in Groningen and the VGVZ were willing to support this course as a pilot. The response from chaplains all over the Netherlands was overwhelming, and, within a timeframe of three years, 117 chaplains (humanistic, protestant and catholic) had been trained. Compared to the number of members of the VGVZ (about 825), this shows how the initiative served the need to clarify the concept of spiritual care and the position of chaplains in its development.

This master class opened a new view for Dutch healthcare chaplains on the connection between their work and the international debate on spirituality and spiritual care based on the WHO definition. First drafts of the multidisciplinary guideline were discussed in these master classes. It gradually became clear that a guideline on spiritual care should be written primarily for doctors and nurses, and that the commitment of chaplains was needed as experts in this field. During the comment phase of the guidelines, the discussions were intense and vivid. However, after all the reactions had been processed, the editors accepted the final draft, which was published as a consen-

sus-based guideline on spiritual care in the third edition of the practice-based multidisciplinary guidelines for the practice of palliative care in 2010 (for a summary of this guideline, see Appendix 1).(14) In the same year the VGVZ amended the professional definition by introducing the concept of spirituality into their professional standard for healthcare chaplaincy.

Within the same timeframe, the Agora working group on ethics and spiritual care started two other national initiatives that were financially supported by the Dutch government. First, an inventory on expert opinion regarding competencies for spiritual care was created,(15,16) and, second, expert meetings and invitational conferences on the question of how to further develop spiritual care in palliative care in the Netherlands were organised. Both initiatives resulted in publications based on expert opinion and consensus, which were brought to the attention of policymakers by Agora's National Platform for Palliative Care. The last publication has the expressive title *Spiritual care, connecting link in palliative care.*(16)

As a result of these developments, in 2011 the Dutch government mentioned spiritual care as one of the items that will be elaborated upon in a new improvement programme for palliative care.(17)

The actual Dutch situation on spiritual care in palliative care, and its impact on system and practice

Can we say that spirituality is integrated system-wide in the Netherlands Palliative Care National Programme? System-wide integration would be a very pretentious claim. Yet professionals and organisations are making progress with regard to new understandings and practices of spiritual care. An important infrastructure has thus been built in recent years, consisting of:

- a consensus-based multidisciplinary and multid denominational guideline on spiritual care in palliative care;
- an inventory of competencies for spiritual care;

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- the introduction of the concept of spirituality in the Dutch professional standard of healthcare chaplaincy;
- a vision on the development of spiritual care; and
- recognition of the importance of spiritual care by the Dutch government.

The acceptance by the editors of the multidisciplinary guidelines for the practice of palliative care of this new guideline on spiritual care is huge. These guidelines are valued by the experts in the multidisciplinary consultation teams throughout the country. The fact that the guideline is consensus based gives caregivers and researchers common ground for practice, education and research. Together with the inventory of competencies of spiritual care, the guideline can contribute to the integration of spirituality in the current national project on competencies for palliative care for all healthcare disciplines. The introduction of spirituality in the professional standard of healthcare chaplaincy expresses the willingness of the majority of healthcare chaplains to contribute to the development of this vital dimension of palliative care.

The EAPC Taskforce Spiritual Care

From the start, members of the Agora working group on ethics and spiritual care oriented themselves on the international debate and research on spirituality. Visiting the congresses of the European Association for Palliative Care (EAPC), they witnessed a significant difference in the quality of presentations and contributions on spirituality in each programme. Scientific and organising committees of these congresses showed interest in this important dimension of palliative care often by inviting national or regional experts. But these contributions lacked a common conceptual basis and were not connected to an ongoing debate. Within the Dutch delegation, the need was felt for a more integrated approach on spirituality within the EAPC. Encouraged by the publication of the Report of the 2009

National Consensus Conference(18) in the United States they wondered: would it be possible to form a platform for exchange of successful training programmes, guidelines, standards, educational projects and research in Europe? Exchange of good practice and development of spiritual care in Europe is not easy because it is integrated in its cultural and linguistic context. Most publications relevant to spiritual care in palliative care are, by their very nature, written in the native language of the primary caregivers.

The Agora Foundation, supported by the Dutch government, organized an invitational conference in October 2010 where 13 participants (doctors, nurses, chaplains, researchers) from eight European countries exchanged and discussed background information on each country and the perception of the field of spirituality in healthcare and its problems.(19) Furthermore, they elaborated a working definition of spirituality (Appendix 2), a mission statement for an EAPC Taskforce on Spiritual Care in Palliative Care, and identified and prioritised four key areas of work: service improvement, strategic planning, research and education. In May 2011 the Taskforce had its first official meeting in Lisbon. A total of 37 congress participants from 14 European countries joined this meeting and formed three working groups: research, education and implementation/recognition. From the outset, the Taskforce had a good balance from a multidisciplinary perspective: twelve primary caregivers (eight doctors and four nurses), thirteen spiritual care providers (catholic and protestant chaplains, humanistic counsellor, philosopher), nine researchers (using various scientific paradigms) and three other professionals (psychologist, social worker, policymaker). The Taskforce has an open character and expects its participants to form or use their own national structures to connect and communicate on a national level. All three international and multidisciplinary groups are coordinated from different European countries: research from the United Kingdom, education from Germany, implementation and recognition from Italy and the steering committee is facilitated by the Agora Foundation in the Netherlands.

By definition EAPC taskforces have a two-year life cycle. At the first meeting participants decided to accept the working definition on spirituality for the next two years, made feasible plans for this first period and welcomed the written invitation to collaborate from the director of the George Washington Institute for Spirituality and Health (GWish), Dr Christina Puchalski. For all three working groups, the first step seemed to require making a map or inventory of successful training programmes, guidelines, standards, educational programmes and research projects. Meetings of the Taskforce will be held at the biannual EAPC congresses and the biannual EAPC scientific congresses. The coordinators of the working groups and the steering committee will have to attract their own funding for attending meetings, translation services and for facilitating this process.

Conclusion

The development of contemporary palliative care within the regular healthcare system in the Netherlands challenged practitioners, researchers and policymakers to reassess the concept of spirituality in palliative care. Within a few years (2007–2011) resistance and scepticism with regard to the necessity and usefulness of the concept gave way to a consensus and willingness to develop the practice of spiritual care.

Key factors in this process were: the existence of an independent national platform on palliative care, where experts could meet and were supported in joint projects; the fact that this process started bottom-up, building on practice-based expert consensus which gradually became confirmed top-down; and the commitment of individuals and other official stakeholders.

The infrastructure is almost finished, and the local practice of spiritual care still varies as before. Key success factors in developing a qualitative multidisciplinary practice of spiritual care seem to be:

- the development, validation and education of practical tools for the primary caregivers in the Dutch context;

- the quality of the input to this process from chaplains as experts, locally as well as in research and implementation (although there are still questions to be solved about e.g. the need for specialized spiritual consultants(20) in palliative care consultation teams);
- the content of the paragraph on spiritual care in the next national programme on palliative care;
- building fruitful cooperation between physicians, nurses and chaplains serving the patients' (and relatives') spiritual needs, based on research methods appropriate to the multidisciplinary and multidimensional concept of spirituality.

In the Netherlands, the creation of the EAPC Taskforce, and the cooperation within this organisation, can be seen as offering promising support for the process of developing multidisciplinary spiritual care in palliative care.

Appendix 1: English summary of Dutch Guideline on Spiritual Care in Palliative Care.

The guideline is primarily written for doctors and nurses, without excluding caregivers of other disciplines, nor volunteers. The guideline offers a practical guide to distinguish between:

- A. situations where ordinary attention for patients life or vital questions in care;
- B. situations where patient need guidance on this or are going through a normal struggle were guidance by an expert can be valuable;
- C. situations where the wrestling with the life or vital questions are leading to an existential crisis that needs crisis intervention by a chaplain, social worker or psychologist.

The position of spirituality is seen as the most intimate and hidden dimension, less measurable than the other three, but continuously in a relation of mutual influence (see Figure 1.).

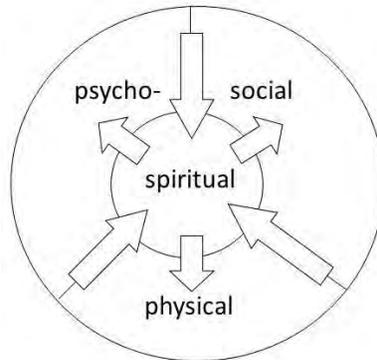


Figure 1 The position of spirituality.

Spirituality is defined as the 'philosophical/life reviewing functioning of man, to which questions of experiencing meaning and giving meaning can be accounted'. Spirituality is related to all possible – from religious to everyday – sources of inspiration. For some people

the accent is on the emotional inner life (e.g. prayer, enjoying nature, literature music, art) or activities (meditation, performing or participating in rituals, or putting effort for a good cause), others experience it more intellectually (contemplation, study). Spirituality influences our entire existence, is dynamic, and has more to do with the source of our attitudes than with a defined area of life.

Spiritual care has three characteristics:

1. attention for this dimension of care is important from the early beginning of the palliative phase, so that questions and expressions in the whole of the spiritual process can be seen / understood;
2. there are always different layers of meaning in language in this dimension of care that interconnect; many expressions of patients or proxies can be understood on different levels:
 - physical level: as an expression with regard to the physical dimension, a verifiable or factual state,
 - psychological level: as an expression of thoughts, images, feelings hidden in the expression,
 - social level: as an expression of the social environment to which the person is connected, expressing a part of his identity,
 - spiritual level: expressing ultimate concerns, inspirations and meaning, often connected with ordinary things in life.
3. it usually concerns questions and expressions to which no solution can be given, demanding presence, attention and commitment.

Development and progress of spiritual processes in palliative care are considered to be similar to development and progress of an existential crisis. Phases can be distinguished as confrontation with approaching end of life, loss of grip, loss of meaning/sense, grief, finding/experiencing, meaning/sense, integration of giving and experiencing meaning/sense. Spiritual distress can be missing. When the spiritual process is blocked it can be seen as an existential crisis. Although it is stressed that spiritual needs should not be treated in a

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problem-oriented approach. Also, positive spiritual needs (as for example celebrating one's life) demand attention and commitment. Primary caregivers have an important role in identifying and opening up spiritual themes and needs. Two kinds of diagnostic instruments are given for screening and history taking. For screening a translation is given of the Mount Vernon Cancer Network spirituality assessment tool(21) with its three cue questions: 1. How do you make sense of what is happening to you? 2. What sources of strength do you look to when life is difficult? 3. Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith? For history taking, first the FICA and SPIRIT tools are given in English with the comment that both of them are functioning in the North American context. Both instruments are not yet tested or used in Dutch. Additional to them, the Dutch *Ars Moriendi* Model (art of dying) of Leget is given with its central concept of *inner space*.(22)

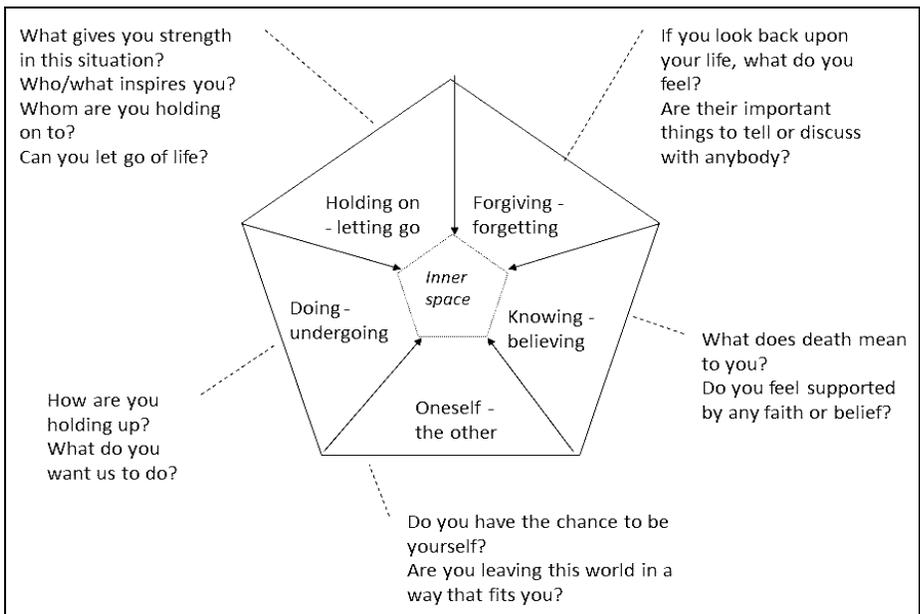


Figure 2 Ars Moriendi Model.

The state of mind that enables one to be aware of one’s actual thoughts and feelings without being overthrown or swept away by them. Spiritual care is directed to the restoration or enhancement of that inner space of the patient, the family and/or the caregiver. In this model Leget distinguishes between 5 fundamental themes that appear as dynamic tension fields when end of life is near. Themes that can be approached from or within the inner space not as choices (either ... or ...) but as tensions (both ... and ...).

For the treatment of spiritual needs or practice of spiritual care the guideline states that it is by definition a multidisciplinary activity. Cooperation is designated but the various disciplines have their own role and task. Based on the distinction between A. situations that need attention, B. situations that need guidance and C. situations that need crisis intervention the role of different caregivers can be situated as in Table 1 Forms of spiritual care.

		Doctors, nurses	Medical social workers, psychologists	Health care chaplains	
	<i>Primary focus, access and frame of reference</i>	<i>Somatic</i>	<i>Psychosocial</i>	<i>Spiritual</i>	
A	Attention <i>(always)</i>	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening, interpreting	Representing and connecting
B	Counselling <i>(at patient's request)</i>	Following the search process, referring, assessing	Following the search process, referring (->) assessing	Following the search process (<-) referring assessing, interpreting and appraising	
C	Crisis intervention <i>(if indicated)</i>	Detecting, referring	Recognizing, counseling, treating referring (->)	Recognizing, counseling, (sometimes) treating, (<-) referring interpreting and appraising	

Table 1 Forms of spiritual care

Appendix 2: EAPC Working definition 2010 on Spirituality

Between 15 and 17 October in Werkhoven, the Netherlands,(19) thirteen palliative care professionals from various backgrounds and eight countries considered the North American ‘consensus definition of spirituality’ to be an important development. They used it as a foundation and, from a European perspective, felt the need for adjustments:

- The phrase ‘Spirituality is the aspect of humanity’ implies that spirituality is but one more component of being human, rather than that which infuses every aspect of human experience ...
- The phrase ‘the way individuals seek’ reinforces an overly individualistic approach to human spirituality, and glosses over the fact that the individual spirit is born into, and thrives within, a community.
- The phrase ‘seek end express meaning and purpose’ seems to limit spirituality to a concern with meaning-making, and leaves it open to being understood as a purely conscious process, whereas much meaning-making is unconscious.
- ... the importance of including transcendence in any definition of spirituality, on the understanding that transcendence, ..., conveys the sense that human beings experience themselves as more than just physical beings. The term is open to being interpreted as psychological transcendence, and /or as implying transcendence in a more traditionally religious sense.

EAPC definition on spirituality:

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and / or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and / or the sacred.

The spiritual field is multidimensional: 1. Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt

and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy). 2. Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself). 3. Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).

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3

Effects of spiritual care training on healthcare professionals and patients in palliative trajectories: a systematic review



Chapter 3. Effects of spiritual care training on healthcare professionals and patients in palliative trajectories: A systematic review

Authors: Joep van de Geer¹, Jan Willem Uringa¹, Ingeborg van Dusseldorp¹, Carlo Leget², Jelle Prins¹, Hetty Zock³, Kris Vissers⁴.

Authors' information

¹ MCL-Academy, Medical Centre Leeuwarden, Leeuwarden, the Netherlands.

² Department of Care and Welfare, University of Humanistic Studies, Utrecht, the Netherlands

³ Faculty of Theology and Religious Studies, University of Groningen, Groningen, the Netherlands

⁴ Department of Anesthesiology, Pain- and Palliative Medicine, Radboud UMC, Nijmegen, the Netherlands.

Abstract

Background: Patients value spiritual care provided by health care professionals, and several studies have indicated that spiritual care provision is positively associated with spiritual care training. The growing number of publications about spiritual care training illustrates that the theory and practice of spiritual care training are still developing.

Aim: To identify the described effects of spiritual care training on patients and healthcare professionals and possible quality indicators useful for training optimization.

Design: Systematic review following PRISMA guidelines.

Data sources: PubMed, Embase, Wiley/Cochrane, EBSCO/ PsycINFO, EBSCO/ERIC and EBSCO/CINAHL, searched from inception up to January 20, 2016. PICO: P = spiritual care for pa-

tients in palliative trajectories in hospitals and other healthcare institutions (including hospices), I = care/treatment performed by healthcare professionals trained in spiritual care, C = care/treatment performed by healthcare professionals not trained in spiritual care, and O = effects of training on quality of care, physical, psychosocial or spiritual symptoms, effects on healthcare professionals attitudes, perceived barriers, skills and competencies.

Results: A total of 16 selected articles written in English were identified and were variable in study design and outcomes.

Conclusions: The practice and theory of training spiritual care are still developing, showing a tendency towards competency-based education. In the identified best practices, training is part of a quality improvement project, following a plan-do-check-act cycle by an initial audit to identify barriers, formulate policy, implement training aimed at provision of spiritual care as formulated in the policy, and evaluate the effects of the training and the policies.

What is already known about the topic?

- The rarity of spiritual care may be primarily due to the frequent lack of spiritual care training.
- Most reported barriers for spiritual care provision are the understanding (who, what, and when) of spiritual care and staff education regarding spiritual care.
- The research literature is still developing and shows a growing consensus on defining spiritual care and a growing number of spiritual care standards.

What this paper adds?

- This paper reports the results of a systematic review of publications reporting effects of spiritual care training on patients and healthcare professionals (nurses, physicians, and healthcare chaplains) and possible quality indicators useful for the optimization of training.

- This paper presents a qualitative analysis of 16 studies after eligibility selection of 88 full-text articles.
- Publications on spiritual care training theory, methods and outcome measures are still too limited and too diverse to perform a quantitative analysis.
- The selection shows a tendency towards competency-based training in spiritual care.

Implications for practice, theory or policy?

- In Where national standards on the provision of spiritual care are still lacking, they need to be developed to provide aims and measurable outcomes for spiritual care training.
- Spiritual care training is expected to be optimal when it is part of a quality improvement project, based on a plan-do-check-act cycle, starting with an initial audit to identify barriers, followed by formulating a policy, implementing training aimed at provision of spiritual care as formulated the policy, and evaluation of the effects of the training and the policy.

Keywords: palliative care, spiritual care, training, quality improvement.

Introduction

Researchers and decision makers, looking for guidance in the research literature in the development of spiritual care (SC) in palliative care (PC), find a growing consensus in the literature between practitioners and researchers across various healthcare disciplines, resulting in the publication of multidisciplinary consensus documents on SC, such as in the United States(1) and Europe.(2,3) This formal consensus developed to a broader, global base in subsequent consensus conferences.(4) Cockell and McSherry(5) provided an overview of published international research between 2006 and 2010 to provide nurse managers with evidence to inform their spiritual care training, planning and delivery. The authors strongly advocated for

patient involvement in SC research and emphasized the need for research that is translatable into contexts other than the setting under study. While studying the reasons for the infrequency of SC at the end of life to implement new national standards, Balboni et al.(6) concluded that the rarity of SC may be primarily due to the frequent lack of SC training.

The research subgroup of the Taskforce on Spiritual Care of the European Association for Palliative Care (EAPC)(7) confirmed this need for training in their publication of research priorities, based on an international survey among 971 palliative care researchers and clinicians. From a list of 15 pre-formulated research topics, the highest priority was the development and evaluation of conversation models and overcoming barriers to SC in staff attitudes. The most reported barriers were the understanding (who, what, and when) of SC and staff education regarding SC.

The education subgroup of this EAPC task force discovered that the theory and practice of SC training still varied too much to give a systematic overview of the effects of such training. Based on this survey, including 36 courses in 14 (mostly European) countries, nine recommendations were formulated:(8) 1. although many courses are designed for all healthcare professionals, it is important to be clear about the tasks and goals of each one (who should be doing what); 2. to develop online learning platforms, information exchanges and mentoring methods to reach larger numbers of professionals and volunteers; 3. to integrate spiritual care training in broader palliative care courses, embedding these core skills in palliative care practice generally and not as an additional part of the service; 4. to develop courses on core competencies in self-reflection, theory and integration into daily practice; 5. to formulate clearly stated aims, use theoretical and practical exercises and create a safe environment; 6. to develop long-term ongoing performance evaluation and assessment methods, such as regular briefings, check-ups and mentoring, to ensure lasting results; and 7. to use or connect to single, recognized (consensus) definitions of spiritual care.

Meanwhile, a growing number of chaplaincy organizations(9,10) realized that working in modern healthcare means being accountable and understandable to other healthcare disciplines and decision makers. To clarify their specific contribution to the development of multidisciplinary SC and to communicate the effects of their interventions, chaplaincy needs to develop new research methods and become more evidence-based, similar to other healthcare disciplines, as Handzo et al. formulated in their 'International call to action'.(11) Yet, the 2012 systematic review of Candy et al.(12) clearly defined the boundaries of what is acceptable within the medical discourse. The authors demonstrated that the methods applied in evidence-based medicine do not spontaneously match with the methods for research and development of knowledge in philosophical and religious traditions. Candy et al. found a lack of theoretical consensus combined with methodological weaknesses in the included studies, which added up to inconclusive evidence whether or not interventions with spiritual or religious components for adults in the terminal phase of disease enhanced well-being. Future researchers are advised to design clearly delineated studies reproducible in other settings, with a clear theoretical base, delivered by appropriately trained people who follow guidelines, understanding the aim of the intervention and restraining from emphasizing their own beliefs.

Building forth on the publication of the education group of the EAPC taskforce, we wanted to search for effective training methods for SC since SC provision is positively associated with SC training, as Epstein-Peterson et al. indicated.(13) Our objectives were to identify the described effects of training SC on patients' symptoms or well-being and healthcare professionals' (nurses, physicians, and healthcare chaplains) competencies or behaviour in quantitative, or mixed-method studies based on (consensus-based) definitions of spirituality and to identify possible quality indicators useful for the optimization of SC training.

Methods

This systematic review, conducted according to the methods outlined by the PRISMA statement,(14) is part of a larger research project(15) that was performed in the Netherlands. The only standard for SC in the Netherlands is a multidisciplinary guideline for SC in PC; therefore, we will limit ourselves to PC in this review, although we realize that the growing global development and consensus on research, practice and education of SC does not limit itself to PC, as demonstrated in *The Oxford Textbook of Spirituality in Healthcare*(16).

Eligibility criteria, information sources, search strategy

The PICO (P – patient, problem or population; I – intervention; C – comparison, control or comparator; and O – outcome) was formulated as follows: P = SC for patients in palliative trajectories in hospitals and other healthcare institutions (including hospices), I = care or treatment performed by healthcare professionals trained in SC, C = care or treatment performed by healthcare professionals not trained in SC, and O = effects of training on quality of care, physical, psychosocial or spiritual symptoms, effects on healthcare professionals attitudes, perceived barriers, skills and competencies.

Information sources

In cooperation with an information specialist (IvD), the following databases were searched from inception up to January 20, 2016: PubMed, Embase, Wiley / Cochrane, EBSCO / PsycINFO, EBSCO / ERIC and EBSCO / CINAHL.

The primary concepts of the search strategy were spirituality, PC and training. The search can be reproduced by adding the Boolean operation AND in between the different search sets.

The search terms in Embase, EBSCO/PsycINFO, Wiley / Cochrane, EBSCO/ERIC, and EBSCO/CINAHL were derived from the search terms used in PubMed and are available from the author upon request.

Primary search terms	Search string used
Spirituality	(holistic*[Title/Abstract] OR spiritual*[Title/Abstract] OR wholistic*[Title/Abstract] OR "Holistic health"[Mesh] OR "Religion and Psychology"[Mesh] OR "Holistic Nursing"[Mesh] OR "Religion and Medicine"[Mesh] OR "Chaplaincy Service, Hospital"[Mesh] OR religio*[Title/Abstract] OR "Existentialism"[Mesh] OR existential*[Title/Abstract] OR meaning*[Title/Abstract])
Palliative care	("Palliative medicine"[Mesh] OR "Palliative Care"[Mesh] OR "Hospice Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Terminal Care"[Mesh] OR palliat*[Title/Abstract] OR hospice*[Title/Abstract] OR end of life care[Title/Abstract] OR EOL care[Title/Abstract] OR terminally[Title/Abstract])
Training	("Education"[Mesh] OR education[sh] OR education*[Title/Abstract] OR training*[Title/Abstract] OR workshop*[Title/Abstract] OR trainer*[Title/Abstract] OR assessment*[Title/Abstract] OR coach*[Title/Abstract] OR teach*[Title/Abstract] OR "Health Personnel/education"[Mesh])

Table 1. Search strategy in PubMed

Study selection

Studies in all languages were included to prevent bias. Furthermore, there were no restrictions with regard to publication year. Studies of all methodologies (quantitative, qualitative and mixed-method design) were included.

Publications were included describing effects of SC training on healthcare professionals' (physicians, nurses, and chaplains) competencies or behaviours and/or effects on patients' symptoms or well-being in quantitative or mixed-method studies based on (consensus-based) definitions of spirituality.

Poster abstracts and abstracts of oral presentations were included; one study based on alternative therapeutic interventions was excluded. Finally, 16 publications were included in the analysis.

3. Effects of spiritual care training – systematic review

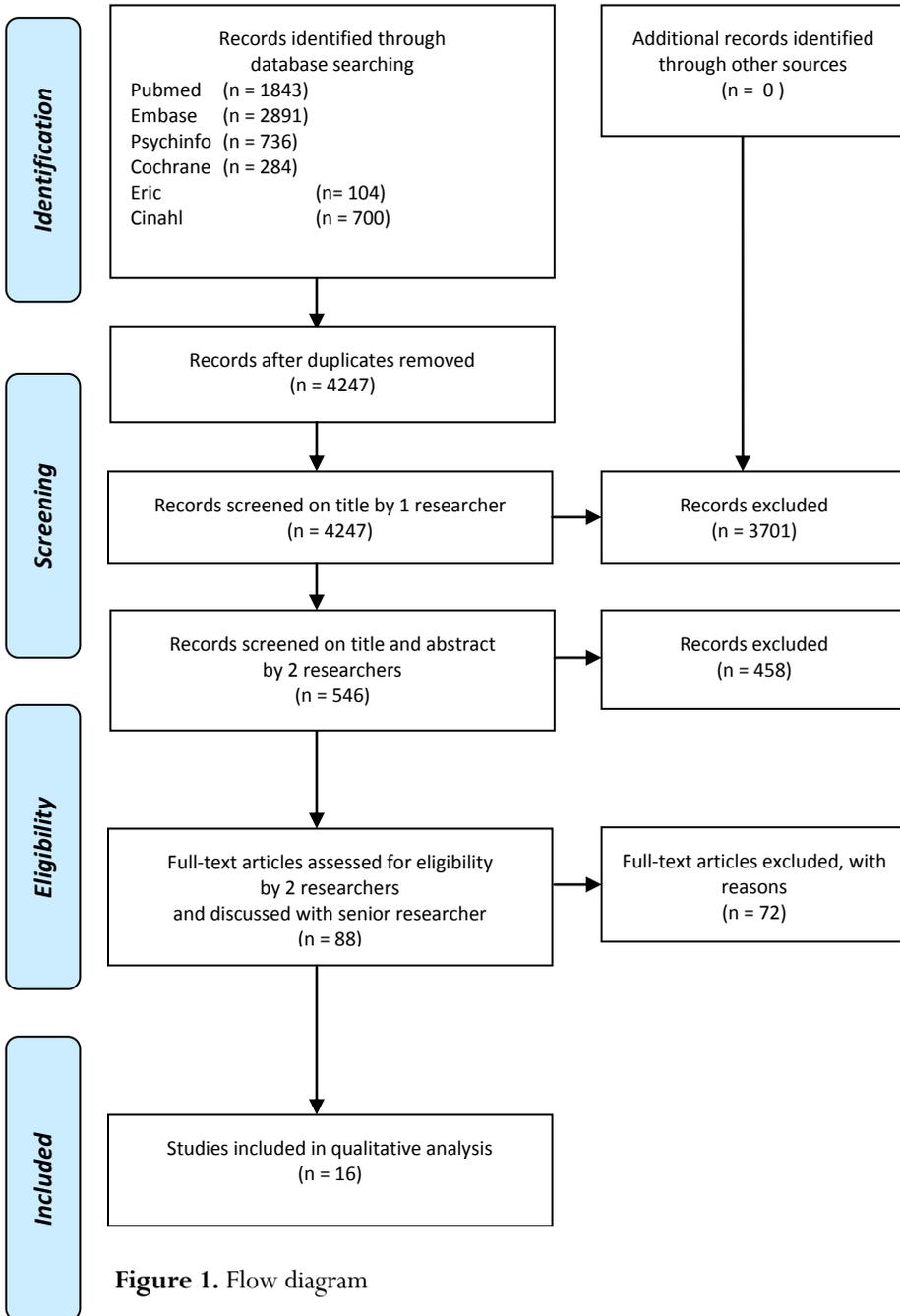


Figure 1. Flow diagram

Results: Table 2 Table of evidence

Author(s) (year)	Country	Setting/participants	Intervention / objectives of training
Study on training SC to patients/family care givers (FCGs) (n = 1)			
(Sun et al., 2015) ¹⁷	USA	Comprehensive cancer center / 475 patients, 354 FCGs	4 Interdisciplinary PC educational sessions by nurses for patients and FCGs, educational manual containing QOL domains, discussion and tips on how to cope with spiritual well-being issues (hope, inner strength, uncertainty, purpose and meaning in life, positive changes, redefining self and priorities, and S/R) and available supportive care services.
Studies concerning SC training aimed at enhancing palliative care /			
(Ford, Downey, Engelberg, Back, & Curtis, 2014) ¹⁸	USA	2 Internal Medicine Programs / 541 patients, 181 physician trainees	Simulation based workshop designed to improve physicians' end-of-life communication skills
(G. R. Tait & Hodges, 2013) ¹⁹	CAN	University Medical Hospital / 12 family medicine and psychiatry resident physicians	1 h interview to dying patients. Resident returned to read the transcribed story back to the patient. Residents' preparation: brief learning guide introducing the intervention, its significance, and the study protocol. Before intervention, brief session with principal investigator (PI) to prepare for the interview. PI was trained in dignity therapy, intention was not to train the residents to be experts in the interview.
Studies concerning SC training by self study aimed at enhancing /			
(Ellman M., 2012) ²⁰	USA	1 University Medical Hospital / 309 interprofessional students (205 medical, 65 nursing, 39 chaplaincy, ? social work (excluded in analysis)	Online interactive, case-based learning module 30-45' and a 90' live, inter-professional simulation workshop / understand PC concepts, recognize misconceptions about opioids, identify and respond to spiritual and cultural needs of patients, recognize and understand importance of interdisciplinary team

3. Effects of spiritual care training – systematic review

Outcome measure(s)	Focus of the study	Method / Bias ^a	Outcome
- FACIT-Sp-12 - Meaning-Peace Subscale - Faith subscale	test effectiveness of an interdisciplinary PC intervention for lung cancer patients and their FCGs	Two group prospective sequential, quasi-experimental trial / serious risk of bias	- negative result for FCGs - positive result for patients - positive result for patients
spiritual care competencies of health care professionals including patients in the training (n = 2)			
Using multiple variable and path analysis illustrated that trainees' self-assessments of their communication skills in religious/spiritual communication was significantly and positively associated with their patients' reports of the occurrence and ratings of religious/spiritual communication.	determine whether physician trainees' self-assessments of their communication skills in religious/spiritual discussions were associated with assessments obtained from patients under their care	Randomized trial / Serious risk of bias	trainees' self-assessments were significantly and positively associated with their patients' reports
This experience was seen as distinct from the 'traditional' medical interview. Residents felt conversations with dying patients, and more broadly the art of soliciting a patient's story are poorly taught and modeled.	Exploring results of a narrative intervention in the context of palliative care education	Qualitative study / Critical risk of bias	Positive results: residents reflected on lessons learned from patients and on their own professional and personal lives.
SC competencies of health care students (including clinicians as control group) (n = 2)			
- quantitative measures of student perspective on effectiveness of the program meeting educational objectives and quality and value of the two components of the program - qualitative analysis of free-text responses to online reflections	Education of health professional students in basic aspects of PC: spiritual, cultural and interdisciplinary working	Mixed method evaluation study / Quantitative study critical risk of bias; qualitative study: content analysis of open ended responses on questionnaire	- positive evaluation of students of all professions: Mean 4 on 5-point Likert scale - positive effects on students of all professions, no effect size.

Learning spiritual care in Dutch hospitals

(Taylor, Mamier, Bahjri, Anton, & Petersen, 2009) ²¹	USA	7 University medical hospitals / self-selected sample of 201 nursing students and registered nurses	Self-study programme (workbook with supplemental DVD) and self-report study instruments.
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Studies concerning SC training aimed at administering or using a specific

(Fillion et al., 2009) ²²	CAN	3 regional districts / 109 PC nurses	4 weekly meetings, topics: (a) characteristics and (b) sources of meaning; (c) creative values in terms of personal perspective, sense of accomplishment at work; (d) suffering as a source of attitudinal change; and (e) affective experiences and humour as experiential avenues to finding meaning
(Morita et al., 2014) ²³	JPN	Self-selected sample of 84 nurses working at PC units/inpatient hospices, PC consultation teams, general medical wards	9 sessions over 2 days interactive education program (10.5 h.), aimed develop competence to perform SpiPas (Spiritual Pain Assessment Sheet) assessment about patients experiencing meaninglessness and to make an according nursing plan.

3. Effects of spiritual care training – systematic review

<p>Daily Spiritual Experience Scale, Spiritual Care Perspective Scale-Revised, Response Empathy Scale, Communicating for Spiritual Care Test, and Information about You form.</p>	<p>efficacy of a self study programme designed to teach nurses about how to talk with patients about spirituality, and to identify factors predicting this learning. Investigation of differences in learning between students and practicing clinicians, and between those in a religious or non-religious institution.</p>	<p>Pretest-posttest pre-experimental design / critical risk of bias</p>	<p>Significant differences were seen between the before and after scores measuring attitude, ability, spiritual experience, and knowledge</p>
<p>spiritual intervention or tool by health care professionals (n = 2)</p>			
<p>The objective of this study was to test its efficiency to improve job satisfaction and quality of life in PC nurses</p>	<p>Address existential and emotional demands using the meaning-centered intervention</p>	<p>Randomized (waiting-list) controlled trial / Serious risk of bias</p>	<p>PC nurses in experimental group reported more perceived benefits of working in PC after intervention and at follow-up. Spiritual and emotional quality of life remained, unaffected.</p>
<p>significant intervention effects in nurse-reported confidence and nurse-perceived value of patients' inner power. Nurse-reported helplessness showed marginally significant improvement after intervention. No sign effects were observed in the self-reported practice scale; attitudes toward caring for patients (willingness to help, positive appraisal, and nurse-perceived value of being); burnout scale, meaning of life, and knowledge score.</p>	<p>aimed at improving skills to relieve feelings of meaninglessness in terminally ill cancer patients. Primary aim of this study was to determine the impact on nurses of a novel two-day education program focusing on care that addresses patients' feelings of meaninglessness.</p>	<p>Randomized (waiting-list) controlled trial / serious risk of bias</p>	<p>Significant beneficial effect on nurses' confidence, modest effects on attitudes.</p>

Learning spiritual care in Dutch hospitals

Studies concerning SC training aimed at enhancing health care			
(Meredith, Murray, Wilson, Mitchell, & Hutch, 2012) ²⁴	AUS	Self-selected sample employees and volunteers in the field of palliative care / 113	Training resources designed to be used as either a self-paced independent learning package or a workshop delivered by a member of any profession.
(Smith & Gordon, 2009) ²⁵	GBR	Mixed settings homecare, hospice and hospital care / self-selected sample of 12 participants	7 week course, 5 weeks online activities 30-60', face-to-face study day in week 6, online follow-up activity week 7
(Wasner, Longaker, Fegg, & Borasio, 2005) ²⁶	DEU	Buddhist course 'Wisdom and Compassion in Care for the dying'. / Self-selected sample of 63 PC professionals and volunteers	3.5 day course, in-depth reflection, active and compassionate listening, recognize and address emotional and spiritual suffering, practical exercises, contemplation and meditation.
(Wittenberg, Ferrell, Goldsmith, & Buller, 2015) ²⁷	USA	Various health care settings / self-selected sample 124 health care providers	2 educational courses, educational intervention insufficiently described.
Studies concerning SC training aimed at enhancing health care professionals'			
(Drijfhout & Baldry, 2007) ²⁸	GBR	1 Hospice / nurses	4 sessions 45' in service training time / defining spirituality, communication, recording, personal evaluation
(Gordon & Mitchell, 2004) ²⁹	GBR	Hospice / 24 staff members	4 sessions aimed at developing a competency model for assessment and delivery of SC

3. Effects of spiritual care training – systematic review

professionals (including volunteers) SC competencies; self selected samples (n = 4)			
Improvements in Spiritual Care and Confidence were maintained 3 month later, with Confidence continuing to grow./ - SSCRS (McSherry et al. 2002) - POWCS (Nolan et al. 1998; Schofield et al 2005) - KCS (Murray and Chan, ?) - DASS-21 (Lovibond and Lovibond 1995; Clara et al. 2001)	Significant increase of SC, spirituality, confidence to provide SC in PC, to be maintained after 3 months after intervention.	Non-randomized trial / critical risk of bias	Significant increases in Spirituality, Spiritual Care, Personalized Care, and Confidence in this field immediately following the workshops.
No information about analysis, nor outcome measures	Aimed at developing blended learning package	Case report / critical risk of bias	Positive evaluation of content and delivery, including online learning.
- FACIT-Sp - Self-Transcendence Scale - Idler Index of Religiosity	Enable participants to recognize different facets of suffering of the dying persons and relatives and to respond effectively	Pre-test/post-test quasi-experimental study using quantitative methods / critical risk of bias	Significant and sustained improvements in attitudes towards work in PC
30 item self developed survey to measure provider communication about spirituality and forgiveness with patients and families.	Assessing professionals' spiritual and forgiveness concerns providing SC	Descriptive study / critical risk of bias	Majority of participants indicated they were involved in spiritual and forgiveness communication.
(including volunteers') SC competencies; team / staff samples (n = 5)			
- spiritual assessment recorded - patients' religious affiliation recorded	Raising staff awareness, creating change in attitude, regular auditing.	Audit / critical risk of bias	Recording levels for spirituality increased from 9>40 >54> 82% Recording levels for religion decreased from 100>100>86>89%
Evaluation of reflective practice seminars; good practice is affirmed, personal skills and limits are recognized, training and development needs are identified.	Search for definition and assessment tool, offering a model for spiritual assessment and care based on the individual competence to deliver spiritual and religious care.	Qualitative pilot study / No information available to base a judgement about risk of bias	Good practice is affirmed, personal skills and limits are recognized. Effect size not described.

Learning spiritual care in Dutch hospitals

(Hall, Shirey, & Waggoner, 2013) ³⁰	USA	Hospice / 38 staff members	2 sessions 90', half day retreats, modelling SC by chaplains
(Udo, Danielson, Henoch, & Melin-Johansson, 2013) ³¹	SWE	1 Hospital, 3 surgical wards / 42 nurses	5 sessions 90 reflection and discussion on life and death, freedom, relations and loneliness, and meaning, after introductory lecture, educational material also containing some reflective questions.
(Walters & Fisher, 2010) ³²	GBR	1 Hospice organization (3 sites and hospice-at-home-service) / non-clinical staff (group 1), clinical staff (group 2) and chaplains	Group 1: 90' session, group 2: half a day; both groups: defining spirituality (FIRM: Faith, Identity, Relationships, Meaning), own contribution to SC discussing case study, referral, documentation and confidentiality, role of the chaplain

Table 2: Table of evidence

3. Effects of spiritual care training – systematic review

<p>Chaplains' referrals were replaced by protocolled spiritual assessment in 5 days and follow-up visit. Interdisciplinary team charts to one plan, regular communication about each patient, chaplains integrated in care planning.</p>	<p>Quality improvement of SC, educate staff members in SC and provide SC to staff members</p>	<p>Quality improvement programme / Critical risk of bias</p>	<p>Based on audit of increased workload 2 fulltime chaplains added to the team.</p>
<p>- Attitudes Toward Caring for Patients Feeling Meaninglessness Scale (59 items) - SOC-13 measuring sub-scales of comprehensibility, manageability and meaningfulness</p>	<p>To describe work-related stress in care of severely ill and dying patients with cancer after participating in an educational intervention on existential issues.</p>	<p>Pre-test/post-test quasi-experimental study using qualitative and quantitative methods / high risk of bias</p>	<p>Enhanced independent decision making in caring and modest but significant decreased feelings of work-related stress and disappointment at work</p>
<p>Schedule for regular audit SC including standards and audit tools.</p>	<p>Multidisciplinary policy for SC based on best available evidence and development of SC audit tool</p>	<p>Audit / critical risk of bias</p>	<p>Recognition of the specialism of chaplaincy as facilitators for SC for / by all staff, acceptance of SC by organization and management structure.</p>

Synthesis of results

In a growing number of countries, palliative care improvement programmes are being developed based on multidisciplinary standards of comprehensive palliative care, including standards on spiritual care. Implementation of these standards is a complex intervention, with education/training playing a vital role. Since the time for training is limited, it is important to know which training methods are effective.

In this study, we identified publications regarding (P) health care professionals (including volunteers) and patients in palliative trajectories in hospitals and other healthcare institutions (including hospices), (I) describing the training intervention, care or treatment performed by these healthcare professionals trained in SC, comparing (C) care or treatment performed by healthcare professionals not trained in SC, and describing (O) the effects of training on quality of care, physical, psychosocial or spiritual symptoms, effects on healthcare professionals attitudes, perceived barriers, skills and competencies.

Figure 1 shows the selection process. The initial search in the 6 databases resulted in 6552 hits, with 2305 duplicates, resulting in 4247 records available for screening. The first screening selection based on the title of these publications was performed by the first author (JvdG), and the second screening selection based on 546 titles and abstracts was performed and discussed until a consensus was reached by 2 researchers (JvdG/JWU). The eligibility selection based on 88 full-text articles was performed and discussed until a consensus was reached by the first and second authors. We found 1 study published before 2000, 37 published studies between 2000 and 2011 and 50 publications between 2011 and 2015. Since we observed an increase in the number of studies on SC training after the publication of the international consensus documents on multidisciplinary SC in 2009-2011, further research is needed to identify this increase as a possible effect of these publications. The studies were included if training SC was described and/or effects of SC were

measured. Although three studies (13,33,34) did not meet this last criterion, they were initially considered relevant and were included since they provided specific palliative patients' perspectives as input for SC training. After the 2 reviewers reached consensus regarding the included articles, a third senior reviewer (KV) was consulted, resulting in the exclusion of these three studies.

Despite the absence of language restrictions, all 16 selected articles were written in English. Variability was present in the study design and outcomes.

To assess the quality of the publications, we used the Risk Of Bias In Non-randomized Studies of Interventions (ROBINS-I) assessment tool. (35)

We identified one study that was exclusively focussed on the patients' perspective. The study of Sun et al.(17) regarding training to patients and family caregivers (FCGs) tested the effectiveness of a PC intervention for lung cancer patients and their FCGs. We also found two studies(18,19) regarding SC training of health care professionals that included patients in the training method.

Two studies reported the evaluation and effects of training by self-study aimed at enhancing PC/SC competencies(20,21).

Fillion et al.(22) and Morita et al.(23) both reported effects of SC training aimed at administering or using one specific spiritual intervention or tool by health care professionals.

We found four studies(24-27) that reported results of SC training on health care professionals' or volunteers' competencies based on self-selected samples.

Finally, we identified five studies(28-32) regarding SC training aimed at enhancing health care professionals' (including volunteers') SC competencies based on team or staff samples, eligible for qualitative synthesis.

Eleven studies(17,18,20-24,26,28,30,31) reported quantitative methods to describe the effects of training interventions using a variety of outcome measures.

Qualitative analysis

The study of Udo et al.(31) was the only study reporting results based on training hospital staff: nurses of surgical wards where severely ill and dying cancer patients were also treated. The study reported effects of an educational intervention on existential issues on nurses' work-related stress. Since we added 'existential' as a synonym to 'Spirituality' in our search strategy, this study passed all filters of our PICO. The purpose of the educational intervention – of five 90-minute sessions, including lectures, reflection and discussion methods – was not to influence the working process directly in giving existential/spiritual care or to improve reporting about existential themes but to support the participants in developing reflective strategies when providing care to these patients. Barriers were described based on the literature, with no report of barrier assessment. Whether the training was provided in working time or whether the trainer was a member of the multidisciplinary team was not described. Directly after the educational intervention, the nurses described increased exhaustion at the end of the shift and reported working under high time pressure. They also described being hindered in caring because of discrepancies between their caring intentions and what was possible in the surgical care context. After six months, the nurses reported that reflecting on their ways of caring for severely ill and dying patients, from an existential perspective, had contributed to enhanced independent decision making in caring and a decrease in feelings of work-related stress and disappointment at work. The effects on patients were not reported.

The four remaining studies(28-30,32) describe the results of quality improvement programmes aimed at the improvement of multidisciplinary SC provided in specialist palliative care hospice settings and/or by 'hospice at home' teams. Three studies were performed in the United Kingdom (UK)(28,29,32) and one in the United States of America (USA)(30).

The first study from the UK reports the effects of the pilot training of the Spiritual and Religious Care Competencies for Spe-

cialist Palliative Care (SRCCSPC) by Gordon and Mitchell(29), which discerns four levels of competencies. Barriers to the provision of SC are mentioned before the project started: spiritual care standards were tried and considered incomplete by a multidisciplinary group, and the disadvantages of using assessment tools outweighed the advantages. Level 1 was for all staff and volunteers who had casual contact with patients and their families. Level 2 was for staff and volunteers whose duties required contact with patients and families/carers. Level 3 was for staff and volunteers who were members of the multidisciplinary team, and Level 4 was for staff or volunteers whose primary responsibility was for the spiritual and religious care of patients, visitors and staff. Following an initial open seminar to introduce the competencies, four 90-minute reflective practice sessions in working hours were facilitated by a person with competency and experience at Level 4. Management involvement is presupposed since the project was implementing locally pre-formulated organization policy. The participants indicated that the four sessions had been valuable as both an exercise in reflective practice and a process of becoming more familiar with the basic theory underpinning these competencies. The SRCCSPC is developed by Marie Curie Cancer Care to bring the principles of SC as formulated in the 2004 publication of the National Institute for Clinical Excellence (NICE), *Improving Supportive and Palliative Care for Adults with Cancer*,(36) into practice. The strength of this study is that it provided an alternative to the spiritual assessment of patients' spiritual care needs at certain set points by an approach based on a continual assessment and development of hospice staffs' competencies. Positive effects on the staff team were identified: (a) development of an increased profile of SC in the hospice, (b) development of SC and religious care viewed as important as all other aspects of care, (c) understanding of the appropriate language and concepts of SC, and (d) improvement of staff communication on SC material and issues. Gordon and Mitchell acknowledged that the sample audit tool is a first step. Reviews of the documentation and integration of these competencies

into the personal and professional review and development processes need to be included to secure the results of this quality improvement programme.

In 2007 Drijfhout and Baldry(28) reported the results of an audit cycle that started in 2001, setting the following two standards, also based on the NICE standards(36) on improving supportive and PC for adults with cancer published in 2004: all patients should have at least one entry in their records concerning the spiritual aspect of their care, and all patients should have their religion recorded. Immediately after the survey, the level of recording of spiritual care increased from 9% to 15% in 2002, demonstrating that merely increasing staff awareness can create a change in attitude. The survey highlighted three main reasons for the low percentage of recording: a lack of time, a lack of staff understanding of the meaning of spirituality, and ambiguity about whose job it was to record spirituality. Four 45-minute training sessions were developed on defining spirituality, opening and closing conversations concerning spirituality, recording and personal reflection. Whether the training was provided by a member of the multidisciplinary team in working time was not reported. Management commitment was clear since an in-house training centre was responsible for the training. Recording of spirituality increased in 2005 to 40%, and recording religious affiliation reached 100%. The introduction of electronic patient health records decreased the scores temporarily, but they stabilized in 2007 to 82% for spirituality and 89% for religious beliefs. Drijfhout and Baldry(28) reported having started to use Gordons' and Mitchells' SRCCSPC(25) as pre- and post-course self-assessment evaluation tools. Regular auditing combined with short effective training sessions increased the staff's skills and confidence when assessing and recording spiritual issues.

The third study from the UK, based on the NICE standards on improving supportive and PC for adults with cancer published in 2004,(36) is the study of Walters and Fisher(32), which describes the development and audit of the spiritual care policy used across three

hospices. The policy recognized that much good spiritual care was already given, and the aim was not to place an extra burden on staff and to encourage and develop what was already being implemented. Gordons' and Mitchells' SRCCSPC(25) was adapted by replacing the word 'levels', which sounded hierarchical, with the word 'groups' and was reduced from four to three, comprising (1) non-clinical staff, (2) clinical staff and (3) chaplains. The language of 'competencies' was dropped in favour of the idea of skills to be recognized and enhanced. Whether these adaptations proved to be improvements or could be considered a methodological weakness was not discussed in the strengths and weaknesses paragraph. The SC policy also addressed (a) issues of referral from non-clinical to clinical staff and from the latter to chaplains, (b) the need for training, (c) the use of chapels on each site not being consecrated for the use of any particular faith group, and (d) appropriate documentation of SC giving. Training by the chaplain in the form of an unknown number (one for each small group?) of 90-minute awareness sessions was given to small groups of non-clinical staff members in group one. Members in group two were offered (a half-day) training introducing the concept of spirituality based on the acronym FIRM (Faith, Identity, Relationships, and Meaning), discussing 'our own contribution' to SC, including a case study, issues of referral, documentation, confidentiality and the role of the chaplains. An audit tool was developed to assess the effectiveness of both policies in patient care and training. Recommendations based on the audit report were acted upon, from which we conclude an active commitment of management, such as training is to be offered during working time (concluding that, initially, this was not the case) to all staff at 2-yearly intervals, the SC policy was amended with a greater commitment to work in the community, and the SC policy was better communicated to patients in the introductory pack.

The study of Hall et al.(30) from the USA was not invoked by the publication of a national standard, as was the case in the three studies from the UK. However, the editors of the journal added a

note that ‘the content from this article is a result of the author’s attendance and participation in a national program: *the ACE Project: Advocating for Clinical Excellence: A Transdisciplinary Palliative Care Education*,⁽³⁷⁾ supported by a grant from the National Cancer Institute of the National Institutes of Health.’ The authors describe that the SC team noticed that the number of referrals was decreasing, despite a dramatic increase in the hospice’s census. A thorough audit of the barriers was conducted within the context of a quality improvement initiative to improve SC in the hospice based on a negotiated mandate of the hospice’s administrators. It appeared that the interdisciplinary care teams believed the chaplains were too overloaded to care for more patients. Staff had differing concepts of what the chaplains do, and, lacking a coherent understanding of that role in hospice, the staff was reluctant to make referrals. After identifying these barriers and performing an audit of the chaplains’ daily allocation of time, three objectives were formulated for this project: (1) educate staff members and provide comprehensive spiritual support to all staff, thereby implementing a holistic interdisciplinary care model, (2) improve communication and collaboration between the interdisciplinary teams and the chaplains, and (3) establish an ongoing quality improvement goal for the training of current and new staff. It is not clear if participation in the two 90-minute training sessions provided by the chaplaincy team was scheduled during working time; likely not, since the authors report that self-care books, chair massage certificates, and other awards were given out as incentives for participation. At the same time, when the training was developed and performed, national compliance regulations and guidelines were revised, resulting in the need to establish different ways of communicating between the chaplains and the care teams. The implementation of holistic care plans in the hospice became the catalyst for the entire team to advocate integrating SC, from the patient’s intake through the end-of-life. Especially the project’s third goal – to establish an ongoing quality improvement cycle – contributed to secure the results and illustrates the crucial role of manage-

ment's commitment: (a) the chaplains' working process has developed from a referral-dependent model to a fully integrated position within the interdisciplinary team; (b) the interdisciplinary team charts to one plan of care, chaplains are integrated in the care planning, case conferencing, and interdisciplinary operations; (c) a new staff orientation procedure has been revised, now including co-visits with chaplains; (d) SC has a greater presence among staff by offering support, self-care opportunities, weekly staff reflections led by chaplains at interdisciplinary team meetings and all-staff meetings, and regular education about spiritual issues; (e) the SC team was expanded with two full-time chaplains based on the audits that the chaplains' time, travel and visitation activities were beyond a sustainable level; and (f) (unspecified) measurable improvements in staffs' understanding and support for SC services were implemented.

A quantitative meta-analysis was not performed since the identified studies included in the table of evidence used different outcome measures.

Discussion

The objectives of this systematic review were to identify the described effects of training SC on patients in palliative trajectories and healthcare professionals (nurses, physicians, and healthcare chaplains) and possible quality indicators useful for the optimization of SC training.

In the 88 full-text articles we assessed for eligibility, we observed a growing number of studies on this topic: 1 article was published before the year 2000, 37 of these articles were published between 2000 and 2011, and 50 were published between 2012 and 2016. However, when we reviewed the published trials in this selection based on the Medical Research Council (MRC) framework for the evaluation of complex interventions,(38) we concluded that all of these studies can be characterized as Preclinical or Phase 1 studies, considering that all of these studies still had an explorative design,

building theory and describing modelling trials and various effects. Although the article of Yardley, Walshe, & Parr(34) did not meet the inclusion criterion of reporting any training method, the study reported on specific palliative patients' perspectives on SC training outcomes that could be relevant to developing patient-reported outcomes.

All three UK studies refer to the 2004 publication of the National Institute for Clinical Excellence (NICE) on *Improving Supportive and Palliative Care for Adults with Cancer*,(36) indicating that a national standard is helpful in setting clear goals for the provision of SC as part of PC as input for local policy to develop SC to reach the national standards using quality improvement programmes. It also seems to illustrate that the lack of consensus about outcome measures for SC and the lack of consensus about SC training goals, prohibiting the next steps of identifying the components of the training intervention and researching the underlying mechanisms influencing the outcomes.

It is possible that it is still too early – and maybe that the cultural, spiritual and religious context is too diverse – to develop standard training interventions. We found substantial diversity in the outcome measures, which made a quantitative synthesis of the results impossible. There seems to be a tendency towards competence-based outcome measures – even a competency-based model for the assessment and delivery of SC(29) – but again, we noted diversity in the formulated competencies. Therefore, we conclude that it is too early to indicate evidence for quality indicators for SC training based on the international research literature.

In the final selection for the qualitative synthesis, four studies(28-30,32) were performed in specialist PC settings (hospices or hospice home care), only one in a hospital setting, (31) and no studies were performed in nursing homes or with regular home care teams. The hospital study was not aimed at the optimization of SC; it passed our PICO because we added 'existential' as a synonym to our primary search term 'spiritual'.

Based on the qualitative synthesis, we conclude that the practice and theory of SC training is still in development. In the identified best practices training, SC is part of a quality improvement project, increasing SC awareness and a change in staff's attitudes, clarifying the tasks and roles of multidisciplinary team members, especially of the chaplains. Such a project can follow a plan-do-check-act cycle, starting with an initial audit to identify the SC barriers in the setting where this improvement is sought, and formulating SC policy based on available national standards (plan), followed by implementation of training aimed to decrease identified barriers and to provide the SC as formulated in the SC policy (do), evaluation of the effects of the training and the policy (check), and improvement of SC training and policy if necessary to reach and secure the formulated standards of SC provision (act). Although the studies performed in hospice settings were specifically designed for this setting, we believe these results to be relevant for quality improvement programmes regarding multidisciplinary SC in other healthcare settings. Where still lacking, national standards on the provision of spiritual care need to be developed to provide aims and measurable outcomes for spiritual care training.

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Declaration of interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical committee

Ethical approval was provided by the medical ethical committee in Leeuwarden, Netherlands on July 4th 2013 (nWMO22).

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4

Training Spiritual Care in Palliative Care in Teaching Hospitals in the Netherlands: A Multicentre Trial



Chapter 4 Multidisciplinary Spiritual Care Training

Training Spiritual Care in Palliative Care in Teaching Hospitals in the Netherlands: A Multicentre Trial

Rev. Joep van de Geer; Prof. Hetty Zock PhD; Prof. Carlo Leget PhD; Nic Veeger PhD; Jelle Prins PhD; Marieke Groot PhD; Prof. Kris Vissers MD, PhD, FIPP.

Abstract

Background: In the Netherlands, the spiritual dimension in health care became marginal in the second part of the twentieth century. In the Dutch health care system, palliative care is not a medical specialization and teaching hospitals do not have specialist palliative care units with specialized palliative care teams. Palliative care in these hospitals is delivered by health care professionals in general departments (mainly curative focused ones), and is based on multidisciplinary guidelines supported by palliative care consultation teams. A national multidisciplinary guideline on spiritual care is included, but standardized training based on this guideline still lacks. Implementation of this guideline is expected to have a positive effect on quality of care but is in an early state, the role of the specialists in this field—the health care chaplains—is developing.

Methods and Findings: This action research study is planned as an explorative multicentre trial. Health care chaplains of ten teaching hospitals will offer training on spiritual care in palliative care for health care professionals. What is the effect of this intervention on the competences of clinical teams? What is the effect on the perceived care and treatment as experienced by patients?

The effects of the intervention on the competences of the clinicians will be measured once pre-study and twice post-study. Effects on patients' physical symptoms and spiritual distress, and the perceived

focus of caregivers on their spiritual needs or existential questions will also be measured pre- and post-study.

Conclusions: The objective of this article is to present the protocol of this study and stimulate discussion about methods of research on spirituality and spiritual care.

Keywords: Multidisciplinary team; Spiritual care; Chaplaincy; Education; Palliative care

Introduction

The development of palliative care (PC) based on the definition of the World Health Organisation (WHO) [1] challenges health care professionals to react not only to the physical symptoms and the psychological and social problems of dying patients and their proxies, but also to the spiritual needs of patients and families confronted with a life-threatening disease. A growing number of publications shows consensus on the definition of spirituality in health care and how to implement this dimension in palliative care [2-5]. The publication of the *Oxford Textbook of Spirituality in Healthcare* [6] was a milestone in this development. A recent pan-European survey [7] on spiritual care research priorities by the European Association for Palliative Care (EAPC) Taskforce on Spiritual Care in Palliative Care [8] illustrates a high need for training and education.

In the Netherlands, the spiritual dimension in professional health care discussions became marginal from the second part of the twentieth century. The nomination of two chairs on palliative care in 2005 increased attention on the spiritual dimension in palliative care, and identified it as one of the challenges facing the Dutch health care system in the next decade [9,10]. From that moment on, an inspiring process led to a consensus-based, multidisciplinary guideline on spiritual care within palliative care in the Netherlands, as part of the national Dutch multidisciplinary guidelines on palliative care for health care professionals [11-13]. It is translated in English [14] and

German [15]. Since Dutch teaching hospitals do not have specialist PC units with specialized PC teams, PC in these hospitals is delivered by health care professionals in general (mainly curative focused) departments. The guideline on spiritual care (SC) recommends that it is delivered by all members of multidisciplinary teams, and expects them to be supported and trained by health care chaplains as the specialists on the spiritual dimension.

Since a multidisciplinary guideline does not automatically change clinical practice, research on specific educational approaches is necessary to increase the knowledge on how to implement the spiritual dimension in palliative care [16]. Furthermore chaplains' knowledge regarding staff education in spiritual care, as well as chaplains' knowledge regarding staff preferences for spiritual assessment tools, is still too limited to formulate quality indicators for training in spiritual care on a national level [17]. Therefore a multicentre action research study, called "Improvement of spiritual care in palliative care by training professional caregivers," was planned for different wards in ten large, non-academic teaching hospitals where patients in a palliative trajectory are admitted regularly.

Aims and objectives

The aim of this action research project is to start the implementation of the new method of delivering multidisciplinary spiritual care as described in the national guideline on palliative care [13]. It is crucial to this new method that professional caregivers are able to assess and respond to the spiritual needs of palliative patients and their families, appropriate to their role as physician or nurse, as well as provide adequate referrals to specialized disciplines on the spiritual dimension in the case of complex care needs and crises.

The main research question is: how to train doctors and nurses in assessing and responding to the spiritual and existential needs of their patients and proxies? What is the effect of hospital chaplains training multidisciplinary clinical teams in these competen-

cies? What is the effect on the perceived care and treatment as experienced by patients?

Our hypothesis is that training in spiritual care contributes to the development of spiritual care competencies and leads to higher quality of care.

The objective of this article is to present the protocol of this study for international exchange and discussion about implementation, education, and research on spiritual care.

Methods

Ethical approval and cooperation

This study is designed and will be conducted according to the World Health Organization (WHO) Good Clinical Practice Guidelines. The medical ethical committee in Leeuwarden, Netherlands gave it ethical approval on July 4, 2013 (nWMO22). This study is registered at the Dutch Trial Register: NTR4559.

The project was initiated in the chaplaincy department of the Medical Center Leeuwarden (MCL). It is supported by Agora (the Dutch national organization for palliative care), the Comprehensive Cancer Centre The Netherlands (IKNL), and the Dutch Association of Spiritual Caregivers in Health Care Institutions (VGVZ), and includes the cooperation of the University of Groningen, the Radboud University Nijmegen Medical Centre, and the University of Humanistic Studies in Utrecht. From 2013 onward, the MCL Academy has taken responsibility for the operational progress of the project.

Design of the study

This action research study is planned as an explorative multicentre trial, in which dedicated teams of health care chaplains of ten non-academic teaching hospitals will perform the intervention: pilot training in spiritual care in palliative care (SCPC) for health care professionals.

Action research is defined by Elizabeth Koshy, Valsa Koshy, and Heather Waterman as “an approach employed by practitioners

for improving practice as part of the process of change. The research is context-bound and participative. It is a continuous learning process in which the researcher learns and also shares the newly generated knowledge with those who may benefit from it. ... The key concepts include *a better understanding, participation, improvement, reform, problem finding, problem solving, a step-by-step process, modification and theory building.*" [18, p. 9-10].

Influencing professionals to develop spiritual care as a multi-disciplinary team can only be successful when it builds on local-specific resources that are connected with the unique culture of each participating institution/hospital/department. Therefore the intervention in our study had to be open to local variety. We chose an explorative prospective action research design, combining qualitative and quantitative methods.

Both Michelle Campbell (1) and Richard Grol (2) consider influencing professionals' behaviour to be a complex intervention. Situated on the continuum of increasing evidence according to the Medical Research Council (MRC) framework for the evaluation of complex interventions, this study combines elements of the first three phases of increasing evidence in a phase II trial. (Figure 1).

In our study data will be collected on three levels:

- Patients' perspective: to explore self-reported and proxy spiritual distress, the perceived quality of spiritual care, and the effect of the intervention.
- Health care professionals: to explore barriers for spiritual care, preferences in training spiritual care, use of diagnostic tools for needs in spiritual care, and the effect of the intervention.
- Health care chaplains: to explore spiritual care training methods, health care professionals' preferences, and quality indicators for spiritual care training.

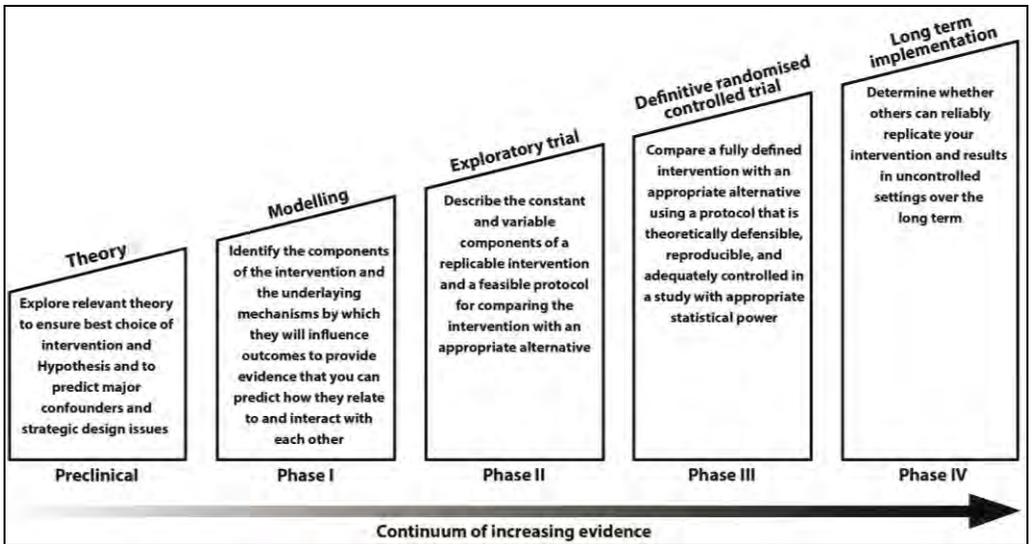


Figure 1. Medical Research Council (MRC) framework for the evaluation of complex interventions

The intervention

To establish a consensus-based framework of ten requirements for the intervention, pilot training in SCPC (see Table 1), the researchers invited 33 professionals and researchers with expert knowledge on PC and SC to discuss the requirements at a conference in Enschede, The Netherlands on November 4, 2013 (see Table 2).

This prototype of the pilot training in SCPC is based on: the EAPC consensus definition of spirituality [8], the Dutch guideline on spiritual care [13], and an additional literature review on diagnostic tools and education of spiritual care [23].

The pilot training in SCPC is expected to vary due to local differences and contextual factors, such as the local culture and identity of the hospital, personal competences of the teacher(s), and the specific needs of the multidisciplinary team. During the action research process, the pilot training in SCPC can develop based on the experience, learning process, and new knowledge arising from the cooperation between the participating chaplains/teachers.

Learning spiritual care in Dutch hospitals

Target group	Multidisciplinary clinical teams of physicians, nurses and other healthcare professionals of departments in teaching hospitals (not being: specialized palliative care teams or units).
Competencies	Aim is to develop basic competencies for multidisciplinary spiritual care: recognising, referring, self reflectiveness and open attitude towards patient spirituality, as formulated by Kuin (21) based on the work of Van Leeuwen (22).
Preparation	A Dutch e-learning module on SCPC based on the Guideline is considered to be ideal as preparation for a local training. An electronic learning environment with a selection of reading material and video fragments on SC considered to be compatible with the Guideline will be made available to participants who want to prepare themselves before the pilot training SCPC (Available on https://www.mcl.nl/patient/specialismen-en-centra/geestelijke-verzorging/spirituele-zorg).
Planning	Implementation of the training is considered ideal when planned as two lessons of 90'-120' with an interval of at least three weeks. Minimum is one lesson of 90' with follow up teaching methods (coaching on the job, bedside teaching).
Structure	The local format of the training has to be designed with the aim to (1.) sensitize participants for the spiritual dimension of palliative care, (2.) make participants realize the importance of their own spiritual and existential dimensions, in order to (3.) integrate it into professional practice.
Tools	No screening tools for spiritual care or spiritual care models proposed by Pennaertz are admitted to the pilot training SCPC. Because of lack of validated translations the choice is limited to those already mentioned and translated in the NL Guideline: symbolic listening according to Weiher (23), the translation of the three screening questions developed by the Mount Vernon Cancer Network (24) and the Dutch spiritual care model Legets Ars Moriendi (25).
Practice based learning	Teaching has to be practice oriented, practice based, participants should be stimulated to deliver case descriptions and receive feedback on these descriptions from the teacher/chaplain
Freedom for local adjustments	Given the local diversity in teaching hospitals and the nature of teaching spiritual care the pilot training SCPC is not possible without any diversity in tone, language and methods. The local teachers/chaplains receive a relative freedom in methodology and planning. Educational aims and goals as mentioned above are to be considered. Teaching to only one discipline of the multidisciplinary clinical team is not an option.
Teaching methods	No mandatory teaching methods. Selected core concepts and definitions of the guideline will be delivered on slides. Basic knowledge of Kolb's experiential learning model will be taught to the group of teachers/chaplains, preferred methods of teaching spiritual care will be exchanged in the group during the study.
Accreditation	The intervention needs approval by professional organisations of physicians and nurses, so participants can score the training to meet their professional registration requirements.

Table 4. Requirements for the Pilot Training Spiritual Care in Palliative Care (SCPC)

Table 2. Participants at invitational conference Enschede, NL. Disciplines	N
Health care chaplains (spiritual care experts)	5
Health care chaplains (candidate teachers with pilot training in SCPC)	11
Registered nurses (palliative and/or spiritual care experts)	3
Medical doctors (palliative and/or spiritual care experts)	3
Psychologists (palliative and/or spiritual care experts)	2
Researchers	4
Educational consultants	2
Palliative care policy advisor	1
Health care academy manager	1
Project assistant	1

Table 2. Participants at invitational conference Enschede, Netherlands

In the participating hospitals, the chaplains/teachers performing the pilot training in SCPC will have the status of co-researcher in this study, and will be responsible for organizing active support of the palliative care consultation team; raising support by hospital management and approval by the local scientific and ethical committees; identifying departments open for the intervention (multidisciplinary teams of any clinical department interested in the improvement of SCPC by means of the pilot training in spiritual care); selecting control departments not receiving the intervention; planning, organizing, and teaching the pilot training in SCPC; and organizing cooperation with the palliative care consultation team for the inclusion of and interviews with patients in the pilot departments and the control departments.

Hospital inclusion criteria:

- Fulfilling the criteria of a non-academic teaching hospital in the *Stichting Topklinische Ziekenhuizen* (Association of Tertiary Medical Teaching Hospitals),
- Being actively involved in developing palliative care by means of a specialist consultation team, and
- Implementing palliative care quality improvement programs.

Chaplaincy team inclusion criteria:

- Being actively involved in the PC improvement program in the hospital,
- Being responsible for the way SC is developed in that program,
- Having at least one member of the team specialized in SC in PC (mandatory specialized training program: five-day master class on spirituality in palliative care organized by Leerhuizen Palliatieve Zorg Rotterdam) [28],
- Participating chaplains will have to be experienced teachers and have their own learning style assessed using the Kolb Learning Style Inventory 3.1 [27].

The selected teachers will be prepared with one and a half days of education on learning styles and methods. In order to collect/gather practical and experiential knowledge, they will be asked to keep a log during the process of organizing, teaching, and following-up with the multidisciplinary teams they educate.

According to the action research perspective and the explorative character of this trial, an extra training day based on first experiences is planned between the first group of four participants and the second group of six participants, for possible improvement of the intervention.

Planning of the intervention

All interventions will have to be planned within the period of one year. A minimum of at least ten is targeted to reach consistent data. The pilot training in SCPC can be given to any clinical team of curative departments in the hospital that also treats palliative patients. See Figure 2.

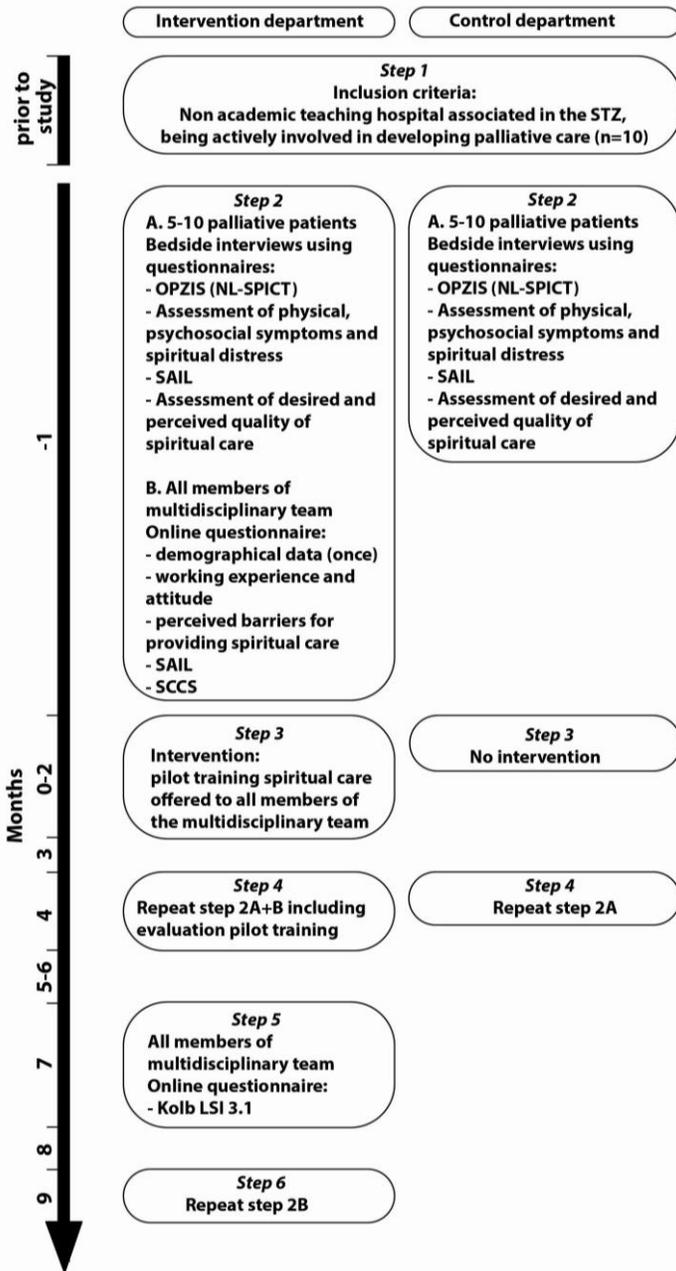


Figure 2. Planning intervention and data collection

Standardized evaluation of the intervention

Effects of the intervention on the competences of the professional caregivers will be measured pre-intervention (one month before training) and twice post-intervention (one month and six months after training).

The effects on patients' physical, psychosocial, and spiritual distress are measured one month before and one month after the caregivers participate in the educational program. Patients' physical symptoms, spiritual distress, and the perceived focus of caregivers on their spiritual needs, quest for meaning, or existential questions will be measured.

Patient-inclusion criteria

For the inclusion of palliative care patients from the hospital departments where clinicians participate in the pilot training in SCPC and the control group of departments that do not participate, a Dutch translation of the Supportive and Palliative Care Indicators Tool [29], called Ondersteunende en Palliatieve Zorg Indicatoren Set (OPZIS), was developed in cooperation with the University Medical Center Groningen to identify palliative patients. The OPZIS [30] (see Appendix 1) seems feasible in the context of this study.

The target is to include five to ten patients from each pilot and control department following Good Clinical Practice (GCP) guidelines on informed consent, privacy, and processing of collected data.

Measuring the effect of the pilot training in SCPC on consumer quality of care

After informed written consent, questionnaires will be given by specialist palliative care nurses or ward nurses with additional palliative care training that function as palliative care ambassadors in their department. The questionnaire contains items on age, gender, demographical data; 15 items on physical and psychosocial symptoms using the Utrecht Symptom Diary [31]; four spiritual items using

adapted items of the Distress Thermometer [32] (see Appendix 2); 26 items using the Spiritual Attitude and Interests List [33]; and six items related to spiritual care from the NIVEL report on consumer quality indicators of palliative care [34]. Patient data will be coded referring to hospital, department, and numerical order of inclusion.

Measuring the effect of the pilot training in SCPC on professional caregivers competencies

Based on the methods used by Maria Wasner, Christine Longaker, Martin Johannes Fegg, and Gian Domenico Borasio [35], Katrien Cornette and Jenny Put [36], and René van Leeuwen [21] to assess spiritual care competencies of health care professionals/students and the effect of training in spiritual care, an online questionnaire is has been developed. This questionnaire is divided into nine items on demographical data, ten items on work experience and attitude, 11 items on perceived barriers for providing spiritual care, 26 items of the Spiritual Attitude and Involvement List (SAIL), and 27 items on Spiritual Care Competence Scale (SCCS).

Expected outcome

We expect to see on the following dimensions emerge due to the effect of this training:

- Decrease of perceived barriers to spiritual care, according to caregivers compared with baseline,
- Development of caregivers competencies compared with baseline,
- Higher consumer quality of care compared with baseline on pilot departments, no difference on control departments,
- (For chaplains:) understanding of/knowledge concerning the needs of primary caregivers in the application of spiritual care after training; understanding of/knowledge concerning the possibilities of the integration of spiritual care in the working process of the multidisciplinary team; and knowledge concerning the education of spiritual care.

Our target is to collect data from ten multidisciplinary teams (approximately 330 caregivers) and from 110 to 180 palliative patients treated in hospital settings.

Data analysis

Earlier studies were based on different definitions of spirituality, and validated instruments in Dutch that are based on international consensus definitions still lack in this rather new—for the Netherlands—field of multidisciplinary spiritual care. Therefore this trial is explorative (phase one) and a power analysis is not possible.

For this pilot study, the target number of multidisciplinary teams ($N = 10$), as well as the target number of patients ($N = 18$ per site) is not based on a formal sample size calculation. With the planned study size, this pilot will generate valuable data for an exploratory evaluation of the introduction of the new method of delivering multidisciplinary spiritual care, from the perspectives of the caregivers and the patients. In both settings, summary statistics (point estimates and standard deviation range) will be used to evaluate the respective effects of the new method. Any hypothesis testing on observed changes in professional caregivers' competencies and perceived barriers for spiritual care will be performed using paired samples, *t*-tests, and Wilcoxon Sign Rank Tests. Patients' spiritual distress and perceived quality of care will be interpreted within the setting of an explorative study rather than a confirmative one.

Qualitative data from the semi-structured interviews with the teachers/hospital chaplains will be transcribed verbatim and analysed. Subsequently a qualitative thematic analysis will be done using ATLAS-TI in two rounds: immediately after all pre-intervention interviews with the pilot teachers are conducted and after all post-intervention interviews are conducted.

Strength and limitations discussion

This study has several strengths.

- It is a first systematic implementation of the multidisciplinary guideline on SC, monitoring its effect on health care professionals' competences and patients' spiritual well-being at the same time.
- The strength of designing this study as a multicentre trial at the threshold of its implementation process is that it stimulates almost 36 percent of the teaching hospitals in our country to start the implementation of the guideline on SC.
- This pilot study opens new, multidisciplinary territory combining quantitative and qualitative research methods from different research paradigms.
- It is able to create bottom-up commitment from and local multidisciplinary cooperation between medical, nursing, and spiritual disciplines.
- It can contribute to developing the guideline from consensus based to practice based.
- It will develop knowledge about the use of diagnostic tools for the screening or assessment of the spiritual dimension by professional caregivers.
- This knowledge can be used for a first revision of the guideline.
- Together with the quantitative evaluation, this action research approach aims for developing bottom-up quality indicators for spiritual care. Learning together about the spiritual needs and resources of our patients, their proxies, and ourselves can invoke local renewals of the multidisciplinary cooperation between doctors, nurses, and health care chaplains.
- The strength of this study lies in the attempt to combine the very different academic paradigms of medical, nursing, and chaplaincy disciplines; however, this also might complicate its evaluation.

Studying at the threshold of a national implementation process on spiritual care creates some important limitations:

- To measure patients’ spiritual symptoms and spiritual needs in Dutch, only two tools were validated and considerable for application: the Spiritual Attitude and Interests List (SAIL) (3) and the spiritual items of the Lastmeter, a measurement tool recommended by the Dutch oncology guideline for detection of psychosocial needs [37].
- SAIL is not developed to measure spiritual symptoms and the needs of clinical patients, and the tool is not based on an inclusive/consensus definition of spirituality. It is based on a specifically non-theistic definition of spirituality [33, p. 142]. However, as it might be able to generate data on patients’ spirituality and needs that are relevant in the context of developing training in spiritual care, the research team decided to use SAIL. Adaption of SAIL to the broader national and international consensus definitions of spirituality would enhance its relevance.
- The spiritual items of the Lastmeter were developed before the new consensus definitions of spirituality were published. The research team considered these items not to be compatible with the directives of the multidisciplinary guideline on spiritual care. We used the official **suggested items** of the Dutch professional organization for health care chaplains (VGVZ) on the concept oncology Guideline Detection of psychosocial needs. The research team proposed a combination of the suggestions by the VGVZ, relevant spiritual care items of the national quality indicator set for palliative care, and basic items on religion and religious or spiritual practices, and this was accepted by the experts in the invitational conference on November 4, 2013. (See Appendix 2: Adapted Spiritual Items of the Distress Thermometer.) To the best of our knowledge these are the optimal questions to use, however formal validation has not yet been performed.

In June 2014, the Dutch professional organization of health care chaplains (VGVZ) showed its appreciation for this design of health care chaplains' research by awarding the first VGVZ Research Award to a Dutch abstract of this protocol.

Abbreviations

OPZIS *ondersteunende en palliatieve zorg indicatoren set* is a translation of the Supportive and Palliative Care Indicators Tool (SPICT)

SAIL Spiritual Attitude and Involvement List

SCCS Spiritual Care Competence Scale

SCPC Spiritual Care in Palliative Care

SPICT Supportive and Palliative Care Indicators Tool

STZ Stichting Topklinische Ziekenhuizen (Association of Tertiary Medical Teaching Hospitals)

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Appendix 1. Supportive and Palliative Care Indicators tool (SPICT™)

Ondersteunende en Palliatieve Zorg Indicatoren Set (OPZIS) Gebruik de OPZIS om patiënten te identificeren met gevorderde, progressieve, ongeneeslijke aandoening(en)	
1. ZOEK NAAR TWEE OF MEER ALGEMENE KLINISCHE INDICATOREN VAN DE VERSLECHTERENDE GEZONDHEID	
<ul style="list-style-type: none"> • Functionele status, slecht of verslechterend met beperkte kans op herstel (Symptomatisch, niet volledig bedlegerig, ligt 50% of meer van de dag op bed). • Twee of meer ongeplande ziekenhuisopnames in de afgelopen 6 maanden. • Gewichtsverlies (5 - 10%) over de afgelopen 3-6 maanden en / of Body Mass Index <20. • Aanhoudend, vervelende symptomen ondanks optimale behandeling van eventuele onderliggende aandoening (en). • Risico op overlijden aan een plotselinge, acute verslechtering. • Woont in verpleeghuis, verzorgingshuis of zorginstelling, of heeft zorg nodig thuis te blijven. • Patiënt vraagt om ondersteunende en/of palliatieve zorg, of staken van de behandeling. • Een nieuwe diagnose van een progressieve levensverkortende aandoening 	
2. ZOEK NU NAAR EVENTUELE KLINISCHE INDICATOREN VAN GEVORDERDE AANDOENINGEN.	
<ul style="list-style-type: none"> • Hart / vaatziekten <ul style="list-style-type: none"> • NYHA klasse III / IV hartfalen, of uitgebreid, onbehandelbaar coronaar vaatlijden; • kortademigheid of pijn op de borst in rust of bij minimale inspanning. • Ernstig, inoperabel perifeer vaatlijden. • Luchtwegaandoeningen <ul style="list-style-type: none"> • COPD of ernstige pulmonale fibrose • ademloos in rust of bij minimale inspanning tussen de exacerbaties. • Voldoet aan de criteria voor langdurige zuurstoftherapie (PaO₂ <7,3 kPa). • Heeft ventilatie/beademing nodig voor respiratoir falen of ventilatie is gecontraindiceerd. • Nieraandoening <ul style="list-style-type: none"> • Fase 4 of 5 chronische nierziekte (eGFR <30ml/min) met verslechterende gezondheid. • Nierfalen als gevolg van een ander leven beperkende aandoening of de behandeling ervan. • stoppen van dialyse • Leverziekte <ul style="list-style-type: none"> • Gevorderde cirrose met een of meer complicaties in het afgelopen jaar: • diureticaresistent ascites • leverencefalopathie • hepatorenaal syndroom • bacteriële peritonitis • recidiverende variceel bloedingen • Serum albumine <25 g / l, INR langdurige (INR> 2). • Levertransplantatie is gecontraindiceerd. • Kanker / oncologie <ul style="list-style-type: none"> • Functioneren van de patiënt verslechtert als gevolg van progressieve uitgezaaide kanker. • Te zwak voor oncologische behandeling als gevolg van geavanceerde multimorbiditeit of behandeling is voor symptoom controle. • Neurologische aandoening <ul style="list-style-type: none"> • Progressieve verslechtering in fysieke en / of cognitieve functie ondanks optimale therapie. • Spraakproblemen met toenemende moeite om te communiceren en / of progressieve dysfagie • Recidiverende aspiratie pneumonie; ademnood of respiratoir falen. • Dementie / kwetsbaarheid <ul style="list-style-type: none"> • Niet in staat om te kleden, lopen of eten zonder hulp. • Minder eten, moeite met onderhouden van voeding. • Urine- en fecale incontinentie. • Progressieve zwakte, vermoeidheid, inactiviteit. • Niet in staat om zinvol te communiceren; weinig sociale interactie. • Gebroken dijbeen; meerdere valpartijen. • Recidiverende febrile episodes of infecties; aspiratiepneumonie. 	
3. STEL DE VRAAG: Zou het je verbazen als deze patiënt overleed in de komende 12 maanden?	NEE
4. PLAN ONDERSTEUNENDE EN PALLIATIEVE ZORG	
<ul style="list-style-type: none"> • Herzie huidige behandeling / zorgplan, en medicatie zodat de patiënt optimale zorg krijgt. • Overweeg consultatie van palliatief team bij complexe en moeilijk te managen symptomen of behoeften . • Bespreek de huidige en toekomstige zorgdoelen/-plannen met patiënt en familie. • Plan vooruit als de patiënt risico loopt op verlies van krachten. • Leg vast in zorgplan: wat-als-beleid, zo-nodig-medicatie, behandelingsbeperkingen. • Coördineer de zorg met de huisarts en eerstelijnszorg zorgverleners. 	
	

Gebaseerd op de Supportive and Palliative Care Indicators Tool (SPICT™).

Appendix 2. Adapted spiritual items of the Distress Thermometer.

View of life, life questions, existential questions

View of life, life questions or existential questions have to do with: what you believe life means, what the value of it is to you and how it should be lived. It can also be linked to a particular religion. Here are a few questions about your beliefs. Cross always the option that best describes your situation. We realize that you may find it difficult to answer some questions, perhaps because you are using other words to describe your beliefs or that you have not given it much thought. Yet it is important that you complete all the questions.

Please consider the following points completing the questions:

- Circle always the answer that best suits you (1 mark per question)
- There are no "right" or "wrong" answers
- Often, your first impulse the best, do not think too long about your answers

1. Please indicate whether you have experienced trouble or problems last week (including today) on the field view of life / life questions, for example:

- coping with loss
- questions about the end of life / death
- loss of confidence
- questions about the fulfillment / meaning of my life
- guilt
- questions about the purpose of the treatment
- need for rituals

No dis- tress	0	1	2	3	4	5	6	7	8	9	10	A lot of distress
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2. Please indicate whether your proxies have experienced trouble or problems last week (including today) on the field view of life / life questions, for example:

- coping with loss
- questions about the end of life / death
- loss of confidence
- questions about the fulfillment / meaning of my life
- guilt
- questions about the purpose of the treatment
- need for rituals

No dis- tress	0	1	2	3	4	5	6	7	8	9	10	A lot of distress
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3. Do you think it is important that healthcare professionals (doctors, nurses, other health care professionals) on this ward pay attention to difficulties or problems related to the above topics or questions?

Not important	0	1	2	3	4	5	6	7	8	9	10	Very impor- tant
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4. Do you experience attention of healthcare professionals (doctors, nurses, other health care professionals) to difficulties or problems related to the above topics or questions?

No attention	0	1	2	3	4	5	6	7	8	9	10	A lot of attention
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5

Training hospital staff on spiritual care in palliative care influences patient-reported outcomes.
Results of a quasi-experimental study



Chapter 5. Training hospital staff on spiritual care in palliative care influences patient-reported outcomes. Results of a quasi-experimental study

Authors: Joep van de Geer¹, Marieke Groot², Richtsje Andela¹, Carlo Leget³, Jelle Prins¹, Kris Vissers², Hetty Zock⁴.

Authors' information

¹ MCL-Academy, Medical Centre Leeuwarden, Leeuwarden, the Netherlands.

² Department of Anesthesiology, Pain- and Palliative Medicine, Radboud UMC, Nijmegen, the Netherlands.

³ Department of Care and Welfare, University of Humanistic Studies, Utrecht, the Netherlands

⁴ Department of Theology and Religious Studies, University of Groningen, Groningen, the Netherlands

Abstract.

Background: Spiritual care is reported to be important to palliative patients. There is an increasing need for education in spiritual care (SC).

Aim: To measure the effects of a specific SC training on patients' reports of their perceived care and treatment.

Design: A pragmatic controlled trial conducted between February 2014 and March 2015.

Setting/Participants: The intervention was a specific SC training implemented by healthcare chaplains to 8 multidisciplinary teams in 6 hospitals on regular wards in which patients resided in both curative and palliative trajectories. In total, 85 patients were included based on the Dutch translation of the Supportive and Palliative Care Indicators Tool (SPICT). Data were collected in the intervention and control wards pre- and post-training using questionnaires on physical symptoms, spiritual distress, involvement and attitudes (SAIL) and on the perceived focus of healthcare professionals on patients' spiritual needs.

Results: All 85 patients had high scores on spiritual themes and involvement. Patients reported that attention to their spiritual needs was very important. We found a significant ($p=.008$) effect on healthcare professionals' attention to patients' spiritual and existential needs, and a significant ($p=.020$) effect in favour of patients' sleep. No effect on the spiritual distress of patients or their proxies was found.

Conclusion: The effects of SC training can be measured using patient-reported outcomes and seemed to indicate a positive effect on the quality of care. Future research should focus on optimizing the SC training to identify the most effective elements and developing strategies to ensure long-term positive effects. This study was registered at the Dutch Trial Register: NTR4559.

What is already known about the topic?

- Spiritual care is reported to be important for palliative patients.
- There is an increasing need for education in spiritual care (SC).
- Consensus-based multidisciplinary guidelines for spiritual care (SC) in palliative care (PC) are available to be implemented.

What this paper adds?

- This paper shows that the effects of SC training can be measured using quantitative methods in patient-reported outcomes related to the quality of care.
- This paper shows the importance to patients of healthcare professionals' attention to their spiritual needs in the Netherlands.
- This trial shows that SC training of healthcare professionals had a significant effect on patients' reports of healthcare professionals' attention to their spiritual needs and even on their sleep.

Implications for practice, theory or policy?

- SC education based on multidisciplinary guidelines is an important tool for quality improvement of PC. Future research should focus on optimizing SC training to identify the most effective elements and on developing strategies to ensure long-term positive effects.

Keywords: palliative care, spiritual care, training, patient reported outcome measures.

Background and objectives

There is a growing consensus worldwide concerning the integration of spiritual care into whole person care (1). In the Netherlands, this consensus is strongly related to the development of modern palliative care. After the decline of the compartmentalization of Dutch society, in which healthcare was organized along confessional / denominational lines, spirituality in the Netherlands healthcare system has been neglected or implicitly included in psychosocial terms, such as ‘meaning making’ for decades. From the moment palliative care (PC) became part of a national programme in the Netherlands, healthcare professionals, policymakers, and researchers have been presented with the challenge of reassessing and introducing the complex concepts of spirituality and spiritual care (SC) not only in hospice care but also in hospitals, other facilities and home care (2). The development of the national consensus-based multidisciplinary guideline for SC took approximately three years, and the guideline was published in 2010(3). This guideline for practice was positively amended in the field and guided a systematic integration of the spiritual dimension of care into the national standards for palliative care(4). For English, German and Spanish translations, contact the site of the Taskforce Spiritual Care of the European Association of Palliative Care(5). The guideline advises to adopt a value oriented approach, not simply a problem oriented approach to spiritual needs or distress, also in order to address patients’ spiritual resources and activate patients’ vitality and resilience.

PC in the Dutch healthcare system operates at a high standard(6), but PC is not a separate medical speciality or sub-speciality, and most hospitals do not have dedicated PC units(7). Hence, PC is often delivered by healthcare professionals in curative departments without specific training in SC.

Although most healthcare professionals are generally not trained in the basic concepts and methods of SC, the national practice guidelines focusses on SC as a dimension that can be delivered by all

healthcare professionals in any setting in which palliative patients are treated. Implementation of this new approach or method in institutions such as hospitals is considered to be a complex intervention(8) that requires specific education. Therefore, new educational programmes that train healthcare professionals in SC need to be developed, implemented and evaluated regarding their effects on patient care.

In this study, a specially designed training on SC based on the consensus definition of spirituality published by the Taskforce on Spiritual Care of the European Association for Palliative Care (EAPC)(9) and the Dutch guideline on spiritual care(3) was developed and evaluated in an intervention study. Trained hospital chaplains educated multidisciplinary teams of healthcare professionals in the clinical wards of non-academic teaching hospitals. Table 1 shows the profiles of the hospitals in the Netherlands.

Table 1 Hospital profiles in the Netherlands	
8 university medical centres	- complex and highly specialized care - research and innovation - education and training of medical and nursing disciplines
27 teaching hospitals, members of the Association of tertiary medical teaching hospitals (STZ)	- standard and complex specialized care - research and innovation - education and training of medical and nursing disciplines
55 general hospitals	- standard care for less specialised problems
4 specialized topclinical centres	(specialized in e.g. cancer, organ transplantation, in vitro fertilisation (IVF))

Table 1 Hospital profiles in the Netherlands.

The aims of the intervention was to improve healthcare professionals' attention to patients' expressions of spiritual needs, not to implement one specific tool for spiritual interventions, to raise healthcare professionals' competencies in supporting patients on this dimension, and raise the quality of care as perceived by palliative

patients on the wards that received the training. In this paper, we present the results of the patient-reported outcomes.

Methods

Study design

This pragmatic multicentre trial(10) on patient outcomes followed a quasi-experimental pre-test-post-test design and was part of an exploratory mixed methods action research study. We used quantitative methods to assess the effects of the intervention, SC training for PC, on the patients. This study was designed and conducted in accordance with the WHO Good Clinical Practice Guidelines. Ethical approval was granted by the medical ethical committee in Leeuwarden, Netherlands on July 4, 2013 (nWMO22). This study was registered at the Dutch Trial Register: NTR4559(11).

Participants

Hospitals The hospitals were selected based on three inclusion criteria: being a member of the association of tertiary medical teaching hospitals (*Stichting Topklinische Ziekenhuizen*), being actively involved in advancing palliative care by having a specialist consultation team or implementing palliative care quality improvement programmes, and having a dedicated trained healthcare chaplain specialized in SC for PC.

Wards The intervention and control wards were selected by the local co-researchers, i.e., the dedicated chaplains; as the teachers, the chaplains were responsible for the SC training for PC. The criteria for the intervention wards were that the chaplain was connected to the intervention ward, that the ward was willing to facilitate and encourage staff to follow the training, and that the ward was willing to facilitate patient interviews.

Patients The physician responsible for each patient was asked to provide the patients' advanced clinical conditions (table 2) as well as the indicators for supportive or palliative care (table 3). The physi-

cians were asked, “Would it surprise you if this patient died in the next 12 months?” When the answer was negative, the patient was asked to participate, was provided written information about the study and after providing written informed consent, was included in the study. The included patients were asked to complete the questionnaire independently. If needed, the questionnaire was read at bedside by a specialist palliative care nurse or a ward nurse from another department with additional palliative care training (12).

Patients were included based on the Dutch translation of the Supportive and Palliative Care Indicators Tool(13) (OPZIS). The OPZIS seemed feasible in the context of this study(14). We have included four independent groups on two time moments. At T1: intervention group 1 one month before the training on the intervention ward, control group 1 simultaneously on a control ward in the same hospital. At T2: intervention group 2 one month after the training on the intervention ward, and control group 2 simultaneously on the control ward. In the protocol we asked the local researchers for the total number of patients on a ward during the measurement, the total of number of palliative patients and the number of excluded palliative patients, but no team was able to gather this information within reasonable time limits as illustrated in the Flow diagram.

Because the intervention training was provided to the clinical staff, randomization of the patients was not an option. Since we did not perform a spiritual intervention to patients directly, diagnostic awareness was not measured.

Intervention

The intervention in this trial is not a standardized spiritual intervention administered to patients with a high score (e.g. ≥ 4 on a scale from 0-10), but a training spiritual care, based on the Dutch multidisciplinary guideline on SC and the EAPC definition of spirituality, to multidisciplinary teams of regular wards, where patients are treated in curative and palliative trajectories.

5. Effects on patient-reported outcomes

Table 2 Sample description	Intervention group		Control group		p-value	Total
	T1 intervention group 1 n = 29	T2 intervention group 2 n = 24	T1 control group 1 n = 19	T2 control group 2 n = 13		
N = 85						
Age in years (mean, SD)	67.11(9.9)	66.17(9.3)	66.88(13.6)	71.75(8.9)	.632 ^a	
Gender: Female (n,%)	14(16.5)	10(11.8)	10(11.8)	4(4.7)	.627 ^b	38(44.7)
Clinic. indicators of advanced conditions^d						
Heart/vascular disease (n,%)	1(1.2)	1(1.2)	2(2.4)	5(5.9)	.004 ^b	9(10.6)
Respiratory disease (n,%)	10(11.8)	6(7.1)	2(2.4)	3(3.5)	.313 ^b	21(24.7)
Kidney disease (n,%)	6(7.1)	4(4.7)	8(9.4)	5(5.9)	.176 ^b	23(27.1)
Liver disease (n,%)	0	0	0	0		0
Cancer (n,%)	9(10.6)	8(9.4)	13(15.3)	8(9.4)	.026 ^b	38(44.7)
Neurological disease (n,%)	1(1.2)	0	1(1.2)	0	.627 ^b	2(2.4)
Dementia/frailty (n,%)	7(8.2)	5(5.9)	5(5.9)	2(2.4)	.892 ^b	19(22.4)
Religion					.437 ^b	84(98.8)
None (n,%)	9(10.7)	10(11.9)	5(6.0)	6(7.1)		30(35.7)
Roman Catholic (n,%)	3(3.6)	3(3.6)	3(3.6)	3(3.6)		12(14.3)
Protestant (n,%)	10(11.9)	6(7.1)	9(10.7)	1(1.2)		26(31.2)
Muslim (n,%)	2(2.4)	1(1.2)	1(1.2)	0		4(4.8)
Humanist (n,%)	2(2.4)	3(3.6)	0	0		5(6.0)
Buddhist (n,%)	0	0	0	1(1.2)		1(1.2)
Other (n,%)	3(3.6)	1(1.2)	1(1.2)	1(1.2)		6(7.1)
SAIL						
Meaningfulness (mean,SD)	4.43 (0.86)	4.42 (0.99)	4.59 (0.87)	3.94 (0.97)	.294 ^c	82(96.4)
Trust (mean,SD)	4.40 (0.79)	4.47 (0.91)	4.31 (0.88)	4.54 (0.89)	.893 ^c	85(100)
Acceptance (mean,SD)	4.64 (0.86)	4.35 (1.08)	4.82 (0.80)	4.36 (1.00)	.446 ^c	85(100)
Caring for Others (mean,SD)	4.80 (0.83)	4.53 (0.82)	5.05 (0.72)	4.23 (1.48)	.183 ^c	85(100)
Connectedness with Nature (mean,SD)	4.55 (1.31)	4.78 (1.34)	5.29 (0.90)	5.12 (1.52)	.107 ^c	84(98.8)
Transcendent Experiences (mean,SD)	1.99 (1.12)	2.79 (1.56)	2.04 (.88)	1.93 (1.26)	.128 ^c	78(91.6)
Spiritual Activities (mean,SD)	2.82 (1.59)	2.79 (1.38)	3.19 (1.37)	1.85 (1.05)	.065 ^c	82(96.4)
Nu. of patients in departments						
Oncology (n,%)	7(8.2)	10(11.8)	11(12.9)	5(5.9)		33(38.8)
Lung diseases (n,%)	17(20.0)	10(11.8)	1(1.2)	0		28(32.9)
Renal unit (n,%)	5(5.9)	4(.7)	5(5.9)	5(5.9)		19(22.4)
Internal diseases (n,%)	0	0	2(2.4)	3(3.5)		5(5.9)

SD: standard deviation; SAIL: Spiritual Attitude and Involvement List

^a One-way ANOVA, ^b Pearson Chi-Square, ^c Kruskal-Wallis,

^d Total is more than 100% because some patients had multiple diseases.

Table 2 Description of the sample.

Table 3 Indicators for Supportive or Palliative Care	Intervention group		Control group		p value ^a	Total
	T1 intervention group 1 n = 29	T2 intervention group 2 n = 24	T1 control group 1 n = 19	T2 control group 2 n = 13		
N = 85						85(100)
Performance status (ECOG >2)	n(%) 19(22.4)	n(%) 19(22.4)	n(%) 18(21.2)	n(%) 13(15.3)	.018	n(%) 69(81.2)
General indicators of deteriorating health						
Unplanned hospital admissions (≥2) in the past 6 months	17(20.0)	11(12.9)	9(10.6)	5(5.9)	.623	42(49.4)
Weight loss (5-10%) over 3-6 months and/or BMI <20	4(4.7)	1(1.2)	6(7.1)	8(9.4)	.000	19(22.4)
Persistent, troublesome symptoms despite optimal treatment	13(15.3)	10(11.8)	9(10.6)	6(7.1)	.984	38(44.7)
Risk of dying due to acute deterioration	11(12.9)	9(10.6)	16(18.8)	6(7.1)	.007	42(49.4)
Living in nursing care home/unit or needs care at home	2(2.4)	2(2.4)	7(8.2)	1(1.2)	.015	12(14.1)
Patient requests supportive/palliative care or treatment withdrawal	0	4(4.7)	5(5.9)	0	.012	9(10.6)
New diagnosis of a progressive life-threatening disease	2(2.4)	2(2.4)	4(4.7)	1(1.2)	.414	9(10.6)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Mean Utrecht Symptoms Diary	2.8(1.4)	2.6(1.5)	3.4(1.9)	3.2(.9)	.263	

ECOG: Eastern Cooperative Oncology Group; BMI: Body Mass Index; SD Standard Deviation

^a Pearson Chi-Square

Table 3 Indicators for Supportive or Palliative Care

The Dutch multidisciplinary guideline instructs healthcare professionals to look for patients’ spiritual resources and not to limit themselves to a problem oriented approach towards patients’ spirituality. In accordance with the action research approach(15), the SC training intervention given by specially trained local healthcare chaplains varied locally within the preliminary set of requirements of the study protocol(RW.ERROR - Unable to find reference:13400). The core skills to train were screening or assessing spiritual needs, accompanying patients within a professional role, and referring patients to specialists when the patients are in a crisis. Multidisciplinary education was mandatory. Local variations in training were possible for 2 of the 3 provided tools for screening/assessment, for 1 or 2 lessons, for the

teaching methods and when adapting to locally existing quality programmes in (palliative) care. For more detailed information see the set of requirements of the training in Table 4.

Objectives

The objective of the study was to measure the effects of SC training in PC on patients' perceptions of their care and treatment.

Primary outcome: healthcare professionals' attention to patients' life issues and their existential and spiritual distress.

Secondary outcomes:

- healthcare professionals' openness to conversations about life questions and existential and spiritual distress,
- healthcare professionals' respect for patients' beliefs or philosophies on life,
- access to the healthcare chaplain in the department,
- feeling that life was worthwhile during the last three days, and
- other possible physical or psychosocial symptoms.

Outcome measurements:

The levels of palliative patients' physical, psychosocial and spiritual distress were measured one month before and one month after the specific training of the healthcare professionals on the experimental wards. The levels of palliative patients were simultaneously measured on the control wards. The target was to include 5-10 patients in the experimental and 5-10 patients in the control wards: 10-20 patients pre and 10-20 patients post each intervention. The questionnaire contained items on age, gender, demographics, and indicators for supportive and palliative care, 15 items on patients' physical and psychosocial symptoms using the Utrecht Symptom Diary(16) 4 spiritual items adapted from the Distress Thermometer(17,18), 26 items from the Spiritual Attitude and Interests List(19) and 6 items related to spiritual care from the NIVEL report on consumer quality indicators of palliative care(20).

Table 4. Requirements for the Pilot Training Spiritual Care in Palliative Care (SCPC)	
Target group	Multidisciplinary clinical teams of physicians, nurses and other healthcare professionals of departments in teaching hospitals (not being: specialized palliative care teams or units).
Competencies	Aim is to develop basic competencies for multidisciplinary spiritual care: recognising, referring, self reflectiveness and open attitude towards patient spirituality, as formulated by Kuin (21) based on the work of Van Leeuwen (22).
Preparation	A Dutch e-learning module on SCPC based on the Guideline is considered to be ideal as preparation for a local training. An electronic learning environment with a selection of reading material and video fragments on SC considered to be compatible with the Guideline will be made available to participants who want to prepare themselves before the pilot training SCPC (Available on https://www.mcl.nl/patient/specialismen-en-centra/geestelijke-verzorging/spirituele-zorg).
Planning	Implementation of the training is considered ideal when planned as two lessons of 90'-120' with an interval of at least three weeks. Minimum is one lesson of 90' with follow up teaching methods (coaching on the job, bedside teaching).
Structure	The local format of the training has to be designed with the aim to (1.) sensitize participants for the spiritual dimension of palliative care, (2.) make participants realize the importance of their own spiritual and existential dimensions, in order to (3.) integrate it into professional practice.
Tools	No screening tools for spiritual care or spiritual care models proposed by Pennaertz are admitted to the pilot training SCPC. Because of lack of validated translations the choice is limited to those already mentioned and translated in the NL Guideline: symbolic listening according to Weiher (23), the translation of the three screening questions developed by the Mount Vernon Cancer Network (24) and the Dutch spiritual care model Legets Ars Moriendi (25).
Practice based learning	Teaching has to be practice oriented, practice based, participants should be stimulated to deliver case descriptions and receive feedback on these descriptions from the teacher/chaplain
Freedom for local adjustments	Given the local diversity in teaching hospitals and the nature of teaching spiritual care the pilot training SCPC is not possible without any diversity in tone, language and methods. The local teachers/chaplains receive a relative freedom in methodology and planning. Educational aims and goals as mentioned above are to be considered. Teaching to only one discipline of the multidisciplinary clinical team is not an option.
Teaching methods	No mandatory teaching methods. Selected core concepts and definitions of the guideline will be delivered on slides. Basic knowledge of Kolb's experiential learning model will be taught to the group of teachers/chaplains, preferred methods of teaching spiritual care will be exchanged in the group during the study.
Accreditation	The intervention needs approval by professional organisations of physicians and nurses, so participants can score the training to meet their professional registration requirements.

Table 4 Requirements for the Pilot Training Spiritual Care in Palliative Care

Statistical methods

Patient data were coded referring to the hospital, ward and numerical order of inclusion.

Earlier studies in the Netherlands were based on different definitions of spirituality or religion. Validated instruments for SC in Dutch based on (inter-)national consensus definitions still lack in this—for the Netherlands—rather new field of multidisciplinary spiritual care. Therefore this trial was explorative (phase one) and a power analysis was not possible. For this pilot study, the target number of multidisciplinary teams ($n = 10$), as well as the target number of patients ($n = 18$ per site) were not based on a formal sample size calculation. Frequencies were calculated to describe the patients, and characteristics were tested for group differences between the four groups, or calculated as group means to test for group differences using the One-way ANOVA, Pearson's Chi-Square and Kruskal-Wallis tests. The Mann-Whitney test was performed to test for differences between two groups (intervention group 2 versus intervention group 1 with control groups 3, 4) showing the effect of the intervention. The data were analysed using the Statistical Package for the Social Sciences, IBM Statistics for Windows version 19.0.

Results

Study population

Hospitals, wards In August 2013, the chaplaincy teams of all 27 teaching hospitals were invited to participate in this trial (Figure 1. Flow diagram). Eight hospitals were able to fulfil the inclusion criteria. One chaplaincy team could not implement the intervention because of the limited capacity of their local palliative care consultation team and chaplaincy department. In another hospital, the intervention was administered to a group of palliative care ambassadors working on different wards; therefore, we could not include patient data from this intervention. Two hospital chaplaincy teams trained two wards, one of which functioned as a control ward for the first intervention. This explains the difference in the number of intervention and control wards in the flow diagram. Eight wards were trained: four pulmonology wards, two oncology wards, one internal medicine ward and one renal ward. The control wards included three

oncology wards, one internal medicine ward, one pulmonology ward, and one nephrology ward.

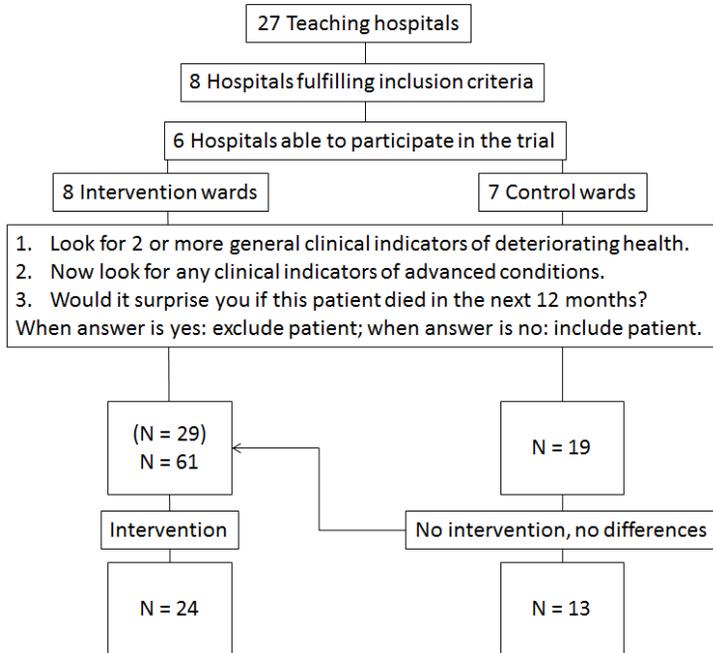


Figure 1 Flow diagram

Patients In the remaining six hospitals in which we trained eight multidisciplinary teams, we were able to collect data from 85 palliative patients. We were not able to collect the total number of patients treated at the wards during the measurements. Because we cannot give a point prevalence of palliative patients in the hospital population, we maintained the three question marks in the flow diagram. The data were divided into four groups: pre-intervention group 1 (n=29), post-intervention group 2 (n=24), control group 3 (n=19) and control group 4 (n=13).

Patient groups had a mean age varying between 66.2-71.8 years, and 44.7% were female. Almost half of the patients had cancer (44.7%), a quarter had kidney disease (27.1%), a quarter had respir-

atory disease (24.7%), a fifth suffered from dementia/frailty (22.4%), and others had diseases including heart/vascular disease (10.7%) and neurological disease (2.4%). These patients were treated and cared for in oncology wards (38.8%), pulmonology wards (32.9%), nephrology units (22.4%) and internal medicine wards (5.9%).

The four groups of patients had high mean values (3.94 – 5.29) on the same subscales of the Spiritual Attitude and Interests List: meaningfulness, trust, acceptance, caring for others and connectedness with nature. Subscales with a value ≥ 4 are considered important dimensions of responders' spirituality.

The mean values of patients' (2.9/3.4) or proxies' (4.2/3.3) life issues and existential and spiritual problems or needs were within the range of the mean values of the other symptoms. Patients rated the importance of healthcare professionals' attention to their and their proxies' life issues and existential and spiritual problems or needs as high (8.5/7.2).

Outcomes

After we tested for differences between the four groups and found no relevant differences between the patient population of different wards, we also tested for differences, between group 3 (control ward pre-intervention) and group 4 (control ward post-intervention) and found no significant differences, concluding that we can ascribe a possible difference in the post intervention group 2 as an effect of the intervention. We added groups 3 and 4 to group 1 to obtain a larger control group/baseline (see Table 5 Symptoms and existential or spiritual needs). As the effects of educating healthcare professionals were being measured, there was no reason to select patient groups based on their specific conditions. Because we did not train a cardiology ward, the outcomes related to heart/vascular disease, although statistically significant, were considered not relevant.

For the primary outcome measure of 'healthcare professionals' attention to life issues and existential and spiritual distress,' the

post-intervention group (group 2) showed a significant improvement (7.0 > 8.0, p-value=.008). The secondary outcome measures showed no significant effects.

Table 5 Symptoms and existential or spiritual needs	Intervention group 2, n = 24	Baseline group 1,3,4, n = 61	p-value ^a	Total N = 85
Utrecht Symptoms Diary: no symptom,0-10, extreme symptom	Mean(SD)n	Mean(SD)n		n/N
Pain	2.33(2.7)	2.6(2.6)	.592	
Activity	4.9(2.9)	5.2(3.1)	.694	
Nausea	1.3(2.4)	1.9(3.1)	.623	
Depression	2.0(2.8)	2.5(3.1)	.407	
Anxiety	2.1(2.7)	1.5(2.6)	.250	
Drowsiness	1.0(1.5)	1.4(2.3)60	.854	84/85
Appetite	3.6(3.5)	4.8(3.5)	.193	
Wellbeing	4.3(3.1)	4.4(2.9)	.937	
Shortness of Breath	2.6(2.9)	2.1(2.8)	.249	
Sleeping	2.1(2.6)	4.0(3.3)	.020	
Tiredness	5.3(3.2)	5.8(2.9)	.676	
Constipation	1.5(2.3)	2.4(3.3)	.402	
Confusion	.46(1.1)	.52(1.3)	.945	
Dry mouth	4.2(3.4)	5.4(3.5)60	.133	84/85
Vomiting	.46(1.5)	1.3(2.6)	.150	
Existential, spiritual problems or needs: no distress, 0-10, extreme distress				
Patients' life issues, existential, spiritual distress	2.9(3.3)	3.4(2.9)	.480	82/83
Patient reported proxies' life issues, existential, spiritual distress	4.2(3.3)	3.3(3.3)	.302	77/85
Importance of health care professionals' (HCPs') attention to life issues, existential, spiritual distress	8.5(1.6)	7.2(2.9)	.056	
Patient Reported Outcome Measures				
HCPs' attention to life issues, existential, spiritual distress (0-10)	7.9(1.8)	5.9(3.2)	.008	
HCPs' openness to conversations about life issues, existential, spiritual distress (0-4)	3.3(.8)22	2.9(1.0)48	.114 ^b	70/85 ^c
Caregivers respect for patients beliefs or philosophy of life (0-4)	3.6(.6)16	3.4(.7)29	.620 ^b	45/85 ^c
Access to healthcare chaplain at this department (0-4)	3.2(1.1)14	2.9(1.3)30	.391 ^b	44/85 ^c
Feeling life is worthwhile during the last three days (0-6)	4.4(1.3)22	4.6(1.2)61	.091 ^b	83/85

SD: standard deviation

^a Mann-Whitney, ^b Pearson Chi-Square, ^c Due to the editing of the questionnaire there is a higher value Missing.

Table 5. Symptoms and existential or spiritual needs

The outcomes of the Utrecht Symptom Diary showed no effects of the intervention on physical and psychosocial symptoms, with one relevant exception: a positive significant effect in favour of 'Sleeping' ($4.0 > 1.0$ p-value=.020). There was no significant correlation between both significant effects 'healthcare professionals' attention to life issues, existential or spiritual distress' and 'sleeping' ($p = .86$).

Discussion

With this sample size, the study generates sufficient data for an exploratory evaluation, of the effect of an educational intervention administered to healthcare professionals, from the perspective of the patients. At the same time our study provides a method for an exploratory evaluation of the implementation of a multidisciplinary guideline on SC. It is important to realize that we did not evaluate a training of one specific spiritual intervention and its effect when administered to patients directly.

The performance status, general indicators of deteriorating health and the mean symptom values reflected the fact that the four groups of (palliative) patients with severe conditions were not in their dying stages.

The variation in religious affiliation (Table 3) compared with the 2014 national statistical data in the Netherlands showed an underrepresentation of non-believers and humanists (35.7% + 6%=41.7% vs. a total of 49.2% in the national data), an underrepresentation of Catholics (14.3% vs. 24.4%), an overrepresentation of Protestants (31.2% vs. 15.8%) and a normal representation of Muslims (4.8% vs. 4.9%) (26). These findings can be explained by the fact that the participating hospitals were situated in the middle and the north of the Netherlands.

This study demonstrates that the clinical effects of SC training for healthcare professionals can be measured using patient-reported outcomes, despite the fact that the concept of SC was rela-

tively new and the tools to measure SC were still under development. Adding questions to the Utrecht Symptom Diary or other Edmonton Symptom Assessment Scale (ESAS)-like questionnaires, as described in the protocol, seemed to result in the most significant research outcomes. Since we found no correlation between the primary outcome, the improved healthcare professionals' attention to patients' life questions and spiritual and existential needs, and the significant positive effect on patients' sleep, we conclude these are two independent effects of the intervention.

We acknowledge that the significant positive effect of the SC training for healthcare professionals on the quality of care as reported by patients may be a short-term effect. We did not see a decrease of patients' and proxies life issues, existential or spiritual distress. We believe there can be several reasons for this: a) our study design did not direct us to select patients with a relative high score of spiritual distress, b) nor was it aimed to evaluate a standardized intervention to decrease these patients' or proxies' high level of spiritual distress, c) the mean levels of spiritual distress we found were relatively low, d) an educational intervention on healthcare professionals is not likely to expect it to lower it any further and, e) the multidisciplinary guideline instructs to observe if the spiritual distress or existential crisis can be seen as the normal course of a spiritual process needing attention rather than extinction. Our outcomes, as reported by palliative patients, correspond with international(27,28) and national(29) studies that found that patients highly value healthcare professionals' attention to their life questions and their existential and spiritual needs. In the post-intervention group, we were surprised by the higher mean scores on this item compared with the other groups. It is possible that patients' awareness of the importance of the spiritual dimension was raised because they were in wards that paid more attention to this dimension of care.

Although the Spiritual Attitude and Involvement List (SAIL) was not developed to measure short-term or long-term effects in clinical practice, it generated interesting information. In this study,

palliative patients reported that the following themes were important (≥ 4) to them: meaningfulness, trust, acceptance, caring for others and connectedness with nature (see Table 3. Sample description, SAIL). This study indicates that SC training in hospital staff can have a significant positive effect on sleep; however, further research is needed to explore this.

Strengths and limitations

Providing palliative or comfort care to patients with advanced conditions is by its nature a multidisciplinary activity. Training of only one or two specialists in each team would have made the project vulnerable. The strength of this study was that it showed that a team approach can have significant effects on the quality of care as perceived by patients.

This study demonstrated the possibility of using quantitative research on the complex concept of training spiritual care in trials. The measurement method selected, i.e., adding questions to a symptom-oriented tool, was appreciated by the patients and showed quantifiable results. The combination of action research and quantitative research seemed to create opportunities for quality improvement efforts. We were able to generate quality improvement projects in almost a third of the teaching hospitals in our country and, as usually methods developed in our teaching hospitals are more easily disseminated than methods developed in university medical centres, we believe this study to be replicable and our results to be generalizable for many hospital settings.

The main limitation of this study was the sample size. Our target was 20-40 patients per training/intervention per hospital. We only reached the target minimum of 20 patients two times. There are five possible reasons for this: the lack of financial compensation for the nurses' work, the vulnerability of the small and rather new palliative consultation teams in the hospitals during the research period (two sites lacked a palliative team), their limited experience with research protocols, the relatively limited cooperation between the

local researcher and the palliative consultation team in one site, and finally the severe condition of a number of palliative patients on the wards during the assessment.

Quantitative research does not provide valid information about the content of patients' life issues and about the existential and spiritual needs of patients. Future research will need to involve qualitative methods to interpret the meaning of the quantitative measurable effects.

Conclusion

SC education based on multidisciplinary guidelines is an important tool for quality improvement of PC. Future research should focus on optimizing the SC training to identify the most effective elements and on developing strategies to ensure long-term positive effects.

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Declaration of interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical committee

Ethical approval was provided by the medical ethical committee in Leeuwarden, Netherlands on July 4th 2013 (nWMO22). This study is registered at the Dutch Trial Register: NTR4559.

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6

Multidisciplinary training on spiritual care in palliative care improves the attitudes and competencies of hospital medical staff: Results of a quasi-experimental study



Chapter 6. Multidisciplinary training on spiritual care for patients in palliative care trajectories improves the attitudes and competencies of hospital medical staff: Results of a quasi-experimental study

Joep van de Geer, MiDiv¹, Nic Veeger, PhD², Marieke Groot, PhD³, Hetty Zock, PhD⁴, Carlo Leget, PhD⁵, Jelle Prins, PhD² and Kris Vissers, MD, PhD, FIPP³

Affiliations:

¹ Chaplaincy Department, Medical Centre Leeuwarden, Leeuwarden, Netherlands,

² MCL Academy of Medical Centre Leeuwarden, Leeuwarden, Netherlands,

³ Department Palliative care, Radboud UMC, Nijmegen, Netherlands,

⁴ Faculty of Theology and Religious Studies, University of Groningen, Groningen, Netherlands,

⁵ Department Ethics of Care and Spiritual Counselling Sciences, University of Humanistic Studies, Utrecht, Netherlands.

Abstract

Objectives: Patients value healthcare professionals' attention to their spiritual needs. However, this is undervalued in healthcare professionals education. Additional training is essential for implementation of a national multidisciplinary guideline on spiritual care (SC) in palliative care (PC). Aim of this study is to measure effects of a training programme on SC in PC based on the guideline.

Methods: A pragmatic multicentre trial using a quasi-experimental pre-test-post-test design as part of an action research study. Eight multidisciplinary teams in regular wards and 1 team of PC consultants, in 8 Dutch teaching hospitals, received questionnaires before

training about perceived barriers for SC, spiritual attitudes and involvement, and SC competencies. The effect on the barriers on SC and SC competencies were measured both 1 and 6 months after the training.

Results: For nurses (n = 214), 7 out of 8 barriers to SC were decreased after 1 month, but only 2 were still after 6 months. For physicians (n = 41), the training had no effect on the barriers to SC. Nurses improved in 4 out of 6 competencies after both 1 and 6 months. Physicians improved in 3 out of 6 competencies after 1 month but in only 1 competency after 6 months.

Significance of results: Concise SC training programmes for clinical teams can effect quality of care, by improving hospital staff competencies and decreasing the barriers they perceive. Differences in the effects of the SC training on nurses and physicians, show the need for further research on physicians' educational needs on SC.

Keywords: palliative care, spiritual care, multidisciplinary team, healthcare professionals, competencies, healthcare chaplaincy

Introduction

In many Western countries, the role of spirituality and religion became less important in healthcare during the second half of the 20th century. In the Netherlands, the role of spirituality and religion became almost marginal in the national healthcare system. However, the development of palliative care (PC) provided a strong impulse to reintroduce attention to this dimension in the Dutch healthcare system.(1) Concomitantly, a new definition of health was developed by Machteld Huber;(2) she illustrated in her operationalisation study that patients value the spiritual dimension equally as high as the other dimensions of health.(3) The gap between patients' expectations concerning healthcare professionals' attention to their spiritual needs and what they experience was reported by nurses in the Royal Col-

lege of Nursing Spirituality survey of 2010(4) and by doctors in the systematic review of Megan Best.(5) Recently, initiatives to develop measurable spiritual care (SC) competencies(6) or good practices to integrate spirituality and SC in education(7) have been implemented, and national(8,9) and international consensus(10) documents have been published.

In the Netherlands, the sense of urgency to integrate SC in medical practice was prompted by the publication of a national consensus-based guideline on multidisciplinary SC(11) in palliative care (further: the SC guideline). English, German and Spanish translations of this multidisciplinary guideline can be downloaded from the website of the Taskforce on Spiritual Care of the European Association for Palliative Care (EAPC).(12)

For this study, we trained healthcare chaplains and developed requirements, targets and core teaching methods for a SC training programme for multidisciplinary teams of regular medical wards where were treated in curative and palliative trajectories.(13) This training was based on the EAPC consensus definition of spirituality,(14) and aimed at the implementation of the methods presented in the SC guideline. Our main research question was: is it possible to achieve and measure effects on quality of care, and on healthcare professionals' competencies and perceived barriers for SC, with a concise training programme for multidisciplinary teams in hospitals? The effect of the training on the quality of care in patient-reported outcomes is described elsewhere.(15)

In this article, we present the results on physicians' and nurses' attitudes and SC competencies.

Methods

Study design

This pragmatic multicentre trial,(16) on patient-reported and healthcare professional-reported outcomes used a quasi-experimental, pre-test-post-test design, and was part of an exploratory action research study. We used quantitative methods to assess the

effects of the intervention, SC training in PC, on the patients and healthcare professionals. This study, designed and conducted in accordance with the WHO Good Clinical Practice Guidelines, was admitted by the medical ethical committee for the Medical Centre Leeuwarden on July 4, 2013 (nWMO22), subsequently by the research committees at each site, and registered in the Dutch Trial Register: NTR4559. (17)

Participants

Hospitals and wards The included hospitals were non-academic teaching hospitals, members of the Association of Tertiary Medical Teaching Hospitals, actively involved in developing PC using a specialist consultation team, or actively implementing PC quality improvement programs. (13) Within the hospitals, local co-investigators, being healthcare chaplains trained to perform the intervention, self identified wards of various clinical departments, that were motivated to improve SCPC by means of a pilot training programme in SC. The chaplains approached one of the wards to which they were already personally assigned to as the responsible chaplain. All wards that were approached appeared to be willing to participate in the study.

Healthcare professionals These local co-investigators, trained and accredited to train the multidisciplinary teams of primary caregivers, deliberated with the nursing and medical management of the wards, on how to implement this training in the local context. The target was to train the multidisciplinary team, which included all nurses, and physicians responsible for the treatment of the main group of patients on that ward. Teams were informed about the study by the medical and nursing managers, using the study protocol and/or invited the (local co-) investigator for team meeting to raise support for participation. When the decision was made all participants were instructed to participate in the training as a team wise chosen form of improving the quality of SC in PC on their ward. Their data were coded according to hospital, ward and numerical order of inclusion.

Intervention

The SC training intervention (hereafter : the training) was delivered 9 times in 7 hospitals from February 2014 to February 2015, healthcare professionals were scheduled in groups for the training, during working hours for one or two lessons, given by the healthcare chaplains using standard slides for presentation and selected teaching methods. In accordance with the action research approach,(18) the training varied locally within the preliminary set of requirements of the study protocol (see Appendix 1, Requirements for the Pilot Training Spiritual Care in Palliative Care). A publication with detailed information about the experiences of the co-investigators performing the intervention is submitted.

The core skills to train were: screening/assessing spiritual needs, counselling patients (matching their own professional role), and referring patients to specialists when the patients are in a crisis. Multidisciplinary education was mandatory.

Objectives

The objective of this study was to explore training methods for SC for healthcare professionals in hospitals, to measure the effects of the training on healthcare professionals' barriers to SC and SC competencies, and to generate hypotheses for further research.

Outcome measurements

Based on the validated methods used by Wasner et al.,(19) van Leeuwen's Spiritual Care Competence Scale (SCCS) to assess the nurses' SC competencies and the effect of training on SC(6), and the Spiritual Attitude and Involvement List (SAIL)(20) an online questionnaire was used. We also included questions concerning work attitude and perceived barriers to providing SC, developed by Put.(21) The SCCS was adapted, and approved by the original author, for assessing both nursing and medical SC competencies (see Appendix 2). At test 1 (T1) one month before the training, the baseline

questionnaire contained items on demographic data, items on work experience and attitude, items of the SAIL, items on perceived barriers to providing SC, and items of the SCCS.

After the training, at T2 (1 month) and T3 (6 months) questionnaires contained items on perceived barriers to providing SC and items of the SCCS, to measure the effects of the training.

We formulated the primary outcomes for this study as follows: 1. decrease in the perceived barriers to SC compared to baseline: lack of knowledge, maintaining too much or too little distance, difficulties in communication with patients, family, team, and community clergy; 2. higher competencies compared to baseline on the subscales of the SCCS: assessment and implementation of SC, professionalisation and improving quality of care, personal support and counselling, referral to professionals, attitude towards patients' spirituality, and communication.

Statistical methods

For this exploratory study, the targets were not based on a formal sample size calculation. Frequencies were calculated to describe the healthcare professionals, the characteristics were tested for group differences, or calculated as group means to test for group differences, using Fisher Exact, T-test, Chi-square and Mann-Whitney U tests. In this study, hypothesis testing (p-value) is interpreted as explorative, rather than confirmative. Bonferroni correction for multiple comparisons was not performed. We conducted a two-step group analysis for the primary outcomes on the effect of the training: an analysis of the short-term effects after 1 month and an analysis of the long-term effects after 6 months. The data were processed and analysed using the Statistical Analysis System Software for Windows 9.4 (SAS Institute Inc., Cary, NC).

Results

Study population

Hospitals and wards In August 2013, chaplaincy teams of 27 included hospitals were invited to participate in this trial; 11 hospitals responded, 9 hospitals met the inclusion criteria, 1 chaplaincy team had methodological objections, and 1 team could not implement the intervention because of the limited capacity of their local PC and chaplaincy teams (see Figure 1. Flow diagram). At 1 of the 7 sites, we were not able to train a specific ward. Instead, we included a multidisciplinary team of physicians and nurses, working as PC consultants and ambassadors.(22) In the other 6 out of 7 hospitals, 8 multidisciplinary teams were included (4 pulmonology, 2 oncology, 1 internal medicine and 1 renal ward).

Healthcare professionals Although 374 healthcare professionals were scheduled for training, we collected baseline data from 270 individuals. As the intervention was targeted at nurses and physicians, we excluded the other healthcare professionals from the analysis of the effects of the intervention. At T2 we received questionnaires of 124 individuals with data concerning the effects on the barriers to SC, and on their SC competencies, and at T3 we collected data from 65 healthcare professionals (see Figure 1. Flow diagram).

The analysis was performed for two groups: Nursing (n = 214), and Medical (n = 41) (see Table 1. Description of the sample). The sample of nurses is considered representative, in the sample of physicians we see a higher number of male participants. The highest scores for no religion and affiliation to the Humanist tradition were found amongst physicians. Compared to the sample of Wasner et al,(19) our sample showed a higher quality of life, involvement with oneself, patients, and family; a lower fear of death and dying; equal scores for work satisfaction and meaningfulness of work; better relationships with colleagues; and lower scores for work-related stress.

6. Effects on competencies of hospital medical staff

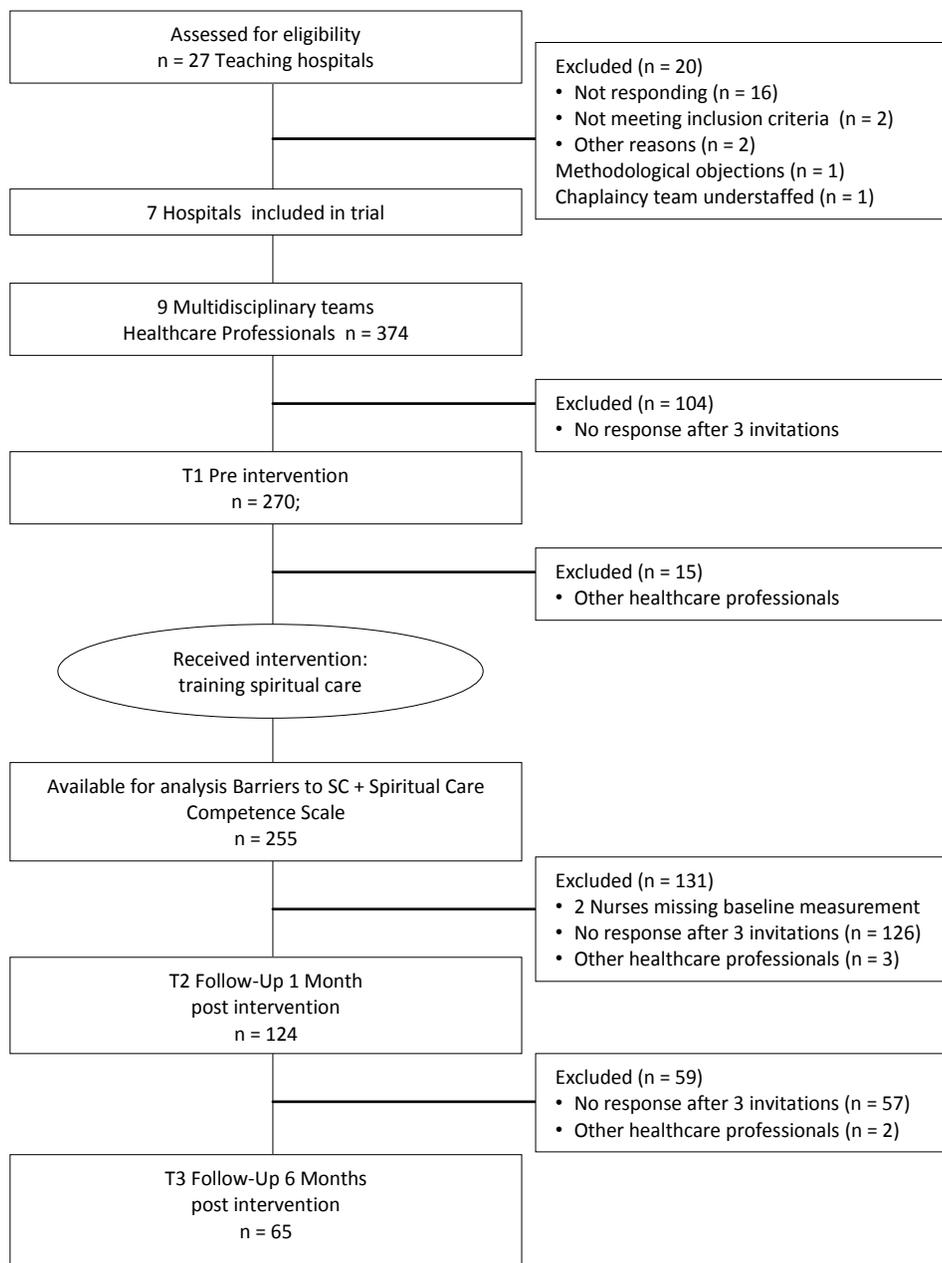


Figure 1. Flow diagram.

Learning spiritual care in Dutch hospitals

Table 1 Sample description healthcare professionals (hcps) at T1 N=255	Nurses	Physicians	p-value
	n = 214	n = 41	
Gender: Female (n,%)	193(90.2)	24(85.5)	0.001 ^a
Age in years (mean, SD)	39.6(11.6)	40.3(10.7)	0.700 ^b
Nu. of years working in healthcare (mean, SD)	18.5(11.9)	14.6(10.2)	0.056 ^a
Departments (n,%)			
Lung diseases	92(49.5)	27(65.9)	
Oncology	69(37.1)	12(29.3)	
Internal diseases	18(9.7)	2(4.9)	
Renal unit	7(3.8)	0	
Religion (n,%)			
None	87(40.1)	20(48.8)	Total 107(42.0)
Protestant	77(36.0)	9(22.0)	86(33.7)
Roman Catholic	31(14.5)	4(9.8)	35(13.7)
Humanist	4(1.9)	2(4.8)	6(2.4)
Buddhist	2(.9)	1(2.4)	3(1.2)
Hindu	1(0.5)	0	1(0.4)
Muslim	1(0.5)	0	1(0.4)
Jewish	1(0.5)	0	1(0.4)
Other	10(4.7)	5(12.2)	15(5.9)
SAIL (mean,SD)			
Meaningfulness	4.5(0.6)	4.6(0.6)	0.30 ^b
Trust	4.4(0.6)	4.6(0.5)	0.13 ^b
Acceptance	4.4(0.7)	4.4(0.7)	0.94 ^b
Caring for Others	4.8(0.5)	4.8(0.4)	0.96 ^b
Connectedness with Nature	4.3(1.1)	4.4(0.9)	0.57 ^b
Transcendent Experiences	2.4(0.9)	2.3(0.6)	0.36 ^b
Spiritual Activities	2.6(1.1)	2.2(0.9)	0.07 ^b
Received previous training SC (n%)			
No	194(90.7)	39(95.1)	0.61 ^c
Short training (1 day or less)	16(7.5)	2(4.9)	
Training (more than 1 day)	4(1.9)	0	
Work attitude (Scale 1: not at all – 10: a lot) (Mean, SD)			
Personal quality of life	8.4(0.9)	8.4(1.0)	0.70 ^d
Involvement with the patient	8.3(1.0)	8.2(0.8)	0.86 ^d
Involvement with the family	8.1(1.1)	7.9(0.9)	0.29 ^d
Involvement with myself	7.9(1.3)	8.0(1.0)	0.56 ^d
Fear of dying phase	3.8(2.4)	3.3(1.8)	0.23 ^d
Fear of death	3.9(2.5)	3.7(2.2)	0.66 ^d
Work satisfaction	7.6(1.4)	7.9(0.9)	0.14 ^d

6. Effects on competencies of hospital medical staff

Work meaningful	8.5(1.1)	8.6(0.9)	0.62 ^d
Good relationship with colleagues	8.2(1.0)	8.1(0.9)	0.52 ^d
Work related stress	5.2(2.4)	5.3(2.1)	0.71 ^d
Sickness around me interferes my engagement on this domain	2.0(1.6)	1.5(0.9)	0.55 ^d
Personal mourning interferes my engagement on this domain	2.0(1.6)	1.5(1.0)	0.04 ^d
Personal questions or spiritual pain interferes my engagement on this domain	2.0(1.6)	1.5(1.1)	0.08 ^d
Absenteeism during last 6 months (n,%)			0.41 ^c
0-5 days	197(92.1)	41(100)	
10-15 days	5(2.3)	0	
15-20 days	2(0.9)	0	
5-10 days	7(3.3)	0	
> 25 days	3(1.4)	0	

Table 1. Description of the sample.

Table 2 Healthcare professionals' barriers to SC and Spiritual Care Competencies at T1, T2 and T3

N = 253	Nurses			Physicians		
	T1 n = 212	T2 n = 105	T3 n = 57	T1 n = 41	T2 n = 19	T3 n = 8
Barriers to SC (Scale 1: not at all – 10: a lot)						
Lack of knowledge of this domain (Mean, SD)	4.7(1.9)	3.9(1.8)	4.0(2.0)	4.5(2.1)	4.3(1.7)	4.3(1.3)
Insecurity on this domain (Mean, SD)	4.2(2.2)	3.4(1.8)	4.0(2.1)	4.0(1.7)	3.8(1.7)	3.8(1.3)
Keeping too much distance (Mean, SD)	3.9(2.0)	3.3(1.8)	3.5(2.0)	4.1(1.7)	3.1(1.6)	3.4(0.9)
Keeping not enough distance (Mean, SD)	3.5(1.8)	3.3(1.8)	3.5(2.0)	3.7(1.7)	3.4(2.0)	3.8(2.3)
Difficult domain in patient communication (Mean, SD)	3.8(2.1)	3.1(1.6)	3.4(2.0)	3.7(1.8)	3.7(1.7)	4.5(1.5)
Difficult domain in family communication (Mean, SD)	3.9(2.1)	3.2(1.7)	3.3(1.9)	3.8(1.8)	3.6(1.6)	5.3(1.9)
Difficult domain in team communication (Mean, SD)	3.4(2.1)	2.6(1.4)	2.9(2.0)	3.5(2.2)	3.1(1.8)	3.1(2.3)
Difficult domain in communication with community clergy (Mean, SD)	3.2(2.1)	2.4(1.5)	3.0(2.1)	3.2(1.8)	2.7(1.3)	2.8(1.9)
Spiritual Care Competence Scale (Scale 1-5 *)						
Assessment and implementation of spiritual care	3.6(0.7)	3.9(0.5)	3.9(0.7)	3.0(0.8)	3.5(0.9)	3.6(0.6)
Professionalization and improving quality of care	2.6(0.7)	3.3(0.7)	3.2(0.7)	2.3(0.8)	3.1(1.0)	2.5(1.0)
Personal support and counselling of patients	3.6(0.6)	4.0(0.4)	3.9(0.5)	2.8(0.8)	3.5(0.9)	3.2(1.0)
Referral to other professionals	3.9(0.6)	4.1(0.4)	4.1(0.5)	3.6(0.6)	4.0(0.9)	4.0(0.7)
Attitude towards patients' spirituality	4.4(0.5)	4.4(0.4)	4.5(0.5)	4.5(0.5)	4.5(0.4)	4.5(0.4)
Communication	4.3(0.5)	4.4(0.5)	4.5(0.6)	4.2(0.5)	4.2(0.4)	4.5(0.4)

* 1 = totally disagree, 2 = disagree, 3 = not disagree, not agree, 4 = agree, 5 = totally agree

Table 2. Healthcare professionals' barriers to SC and Spiritual Care Competencies at T1, T2 and T3

Table 3 Short and longer effect on healthcare professionals' barriers to SC and spiritual care Competencies N = 253

	Nurses				Physicians			
	1 month effect Δ (T1-T2) n = 105	p-value ^a	6 months effect Δ (T1-T3) n = 57	p-value ^a	1 month effect Δ (T1-T2) n = 19	p-value ^a	6 months effect Δ (T1-T3) n = 8	p-value ^a
Barriers to SC (Scale 1: not at all – 10: a lot)								
Lack of knowledge of this domain (Mean, SD)	-0.60(2.5)	0.0157	-0.84(2.6)	0.0178	-0.16(2.8)	0.8055	0.38(1.4)	0.4758
Insecurity on this domain (Mean, SD)	-0.69(2.5)	0.0060	-0.28(2.4)	0.3832	-0.05(2.1)	0.9150	0.63(1.4)	0.2495
Keeping too much distance (Mean, SD)	-0.51(2.1)	0.0158	-0.54(2.1)	0.0561	-0.89(1.9)	0.0529	-0.75(2.1)	0.3506
Keeping not enough distance (Mean, SD)	-0.13(2.3)	0.5842	-0.26(2.4)	0.4145	0.21(2.4)	0.7086	1.5(1.9)	0.0636
Difficult domain in patient communication (Mean, SD)	-0.67(2.1)	0.0013	-0.60(2.8)	0.1088	-0.53(1.6)	0.1716	-0.13(1.5)	0.8153
Difficult domain in family communication (Mean, SD)	-0.58(2.1)	0.0052	-0.77(2.7)	0.0334	-0.68(1.6)	0.0847	0.38(2.3)	0.6622
Difficult domain in team communication (Mean, SD)	-0.67(2.2)	0.0031	-0.62(2.7)	0.1002	-0.47(1.4)	0.1656	-1.63(3.1)	0.1834
Difficult domain in communication with community clergy (Mean, SD)	-0.52(2.2)	0.0178	-0.47(2.8)	0.2084	-0.63(1.7)	0.1173	-0.38(3.0)	0.7358
Spiritual Care Competence Scale (Scale 1-5*)								
Assessment and implementation of spiritual care	0.29(0.7)	0.0001	0.30(0.9)	0.0164	0.44(1.1)	0.0889	1(0.9)	0.0139
Professionalization and improving quality of care	0.59(0.8)	0.0001	0.49(0.7)	0.0001	0.67(0.8)	0.0020	0.10(0.6)	0.6293
Personal support and counselling of patients	0.41(0.5)	0.0001	0.42(0.7)	0.0001	0.55(0.8)	0.0104	0.29(0.6)	0.2430
Referral to other professionals	0.22(0.5)	0.0001	0.27(0.6)	0.0007	0.46(0.9)	0.0481	0.38(0.7)	0.1484
Attitude towards patients' spirituality	0.03(0.5)	0.5560	0.12(0.5)	0.0836	0.05(0.4)	0.5695	-0.19(0.6)	0.4015
Communication	0.04(0.5)	0.4080	0.09(0.6)	0.2732	0(0.5)	1.0000	0(0.4)	1.0000

^a = T-test; * 1 totally disagree, 2 disagree, 3 not disagree, not agree, 4 agree, 5 totally agree

Table 3. Short and longer effect on healthcare professionals' barriers to SC and spiritual care competencies.

Both groups scored high mean values on the same subscales of the SAIL and reported that the following themes were important: meaningfulness, trust, acceptance, caring for others, and connectedness with nature.

No relevant differences were found in the items referring to work attitudes and personal quality of life. Personal quality of life and involvement with patients, families, and oneself scored high in both groups. The fear of dying and death were low in both groups, working stress was almost equal in both groups, and reflected a relatively high level of stress. Personal problems, such as sickness in the private sphere, personal mourning, personal questions or spiritual pain, scored low and were considered not to be barriers to their functioning at work for both groups. Although we observed one statistical significant difference between nurses and physicians for personal mourning, considering the low scores the relevance of this difference is debatable. Absenteeism scores were low, therefore we concluded they did not influence the outcomes. In Appendix C Table C1. Participants' Evaluation of the Spiritual Care Training After 1 Month, we present the evaluation of the chaplains' intervention. Although the number of physicians is very small for a comparison, we saw no differences between the two groups in the overall evaluations of the training.

Outcomes

Regarding the physicians' data, at T1, 27 participants reported having ≤ 7 years of work experience, and 14 reported having more work experience, reaching up to 39 years. At T2, only 1 participant and at T3 not one participant with ≥ 7 years of work experience responded, indicating that the effects of the training on physicians (in Table 2 and 3) reflect the effects on 'young doctors'. We analysed the differences between 'young' and 'older' physician groups at T1 and concluded that there were no significant differences on the SCCS. Regarding the barriers to SC, we found three differences: before the training; the

group of 'younger doctors' experienced more problems in communicating with patients, family and community clergy.

Regarding barriers to SC for nurses, we observed a decrease in seven items at T2: lack of knowledge, insecurity, maintaining too much or not enough distance, and difficulties in communicating with patients, families, team and community clergy. Of these barriers, only two were maintained, and one showed a trend towards maintenance at T3: lack of knowledge, maintaining too much distance, and difficulties in communicating with family.

For physicians, barriers to SC on all eight items had decreased after one month as well, but only one showed a trend towards significance: keeping too much distance. At six months, no item showed decrease.

Regarding nurses' scores on the SCCS, we saw an increase in four out of six competencies at T2: assessment and implementation of SC, professionalisation and improving quality of care, personal support and counselling of patients, and referral to professionals. At T3, the increases of these competencies were maintained.

For the young physicians, we observed an increase in three out of six competencies: professionalisation and improving quality of care, personal support and counselling of patients, and referral to other professionals; we also observed a trend towards significance in assessment and implementation of SC. At T3 we still observed assessment and implementation of SC improved, from a trend towards significance to a significant level.

Discussion

Strengths and limitations

Measuring effects, based on self assessment tools does not give a clear picture of healthcare professionals' SC performance towards patients, however we consider these data in the context of explorative research, strong enough to identify trends for generating hypotheses for further research about SC training, and training effects.

Another limitation is our sample size, as we did not reach our target, but we believe we have sufficient data to perform subgroup analyses. The decrease in responses can be explained by high scores of working stress, combined with feedback that questionnaires were too time consuming, considering there was no compensation in time or other as in the study by Vlasblom, where extra hours were paid as overtime.(23) It is possible that smaller samples at T2 and T3 reflect the characteristics of more interested and motivated healthcare professionals. The sample size for physicians was small, and results must be considered as indicative. Concerning that physicians' results are based on responses of younger doctors, who might be more interested and motivated, it is relevant that we were not able to measure competence improvement. For successful implementation of the SC guideline training has to be improved specifically for this group, otherwise quality improvement will show to be unsustainable. The different results for nurses and physicians might be explained by the fact that nurses spend more time with patients; therefore, the impact of the training might be stronger. Another explanation could be that the chaplains were less familiar with the practice of physicians.

Hospital setting could be potential confounder in our evaluation due to a different approach to palliative services and variation in the pilot training. However, all participating centres were selected based on their ability and willingness to participate in our study. In the Netherlands, specific religiosity currents no longer define medical guidelines around the patient. All hospitals have a common state supervised national format structure. In this respect, palliative services were to some extent comparable and similar from structure (composition of teams), and process (all apply the national guidelines including the guideline on spiritual care published in 2010). Generalizability of our results to hospitals without limited palliative services might be hampered, in this explorative study we primarily focussed on identifying trends in effects (hypothesis generating) rather than performing a confirmatory analysis with results that are applicable in all hospital settings.

We consider the fact that this training was performed with healthcare professionals on regular wards, to be a strength of this study. In other studies about effects of SC training, students, volunteers, or professionals who display a more than average spiritual commitment and are prepared to invest their own time in additional training, are often included, as in the study of Wasner (19). As to our knowledge this study is the first to assess the effects of a training SC on healthcare professionals based on a consensus based multidisciplinary guideline.

In this study, we demonstrated that it is possible to achieve direct, and important effects on quality of care, using a practical and concise training within reasonable time limits (90-180') for hospital staff, and to identify effects on both patient- and healthcare professional-reported outcomes. The study design included training of multidisciplinary teams, which may have contributed to breaking through stereotyping between nurses and physicians.

The fact that results based on the SCCS in the nursing group were maintained after six months, indicates that new knowledge might be internalized in their attitudes and competences. However, we believe it is necessary to monitor and secure these effects in the working process on these wards for sustainable improvement of quality of care, otherwise these effects will decrease. The results for nurses did not deviate from results of other studies based on the SCCS by van Leeuwen et al.(24,25), which showed good results on the first four competencies of assessment and implementation, professionalisation and improving quality of care, personal support and counselling and referral, and minor results for attitude towards patients' spirituality and communication. The last two competencies were at such a high level that significant improvement is not likely, and these competencies can be observed as basic competencies for healthcare professionals. For follow-up studies, we consider using a 10-point scale for the SCCS instead of the 5-point Likert scale, for more nuanced results. The results for physicians cannot be compared because the SCCS was not previously used with physicians.

We consider the effects on both groups encouraging and have used the results as input for a project on implementation of the SC guideline within the Dutch National Programme on Palliative Care.(9)

Conclusions

In this study, we found that a practical and concise training programme on SC in PC for healthcare professionals in teaching hospitals can have a positive effect on staff attitudes and competencies, improved attention to the spiritual dimension and temporarily can decrease barriers to SC for nurses.

Training hospital had positive effects on both nurses and physicians. Stabilising effects were shown in 4 out of 6 competencies for nurses and 1 out of 6 competencies for young physicians. Training and questionnaires on barriers to SC require further adaption to medical practice.

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Collection and assembly of data: LdV, JvdG.

Statistical analysis: NV, JvdG.

Data interpretation, manuscript writing and final approval of this article: All authors.

Ethical committee

Ethical approval was provided by the Medical Ethical Committee in Leeuwarden, Netherlands on July 4th 2013 (nWMO22). This study is registered in the Dutch Trial Register: NTR4559.

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Disclosure

The authors declare no potential conflicts of interest.

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Appendix 1 Requirements for the Pilot Training Spiritual Care in Palliative Care (SCPC)

Table 1. Requirements for the Pilot Training Spiritual Care in Palliative Care (SCPC)	
Target group	Multidisciplinary clinical teams of physicians, nurses and other healthcare professionals of departments in teaching hospitals (not being: specialized palliative care teams or units).
Competencies	Aim is to develop basic competencies for multidisciplinary spiritual care: recognising, referring, self reflectiveness and open attitude towards patient spirituality, as formulated by Kuin (21) based on the work of Van Leeuwen (22).
Preparation	A Dutch e-learning module on SCPC based on the Guideline is considered to be ideal as preparation for a local training. An electronic learning environment with a selection of reading material and video fragments on SC considered to be compatible with the Guideline will be made available to participants who want to prepare themselves before the pilot training SCPC (Available on https://www.mcl.nl/patient/specialismen-en-centra/geestelijke-verzorging/spirituele-zorg).
Planning	Implementation of the training is considered ideal when planned as two lessons of 90'-120' with an interval of at least three weeks. Minimum is one lesson of 90' with follow up teaching methods (coaching on the job, bedside teaching).
Structure	The local format of the training has to be designed with the aim to (1.) sensitize participants for the spiritual dimension of palliative care, (2.) make participants realize the importance of their own spiritual and existential dimensions, in order to (3.) integrate it into professional practice.
Tools	No screening tools for spiritual care or spiritual care models proposed by Pennaert are admitted to the pilot training SCPC. Because of lack of validated translations the choice is limited to those already mentioned and translated in the NL Guideline: symbolic listening according to Weiher (23), the translation of the three screening questions developed by the Mount Vernon Cancer Network (24) and the Dutch spiritual care model Legets Ars Moriendi (25).
Practice based learning	Teaching has to be practice oriented, practice based, participants should be stimulated to deliver case descriptions and receive feedback on these descriptions from the teacher/chaplain
Freedom for local adjustments	Given the local diversity in teaching hospitals and the nature of teaching spiritual care the pilot training SCPC is not possible without any diversity in tone, language and methods. The local teachers/chaplains receive a relative freedom in methodology and planning. Educational aims and goals as mentioned above are to be considered. Teaching to only one discipline of the multidisciplinary clinical team is not an option.
Teaching methods	No mandatory teaching methods. Selected core concepts and definitions of the guideline will be delivered on slides. Basic knowledge of Kolb's experiential learning model will be taught to the group of teachers/chaplains, preferred methods of teaching spiritual care will be exchanged in the group during the study.
Accreditation	The intervention needs approval by professional organisations of physicians and nurses, so participants can score the training to meet their professional registration requirements.

Table 1. Requirements for the Pilot Training Spiritual Care in Palliative Care (SCPC)

Appendix 2 SCCS for multidisciplinary use^{a,b}

Assessment and implementation of spiritual care				
1	I can report orally and/or in writing on a patient's spiritual needs	1	2	3 4 5
2	I can tailor care to a patient's spiritual needs/problems in consultation with the patient	1	2 3	4 5
3	I can tailor care to a patient's spiritual needs/problems through multidisciplinary consultation	1	2 3	4 5
4	I can record the <i>medical, nursing or other</i> component of a patient's spiritual care in the <i>medical records</i> or nursing plan	1	2 3	4 5
5	I can report in writing on a patient's spiritual functioning	1	2 3	4 5
6	I can report orally on a patient's spiritual functioning	1	2 3	4 5
Professionalization and improving the quality of spiritual care				
7	Within the <i>outpatient clinic or clinical</i> department, I can contribute to quality assurance in the area of spiritual care	1	2 3	4 5
8	Within the <i>outpatient clinic or clinical</i> department, I can contribute to professional development in the area of spiritual care	1	2 3	4 5
9	Within the <i>outpatient clinic or clinical</i> department, I can identify problems relating to spiritual care in peer discussions session	1	2 3	4 5
10	I can coach other care workers in the area of spiritual care delivery to patients	1	2 3	4 5
11	I can make policy recommendations on aspects of spiritual care to management of the nursing ward	1	2 3	4 5
12	I can implement a spiritual care improvement project in the <i>outpatient clinic or clinical ward</i>	1	2 3	4 5
Personal support and patient counselling				
13	I can provide a patient with spiritual care	1	2 3	4 5
14	I can evaluate the spiritual care that I have provided in consultation with the patient and in the disciplinary/multidisciplinary team	1	2 3	4 5
15	I can give a patient information about spiritual facilities within the care institution (including spiritual care, meditation centre, religious services)	1	2 3	4 5
16	I can help a patient continue his or her daily spiritual practices (including <i>asking how he is used to do</i> or providing opportunities for rituals, prayer, meditation, reading the Bible/Koran, listening to music)	1	2 3	4 5
17	I can attend to a patient's spirituality during <i>treatment or</i> the daily care (e.g. physical care)	1	2 3	4 5
18	I can refer members of a patient's family (e.g. to a <i>healthcare chaplain / spiritual advisor / pastor / imam, etc.</i>) if they ask me and/or if they express spiritual needs	1	2 3	4 5
Referral				
19	I can effectively assign care for a patient's spiritual needs to another care provider/ worker/ discipline	1	2 3	4 5
20	At the request of a patient with spiritual needs, I can in a timely and effective manner refer him or her to another care worker (e.g. a chaplain/the patient's own priest/imam)	1	2 3	4 5
21	I know when I should consult a spiritual advisor concerning a patient's spiritual care	1	2 3	4 5
Attitude towards patient spirituality				
22	I show unprejudiced respect for a patient's spiritual/religious beliefs regardless of his or her spiritual/religious background	1	2 3	4 5
23	I am open to a patient's spiritual/religious beliefs, even if they differ from my own	1	2 3	4 5
24	I do not try to impose my own spiritual/religious beliefs on a patient	1	2 3	4 5
25	I am aware of my personal limitations when dealing with a patient's spiritual/religious beliefs	1	2 3	4 5
Communication				
26	I can listen actively to a patient's 'life story' in relation to his or her illness/handicap	1	2 3	4 5
27	I have an accepting attitude in my dealings with a patient (concerned, sympathetic, inspiring trust and confidence, empathetic, genuine, sensitive, sincere and personal)	1	2 3	4 5

^aChanges in the SCCS made to include physician practice, are shown in italics.

^b1 = completely disagree, 2 = disagree, 3 = neither agree or disagree, 4 = agree, 5 = fully agree.

Table 2.1. Spiritual Care Competence Scale for multidisciplinary use^{a,b}

Appendix 3 Participants' evaluation of the spiritual care training after one

	Nursing n = 105	Medical n = 19	P-value
1 lesson: N = 124			
2 lessons: N = 100			
Participant's preparation (n, %)			
Yes	n = 111		.29 ^a
Read the suggested literature	56(59.0)	7(43.8)	
Used extra suggested material at project website	39(61.9)	2(25)	
Otherwise	14(22.2)	3(37.5)	
Otherwise	10(15.9)	3(37.5)	
Evaluation of the trainer (Scale 1-5; Mean, SD)	n = 124		
Knowledge	3.9(0.7)	4.1(0.6)	.37 ^b
Presentation	3.8(0.70)	3.7(0.7)	.65 ^b
Interaction with participants	4.0(0.6)	4.0(0.7)	.74 ^b
Handling questions	3.9(0.7)	3.7(0.6)	.49 ^b
Evaluation of 1 st meeting SC training (Scale 1-5; Mean, SD)	n = 124		
Content	3.7(0.7)	3.7(0.6)	.62 ^b
Presentation	3.8(0.6)	3.6(0.6)	.44 ^b
Interaction between participants	3.9(0.7)	3.5(0.8)	.04 ^b
Handling questions	3.8(0.6)	3.6(0.6)	.13 ^b
Case submitted (n, %)	n = 124	70(66.7)	6(31.6)
			.002 ^c
Evaluation of 2 nd meeting SC training (Scale 1-5; Mean, SD)	n = 100	n = 92	n = 8
Content	3.8(0.7)	3.9(0.4)	.78 ^b
Presentation	3.9(0.6)	3.9(0.4)	.97 ^b
Interaction between participants	4.0(0.7)	3.8(0.5)	.22 ^b
Handling questions	3.9(0.6)	4.0(0.5)	.60 ^b
SC Coaching on the job (n, %)	n = 124	19(18.1)	1(5.3)
			.02 ^a
Evaluation of the total SC training (Scale 1-10; Mean, SD)	n = 124	7.4(1.0)	7.2(1.2)
			.60 ^b

^a Fisher exact test; ^b (two-tailed) t test; ^c Chi-square test

Table 3.1. Participants' evaluation of the spiritual care training after 1 month.

We collected data from 124 healthcare professionals on their evaluation of the training. Although the number of physicians is very small for a comparison we did see a few minor differences between the evaluations by physicians and by nurses. As preparation for the training nurses seem to favour reading literature whereas physicians preferred to check the project website containing additional material and videos. The trainers were evaluated positively by both nurses

and physicians, scoring 3.7-4.1 on a scale from 1 to 5, on different aspects, such as knowledge, presentation, interaction with participants and handling questions. Physicians had prepared a case presentation less often. Nurses were more satisfied with the interaction between the participants during the first lesson. A small number of participants received coaching on the job by the chaplain, among whom more nurses than physicians. We saw no differences between the two groups in the overall evaluations of the training.

7

Improving Spiritual Care in Hospitals in the Netherlands: What Do Health Care Chaplains Involved in an Action-Research Study Report?



Chapter 7. Improving Spiritual Care in Hospitals in the Netherlands: What Do Health Care Chaplains Involved in an Action-Research Study Report?

Joep van de Geer, Chaplaincy Department, Medical Centre Leeuwarden, Netherlands

Anja Visser, Faculty of Theology and Religious Studies, University of Groningen, Netherlands

Hetty Zock, Faculty of Theology and Religious Studies, University of Groningen, Netherlands

Carlo Leget, Department of Care Ethics, University of Humanistic Studies, Utrecht, Netherlands

Jelle Prins, MCL-Academy, Medical Centre Leeuwarden, Netherlands

Kris Vissers, Department of Anesthesiology, Pain- and Palliative Medicine, Radboud UMC, Netherlands

Abstract

Health care chaplains participated in a multicenter trial to explore an implementation strategy for the Dutch multidisciplinary guideline for spiritual care. The intervention was a concise spiritual care training for hospital staff of departments where patients in curative and palliative trajectories are treated. Data were collected in semi-structured interviews with chaplains who acted as trainers, before and after the intervention. Results based on nine pre-intervention and eleven post-intervention interviews are presented. During pre-intervention interviews, chaplains describe the baseline situation of palliative care in Dutch hospitals, barriers and opportunities for improving spiritual care. In the post-intervention interviews, characteristics of the training, effects, and critical success factors were identified. Positive effects such as lowering barriers, increasing health care professionals' competences, and increasing health care chaplains'

profile are possible. Chaplain-led, multidisciplinary spiritual care training is a feasible method to start implementation of spiritual care in hospitals, as described in the multidisciplinary guideline.

Keywords: chaplaincy, education, multidisciplinary team, spiritual care, palliative care.

Introduction

The World Health Organization's definition of palliative care,(1) which involves formulating a bio-psycho-social-spiritual model of care, does not only challenge all health care professionals to provide spiritual care to patients in palliative trajectories. It is also likely to have opened a new door for chaplains to reformulate the specific characteristics of their profession. It offers opportunities to articulate the contributions that chaplaincy can make to the quality of patient care, to the multidisciplinary team, and to the culture and organization of the health care institutions where chaplains work. In the literature, the integration of spirituality and the development of a more person-centered, compassionate care within health care is considered by nature a multidisciplinary discourse, with contributions from areas such as nursing,(2) medicine,(3,4) social work,(5) and should not be limited to PC, as explicitly illustrated in title of the *Oxford textbook on spirituality in healthcare*.(6) Although patients value attention to spirituality on the part of doctors, nurses and other health care professionals (7,8), the provision of spiritual care (SC) is infrequent due to a perceived lack of SC training (9).

An important development in these discourses has been the publication of consensus documents on defining and integrating spirituality in modern palliative care (PC), such as the Consensus Report from the United States.(10) And, in the Netherlands, one year after the publication of the US Consensus Report, the publication of a consensus-based multidisciplinary guideline on spiritual care (hereafter: the SC guideline).(11) This SC guideline was published in the

national guidelines for the practice of multidisciplinary PC.(12) English, German and Spanish translations are available online.(13)

One of the essential characteristics of the Dutch PC program is that PC is part of the mainstream healthcare provided by general care providers.(14) Therefore, the SC guideline has been developed primarily for physicians and nurses who are not specialists in PC.

After its publication, this SC guideline was positively received in the field, but there was no strategy for its implementation.(15) Because the guideline acknowledges the position of healthcare chaplains as SC specialists who are available in most hospitals and nursing homes,(16) it created an opportunity for chaplains to explore what they could contribute to a national strategy for the implementation of this guideline. The guideline considers nurses, physicians and health care chaplains to be members of the multidisciplinary team with a common interest to improve the quality of spiritual care for patients, however with different roles and tasks. On a local level that the physicians and nurses will have to be aware of their tasks and be competent on a basic level of SC, and the health care chaplains should take responsibility for implementation of the SC guideline and training their medical colleagues in its recommended methods.

Many chaplains do not have much experience in training other healthcare professionals and the barriers and facilitators of the implementation of the SC guideline will differ both between and within organizations. So a multicenter trial using an action research approach - in which the chaplains acted as trainers and as co-researchers - seemed appropriate. Action research allows the chaplains to improve their practice in a process of change, and the participation in this process of change allows them to gain more insight into the organizational barriers and facilitators of the implementation of the SC guideline. In the multicenter trial it proved to be possible to train physicians and nurses effectively within reasonable time limits. The quantitative results of the pilot training on the quality of care in patient-reported outcomes and on barriers to SC and SC compe-

tences for health care professionals have been published in medical journals.(17,18)

Aims

This paper reports on the qualitative results of a study that was part of a greater research project. The aim of this project was to start the implementation of the Dutch multidisciplinary guideline on SC. For this purpose a multicenter trial in ten hospitals was planned using a mixed-method action-research approach. The intervention in this exploratory practical trial was a SC pilot training for physicians and nurses that was planned in wards where patients are treated in curative and palliative trajectories.(18)

In this article, we focus on the barriers and critical success factors for implementation of the SC guideline, as reported by the participating health care chaplains as co-researchers, based on nine pre-intervention and eleven post-intervention interviews.

Methods

Participants

In August 2013, the chaplaincy teams of all 27 members of the Association of Tertiary Medical Teaching Hospitals (*Stichting Topklinische Ziekenhuizen, STZ*) were invited by email to participate in the study. These hospitals are not university clinics but larger general hospitals for standard and complex specialized care, and they play an important role in the teaching of medical and nursing disciplines and in research and innovation in Dutch health care. Interested chaplaincy teams were invited for an Expert Meeting in November 2013, together with 20 national and international experts on PC and SC. In this meeting, the requirements for the intervention, the pilot training 'spiritual care for multidisciplinary teams' (referred to hereafter as the training), and the action research approach were discussed and determined.

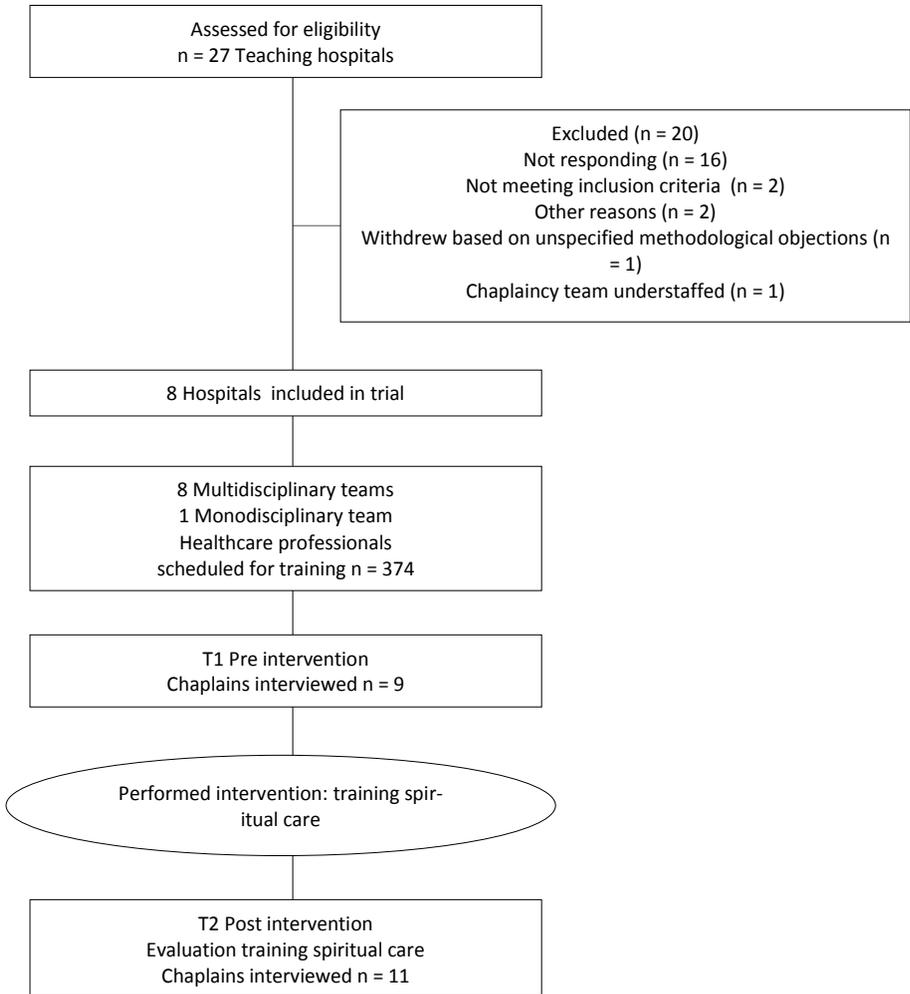


Figure 1. Flow diagram

The mixed-method study of which the interviews were a part was designed and conducted in accordance with the WHO Good Clinical Practice (GCP) Guidelines. Ethical approval was granted by the medical ethical committee in Leeuwarden, Netherlands on July 4, 2013 (nWMO22). The study was registered at the Dutch Trial Register: NTR4559.

7. Improving spiritual care - health care chaplains' reports

The hospital inclusion criteria(18) were as follows: membership in the STZ, active involvement in developing PC, and implementation of a PC quality improvement program.

Chaplain	Gender/ Age	Work experience as (years)		Denomi- nation ^a	Pilot	Ward	Hospital / Beds (n)
		Chaplain	trainer				
Chpl. 1	M >50	> 10	> 10	Prot.	P. 1 ^b	-	H. 1/643
Chpl. 2 (duo)	M >55 M >60	> 25 > 15	> 20 > 20	RC RC	P. 2	Lung	H. 2/883
Chpl. 3	M >60	> 15	> 20	RC	P. 3	Lung	H. 3/623
Chpl. 4.4 ^c	F >50	> 15	> 25	RC	P. 4 ^c	Lung	H. 4/600
Chpl. 4.10	M >55	> 5	> 30	Prot.	P. 10	Oncology	
Chpl. 5	F >60	> 20	> 20	Prot.	P. 5	Oncology	H. 3/623
Chpl. 6 (duo)	F >50 F >45	> 20 > 10	> 10 > 5	Prot. Prot.	P. 6	Internal / Oncology	H. 5/148 (848) ^d
Chpl. 7	F >45	> 5	> 20	Prot.	P. 7	Lung	H. 6/468
Chpl. 8	M >50	> 15	> 15	Prot.	P. 8	PC ^e consultants + ambassadors	H. 7/260 (925) ^d
Chpl. 9	M >55	> 5	> 10	RC	P. 9	Renal	H. 8/850

^a Prot. = Protestant, RC = Roman Catholic;

^b Pilot not performed, chaplaincy and palliative care team became understaffed after the start of the project

^c The first training and postintervention interview were performed as a duo (Chpl.4.4); the second training and postintervention interview was performed by the male chaplain (Chpl.4.10);

^d number of beds at a site which is part of one multi-site hospital organisation, total number of beds between parentheses;

^e PC + Palliative Care

Table 1 Co-Researchers/Trainers, Pilots, Hospitals

The chaplaincy team inclusion criteria were as follows: active involvement in the PC improvement program in the hospital, feeling responsible for the way in which SC is developed in that program, having at least one member of the team specialized in SC in PC (mandatory specialized(19) training program) available as trainer, willing to train local departments according to study protocol.

Our target was to include ten hospitals. Eleven chaplaincy teams showed interest in participating in the trial, but two of these did not meet the inclusion criteria, and one withdrew because of methodological objections, however without specifying these objections upon inquiry. Ultimately, the chaplaincy teams from eight hospitals received approval from the medical-ethical or local research committees and hospital management to participate in the study (see Figure 1).

Procedure

Key concepts of action research are *a better understanding, participation, improvement, reform, problem finding, problem solving, a step-by-step process, modification and theory building*.⁽²⁰⁾ In such a step-by-step research process it is essential to collect the co-researchers' reports of the new practical knowledge from time to time. We planned to interview the chaplains one month before the intervention, to collect practical knowledge about planning and organizing the research project and the intervention; and one month after the intervention, to collect the chaplains' reports of new practical knowledge based on how the training was performed.

Action research is context bound, which means that variation in the intervention is expected, because local adjustments of the study protocol are accepted as a problem-solving strategy, which could generate new knowledge. Stimulating medical professionals to integrate SC with PC in their working process as a multidisciplinary team can only be successful if it builds on location-specific resources that are connected to the unique culture of each participating hospital or department. Therefore, adjusting the training to local circumstances is not considered a deviation from the study protocol and did not lead to hospitals being excluded from the study.

The participating chaplains were as co-researchers responsible for conducting the study according to the protocol: planning and carrying out the training in the intervention wards, including the participating health care professionals in the study of the effects on

barriers and competencies for SC, selecting control wards, and - in cooperation with the local PC consultation teams - organizing the process of selecting palliative patients for the study of the effects on the quality of care.(18)

The chaplains were familiar with the interviewer (first author, JvdG), a male senior healthcare chaplain, PhD candidate and accredited GCP researcher, as a trainer in and ambassador for multi-disciplinary SC. The relation between the local chaplains and the investigator during the interviews in this action research approach is best described as a joint continuous learning process for both parties, sharing newly generated knowledge.

All respondents were experienced chaplains and educators. Most chaplains had experience with teaching nurses, and only two had experience with teaching physicians. None of the chaplains who were interviewed had any previous experience in research.

The participants received the questions before the semi-structured interviews were carried out on site in the hospitals. All participating chaplains were interviewed, and no non-participants were present. Twelve chaplains were interviewed, six of whom worked together as pairs in the training; these pairs participated in a paired interview. In the interviews with this latter category, no differences were observed in the reports of their joint performance and experiences, so they were treated as one respondent (see Table 1).

During the project, 20 interviews were conducted: nine interviews at eight sites before the training (at one site, two separate pilots were conducted with different chaplains as the trainers) between December 9, 2013, and September 25, 2014; one on-site interview between a first and second training; and ten interviews at eight sites (at two sites two pilots were carried out) after the training between September 29, 2014, and March 18, 2015 (duration 50-85", average 55").

All interviews were audio recorded, field notes were made during the interviews, and transcripts were checked and corrected

by the researcher if necessary. Transcripts were not returned to the participants for comment.

Analysis

In order to structure a problem-driven content analysis of the pre-intervention interviews, we developed an initial coding tree, based on the questions sent to the chaplains to prepare for the interview. Transcripts were coded in ATLAS.ti Version 7.1.4. The interviews were coded by two researchers (JvdG, Suzanne Lub (SL)), adding new codes and sub-codes to the tree. They discussed their codes until consensus was reached on coding policy and coding tree, and then they discussed the results with a senior researcher (HZ). One of the researchers (SL) performed the problem-driven content analysis.

For the post-intervention interviews, the initial coding tree was based on the final tree of the pre-intervention. Transcripts of the post-intervention interviews were coded in ATLAS.ti Version 7.5.10. Again, two researchers (AV, JvdG) coded the interviews, adding new codes and sub-codes to the tree. They discussed their codes until consensus was found on the codes and coding tree. A problem-driven content analysis was performed by JvdG. The results of this analysis were also discussed with the senior researcher. An example of a qualitative theme and supporting quotations is presented in Table 3 Coding Example Post-intervention Interviews.

After all participating chaplains were interviewed in two rounds using a semi-structured format that enabled the chaplains to answer the research questions, and new information was not found the authors considered data saturation to be reached within the context of this small study. The research team was confident that they had sufficient data and considered that the presented themes reflected the chaplains' findings.

Pre-Intervention Interview Results

The topics of the semi-structured interviews included motivation for participation, PC in the hospital, chaplains' participation in PC, experiences with teaching SC, characteristics of the participating wards, planning the training, use of diagnostic tools for SC, new experiences or knowledge based on participation in the study, and further plans for implementation of the SC guideline.

General findings are summarized below, and the three themes that are most relevant to the exploration of an implementation strategy for SC are addressed in more detail: (a) the context of PC in the hospitals, (b) chaplains' views on developing SC, and (c) new knowledge based on participation in the study. As an impeding factor for the development of SC, the chaplains mentioned the combination of the obvious curative attitude among primary health care professionals throughout the hospital on the one hand and a lack of knowledge about PC on the other. This often impedes the recognition of the shift to the palliative phase in the treatment of patients or even the start of the dying phase. At the same time, the chaplains observed willingness to improve end-of life-care and the recognition of healthcare professionals' need for PC training, which they considered supporting factors for developing PC and SC. In general, the chaplains reported a positive attitude towards the project among the nurses. Creating physicians' commitment to the project was described as more difficult, but when forced by the protocol to approach physicians in order to include them in the training, the chaplains usually encountered an appreciative attitude towards the development of SC; in only one case the chaplain in question was confronted with an indifferent or even degrading attitude.

a. Context of Palliative Care in Dutch Hospitals at the Time of the Study

For half of the hospital sites, the chaplains reported the cooperation with the PC teams to be stimulating. Although one of the inclusion

criteria for hospitals was the presence of a quality-improvement program for PC or a PC consultation team, a large variation in staffing, structure, and financial set-ups was observed. There was no standard for PC in hospitals at the time. At hospital 5 the PC team was disbanded after the start of the study and had not been reinstated at the end of the study.

In none of the hospitals or PC teams any diagnostic tool for spiritual screening was used. Three chaplains reported the use of the distress thermometer(21) by oncology nurses, a tool recommended in national guidelines for oncology care for the screening of somatic, psycho-social and spiritual distress. This tool, however, is not approved by the Dutch health care chaplains' organization VGVZ (Vereniging van Geestelijk VerZorgers).

b. Chaplains' Motivations and Perspectives Concerning the Development of Spiritual Care

All participating chaplains declared themselves to be strongly aware of the need to develop a more research-based chaplaincy. Their motivation for participating in the study was connected to a desire to improve the quality and profile of the chaplaincy and the opportunities that our study could provide for developing SC as a multidisciplinary dimension of care. Respondents mentioned a tension between their language as chaplains and the common medical language between primary health care professionals.

Chpl. 4.4: Will we really be able to express what we mean by spiritual care? I myself often have the feeling that I am too vague, but at the same time, people do sense what you mean. That's what I find so difficult sometimes.

They formulated the need for a multidisciplinary common language that is complementary to the medical discourse and includes symbolic or metaphorical language.

Chpl. 5: ... therefore, you develop a common language. Now, we have only a medical language that we can speak, but we lack a language for the symbolic reality. And I do hope that the intervention brings some awareness of that.

The chaplains were aware of the fact that developing this language is not possible as a one-way communication; it needs to be developed in dialogue.

Chpl. 4.4: In this kind of care, it is about a way of being, an attitude. You can only do something about that by talking about it together and, let's say, exchanging views referring to that.

Chpl. 3: I think that the chaplain can also learn from the professionals what they mean by spiritual care. Maybe both parties will have to adjust the images they have of spiritual care.

All respondents shared the conviction that SC training is a challenge and an opportunity for the chaplaincy to be more integrated in the multidisciplinary team. Some chaplains pointed to the need to modernize chaplaincy, a process that they characterized as a shift from chaplaincy as a domain to chaplaincy as a specific expertise.

Chpl. 3: So it is not our domain, forbidden to others, but an expertise you want to communicate.

c. New Experiences or Knowledge Based on Participation in the Study

The procedure for obtaining permission for the research project within the hospital was new for all chaplains, but it was considered a fruitful learning process that also improved their profile:

Chpl. 6: You are taken more seriously when you are doing a research project.

It provided chaplains with both new knowledge about the organizational structures in their hospital and new experiences in con-

ducting a quality-improvement project in an action-research approach. It created new relations with physicians and managers.

Chpl. 7: I enjoyed it very much at my lung ward, how, step by step, I was able to get that manager to go along. And how fruitful now [before the training] it already is. He has asked me to initiate a discussion about 'How do we handle troublesome patients?' He would never have done that if we had not embarked upon this study. So now he already has a completely new perspective on me and my work.

Post-Intervention Interview Results

The topics for the semi-structured post-intervention interviews included preparation of the intervention and data collection, the baseline situation in intervention wards, characteristics of the training, critical success factors, health care professionals' preferences for specific SC diagnostic screening tools or models, chaplains' new knowledge and skills, and training effects. After providing the general findings from the post-intervention interviews, we present the most relevant themes for the implementation of SC as reported by the chaplains: (a) characteristics of the training as performed by the chaplains, (b) critical success factors, (c) chaplains' new knowledge and skills, and (d) effects of the training.

The overall finding from the interviews is that the chaplains experienced the research project as a demanding, time-consuming, but fruitful and positive process. For all chaplains, the mandatory specialized training in SC was vital to their preparation for the training, and for most chaplains, the additional training on educating professionals (learning styles, teaching methods) and the exchange of experiences in three group meetings were also vital.

Three chaplains expressed frustration due to external factors: in hospital 1 no pilot was performed because of an understaffed PC team; in hospital 7 the pilot had not been developed fully according to protocol because of the integration of the pilot in a larger PC

training program; and one chaplain reported suboptimal performance during the pilot because of sickness during preparation.

The overall preparation was described as a process, and seven of the nine chaplains reported that, in their view, the objectives of making health care professionals aware of the spiritual dimension of their work and enhancing their competencies were achieved (in particular among nurses).

Nevertheless, chaplains who trained physicians (either mixed with nurses or in mono-disciplinary groups) expressed their doubts about whether their training had met the physicians' training need sufficiently, although they reported to have been able to build bridges between nurses and physicians, and by doing so created possibilities for the implementation of the SC guideline in the departments' working processes.

Three chaplains said they planned to use one of the diagnostic SC tools on which they had trained as a format for reporting their visits in patients' medical records. The other chaplains did not formulate any specific implementation strategy to structure a working process for SC.

Four of the chaplains were planning to offer future structural training on SC in cooperation with education departments, PC consultation teams, or third parties outside the hospitals.

a. Characteristics of the training as performed by the chaplains

The SC training intervention was performed nine times in seven hospitals, between February 2014 and February 2015. The wards that appeared to be most open to SC improvement were the lung and oncology wards. The characteristics of the training varied locally. For a table detailing all requirements of the training, we refer the readers to our study protocol (van de Geer et al., 2016a). The conclusion from the experiences and reports of this group of chaplains was that having only one training session was less effective. Two sessions, preferably of 90 minutes each, made it possible to start in the first lesson

with the basic theory illustrated by the case descriptions prepared earlier. The time between the sessions was used to stimulate participants to provide detailed personal case descriptions, applying the theory learned in the first session. With this setup, these case descriptions were available in the second session to illustrate and practice the trained models and diagnostic tools. These second sessions appeared to be more practical, resulting in enhanced commitment and better evaluation rates.

The chaplains interviewed reported a preference for small groups. For implementation in larger wards, although a training session in larger groups (including interactive training methods in small groups) seemed to be equally effective.

Whenever, for practical reasons, the chaplains opted for mono-disciplinary training of physicians and nurses, they found this to be easier to organize, having the advantage that the training could be adjusted to the specific training needs and reflective competencies of each discipline.

In contrast, chaplains who trained multidisciplinary groups reported that in these groups participation of and contributions by physicians enhanced the quality of the training because this deepened the reflections on case descriptions, broke down mutual stereotypes between physicians and nurses, created a collective commitment to the development of integrated working processes for SC in the ward, and legitimized nurses to engage in SC.

Chpl.5: I was greatly helped here by an internist, who put this into words clearly... She said 'This [How do you make sense of what is happening to you?] is a different question from 'How are you today?' Then, patients start telling you... about their temperature... Asking about meaning is a different question.' Shortly before that, some nurses had walked the rounds with the specialists for a day and had been very surprised to find that these aspects did come up. ... The idea that 'the doctors do not see these things' has been turned completely upside down. But it does not always register with the other party. Of course, it's not the language they speak with each other

7. Improving spiritual care - health care chaplains' reports

Pilot N = 9	Ward/ # scheduled participants	Multidisciplinary/ monodisciplinary training	# Lessons / total minutes	# Groups/ Group size	Themes ^a	Comp. Trained ^b	Models trained ^c	Use of Particip.'s CD / CJ ^d
P. 1	-	-	-	-	-	-	-	-
P. 2*	Lung/63	Multi. Mono.: nurses	1/60' 1/60'	4/15-20 4/10-12	1.2.3. 1.2.3.	1.2.3.4. 1.2.3.	1.2.3. 2.	-/ CD/-
P. 3	Lung/46	Multi.	1/150'	4/7-12	1.2.3.	1.2.4.	1.2.	-/-
P. 4	Lung/35	Multi.**	2/180'	3/8-12	1.3.	1.2.4.	1.2.	CD/-
P. 5	Oncology/91	Multi.	2/180'	5/16-25	1.2.3.	1.2.3.4.	1.2.3.	CD/-
P. 6	Internal/46	Mono.: nurses	2/120'	4/3-12	1.3.	1.2.3.4	2.3.	CD/-
P. 7	Lung/49 Lung/12	Mono.: nurses Mono.: physicians	2/90-120' 2/50'	5/7-9 1/8-12	1.2.3. 1.2.3.	1.2.3.4. 1.2.3.4.	1.2. 1.2.	CD/CJ CD/-
P. 8	Various/16	Multi.	/45'	1/15	1.2.3.	1.3.	1.2.	-/-
P. 9	Renal/13	Mono.: nurses	2/120-240'	2/10-13	1.2.3.	1.3.4.	1.2.3.	-/-
P. 10	Oncology/19 Oncology/5	Mono.: nurses Mono.: physicians	2/180' 2/60'	1/17-20 1/3-5	1.3. 1.2.3.	1.2.3.4. 1.2.3.4.	1.2. 1.2.	CD/- CD/-

* = training started as multidisciplinary during 60', then continued for 60' as monodisciplinary for nurses;

** = 1 physician;

^a 1 = sensitizing, 2 = reflecting on participant's own spirituality and confrontation with end-of-life care, 3 = integrating into professional practice;

^b Competencies trained: 1 = recognizing, 2 = tuning and referring, 3 = self-reflectiveness, 4 = open attitude towards patients' spirituality;

^c 1 = MVCN assessment tool, 2 = symbolic listening Weiher, 3 = Ars Moriendi Leget;

^d Use of participant's CD / CJ = Case Descriptions (CD) / Coaching on Job (CJ).

Table 2. Pilot Training Spiritual Care

Chpl. 2: And nurses... they do have much more of an antenna for that sort of thing. But they also feel a bit uncertain about whether the doctors are OK with it. 'If I take the time to talk to a patient, sit down with them -- do they understand?

At first glance, Table 2 seems to show that in most cases all three themes required by the protocol (sensitizing, reflection on one's own spirituality and confrontation with end-of-life care, and

integration in professional practice) were included and that in most cases, all four SC competencies (recognizing, attuning and referring, self-reflectiveness, open attitude towards patients' spirituality) were trained. However, most chaplains explained that a lack of time forced them to merely mention the relevance of reflection on one's own spirituality and experiences in confrontation with end-of-life care. The main and most successful topics in the training were sensitization to and recognition of the spiritual dimension by using a diagnostic tool and symbolic listening. As Chaplain 3 mentioned,

That was an eye-opener. If a patient says: 'Well, then, I may as well get rid of my caravan', you can interpret that as 'I am at the end of my life, I have to let go of the nice things in my life, I will die very soon.' But you can also hear 'that caravan has been an important part of someone's life; it has been a source of joy.' And then you listen differently. ... Like, 'hey, if someone says something like that, what has been the function of that caravan... What do you hear then?'

When asked which model the physicians and nurses preferred, six out of nine chaplains identified the questions of the Mount Vernon Cancer Network(22) assessment tool as the most practical and compatible with the medical model (see Table 3.). The three questions in this tool are 'how do you make sense of what is happening to you?', 'what sources of strength do you look to when life is difficult?', and 'would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?'. In most training sessions, this screening tool for spiritual needs is combined with symbolic listening.(23) The latter is a method for interpreting patients' daily conversations or answers to the screening questions and for guiding health care professionals' reactions. The third model available for the pilot training, *Ars Moriendi*,(24) was mentioned only occasionally and was used by only two chaplains.

Three chaplains mentioned unexpected chances to secure the results of the training in occasional or structural team meetings and in moral deliberations. Coaching on the job appeared to be the most

effective -however demanding - means to secure the results of a training in SC. Only one chaplain was able to adopt it as a method whenever she was referred to patients in the 'training' ward. She said,

Chpl.7: I do that with all referrals I now get for that ward, I always ... make a point of saying 'look, this is what we talked about [in the training]. look what I have reported, there you can read what I do and what I recommend'. I now consciously use words from the training, so that they see 'this is what you already did and this is what I'm doing now' and 'this is the way you can take this up'. ... And then they want to hear back from you after you've been there. So, I do that much more often now. I do not always manage in person, but then I tell them where to find my report. ... So, this is all coaching on the job.

b. Critical Success Factors

For seven chaplains, a project-based implementation of the SC guidelines would not have been a matter of course without the study protocol or a clear mandate. As Chaplain 5 stated,

... before, I never felt obliged to implement the guideline. Odd, really. I did not know where to start. I use the guideline occasionally in a lesson, if I'm allowed to give one. But in a hospital... where everything is in constant flux ... I would not have introduced a guideline of my own accord. I would have left it. Just because I would have no idea how and where to introduce it in this organization.

Other reported critical success factors with regard to the chaplains' attitude were authenticity, visibility, and personal commitment to the team members on the ward. The research project and the training offered opportunities to break down the traditional stereotypes of chaplaincy among nurses and physicians.

Chaplains' Perspective on Health Care Professionals' Preferences for Spiritual Care Diagnostic Tools

Family Code: 03 Actual Characteristics of Intervention/Training		Code 3.7: Spiritual Care Tools Actually Trained
Codes:		9 out of 17 quotes
03.1	Multidisciplinary vs. Monodisciplinary	Chpl.2: And while we practised listening in layers, in the second half, the question 'how is it for you yourself' also became very prominent.
03.2	Spiritual Care Competences Actually Trained	Chpl.3: Yes, I raised those three Mount Vernon-screening questions, and gave examples. Those are clear questions. I found that I could explain each example using Weiher; I know that would not have been as easy with Carlo's model. Something I also stressed is focusing on sources of strength rather than problems.
03.3	[Participants'] Preparation via Project Website	
03.3.a	[Participants'] Preparation via Answering Baseline Questionnaire about their Spirituality	Chpl. 4.4: I kept things very basic for the nurses and limited myself to those three questions: what are you worried about, who would you like to have with you, from what did you derive strength before?
03.4	Numbers of Sessions, Total Numbers of Minutes (per Participant)	Chpl.4.10: Certainly, I did discuss the three questions, but we also always referred to the four layers in the training.
03.5	Group Size, Total Numbers of Sessions and Participants	Chpl.5: Mount Vernon, listening in layers, but Carlo Leget as well. But only in the second lesson.
03.6	Structure and Composition of Lessons	Chpl.6: The first lesson we practised layers, and wrote various questions that could be asked on the blackboard. That went quite well, so that in the second lesson we could refer back to that topic, like, last time we talked about listening in layers, this time we will do a bit of Ars Moriendi.
03.7	Spiritual Care Tools Actually Trained	Chpl.7: I just trained the three questions and the four layers.
03.8	Practical Assignment, Case Description	Chpl.8: It became clear that in any case we had to end on the three Mount Vernon questions. So I sort of wrote the training in that direction. In this way that was part of the preparation: this is it, folks. The session was supposed to take an hour and a half according to the study protocol, but this could be done in 45 minutes. We ended with what we then thought was the most practical tool: the three Mount Vernon questions.
03.9	Chaplain's Personal Freedom	Chpl.9: For instance, I worked, but in a very limited way, with Carlo Leget's model, the diamond; I also used Erhard Weiher's three-part model, I especially focused on that.
03.10	Effective Teaching Methods for the Introduction Phase	
03.11	Effective Teaching Methods for the Expansion Phase	
03.12	Effective teaching methods for the Rounding-Off Phase	

Table 3. Coding Example Post-intervention Interviews

A reported critical success factor regarding the participating wards was their ownership of the project: active commitment on the

part of management and physicians and the sense of bottom-up commitment on the part of nurses.

According to Chaplain 7, it is important to stress that SC is not an additional task but inherent in health care professionals' practice and deeply connected to their original, deeper motivation for choosing this profession.

Chpl.7: ... I think everyone has in fact been doing this for a long time, and I should not be selling this training as something entirely new, but rather as I'm offering you tools and empowerment to make you more aware of what you are doing and get more out of it. Also, I thought it was a real finding to be able to link it to, what I think was their original motivation for choosing health care as a profession, ... this would help to rediscover the human being behind the diagnosis and the patient. I found this a great help to win people over, eyes started to shine.

c. Health Care Chaplains' New Knowledge and Skills

Action research proved to be an effective method to gather practical knowledge for developing and performing quality improvement or research projects. In our project, knowledge about learning styles and educational theory for training professionals was gathered or renewed, and chaplains' training skills were enhanced. In particular, they discovered the value of learning by doing and the fact that chaplains are more theory-minded than other healthcare professionals.

The chaplains reported an improved understanding of the differences in professional practice between physicians and nurses and of the barriers to SC within both disciplines. They also discovered that the varying levels of reflective competencies within teams were independent of working experience.

Chpl.5: What also struck me is that a physician sometimes has more time for a palliative patient in a short meeting in his office than a nurse rushing from one patient to the next one.

The majority of the chaplains stated that the process reaffirmed their self-consciousness as professionals with a valuable contribution to health care:

Chpl.4.10: True, I found that we do have a good story and that patients are actually waiting for it. More than one doctor confirmed this to me.

d. Effects of the Training

Although most chaplains are positive about the improvement in trainees' competencies, it is difficult for them to measure the effect on the quality of care as perceived by patients. Three chaplains thought that they had improved the quality of their profile and visibility on their wards, and they were able to indirectly deduce improved patient care based on the quality of the referrals.

For three other chaplains, the effect on patient care was outside their field of vision. The remaining three chaplains were skeptical or negative about the effect on patient care.

Six chaplains reported improved and intensified relations with physicians:

Chpl.2: Less than a week after the training, two doctors came to me, one in the bike shed and one in the corridor, and said 'that was an excellent training, it really affected me, it did something'. Mind you, these were specialists, not just junior doctors. You can't tell by looking at them, but something has changed, something is happening. I now report more in the doctors' notes than I used to, I used to do that mainly in the nursing file... I now find it easier to drop in at a specialist's office and say 'Patient such and such has this or that problem.' So, for me, the barrier to contact a specialist has again become a bit lower.

A summary of the findings and practical knowledge for the implementation of the SC guideline based on chaplains' reports is presented in Box 1.

7. Improving spiritual care - health care chaplains' reports

Findings based on pre-intervention reports	Findings, practical knowledge for implementation SC based on post-intervention reports
<p>Context op PC in Dutch hospitals</p>	<p>Action research project</p>
<p>Large variation in staffing, structure and financing PC teams. No standard for PC in hospitals (during study). No SC diagnostic tools. Stimulating cooperation with PC teams.</p>	<p>Demanding, time-consuming, but fruitful process for clinicians. Training (study protocol, intervention) and interaction with co-researchers is vital for preparation. Raised awareness of spiritual dimension of health care professionals' work. Multidisciplinary training creates more chances for implementation SC than mono-disciplinary training. Training SC diagnostic tools influences chaplains' reports of patient contact. Action research is effective for identifying lack of knowledge, gathering practical knowledge, improvement quality of care.</p>
<p>Physicians and nurses</p>	<p>Training SC</p>
<p>Combination of curative attitude en lack of knowledge of PC. Willingness to improve End of Life care. Need for training PC (not only SC). Positive attitude towards improvement SC.</p>	<p>Two sessions are more effective and better evaluated than one session, but still too short to reflect on one's own spirituality and experiences in EoL care. Small or larger groups are equally effective, mono-disciplinary training are easier to organize, better adjustable to specific training needs and reflective competencies. Multidisciplinary training deepens reflection, reduces mutual stereotypes, creates collective commitment. Chaplains assume symbolic listening and 3 screening questions to be more practical for physicians and nurses than Ars Moriendi.</p>
<p>Chaplains' motivations and perspectives</p>	<p>Critical success factors</p>
<p>Improve quality and profile chaplaincy. Developing a more research-based chaplaincy. Protocol provides opportunity to develop multidisciplinary SC. Tension between chaplaincy language and common medical language. Need for multidisciplinary (including metaphorical) language. Expertise based integration of chaplaincy in multidisciplinary team.</p>	<p>A concise program of two sessions (90' each) can include basic theory and training in 2 out of 3 models/diagnostic tools for SC, developing competencies SC aimed at sensitizing, integration of SC in professional practice. First session: basic theory (models, diagnostic tools SC), illustrated by prepared case descriptions. Between sessions: participants write detailed personal case descriptions SC applying theory. Second session: practical training SC models or diagnostic tools using participants' case descriptions. Coaching on the job is a demanding, but effective method to secure results. A clear mandate and/or study protocol for project based implementation of a SC guideline by chaplains. Chaplains' attitude requires authenticity, visibility, personal commitment to the team. Ownership of the quality improvement project, bottom-up commitment. Presenting SC as connected to health care professionals' motivation, not as an additional task.</p>
<p>New practical knowledge</p>	<p>Effects of training</p>
<p>Health care research procedures, action research possibilities, and organizational aspects, resulting in new relations with management and physicians.</p>	<p>- reports about improvement of trainees' (especially nurses') competencies and patient care, - improved visibility and profile of chaplaincy, - research based quality improvement projects reaffirm chaplains' self-consciousness.</p>

Box 1. Summary of findings based on chaplains' reports

Discussion

Our main research question was: what are barriers and possibilities or critical success factors for implementation of the SC guideline as reported by chaplains?

As barriers the chaplains report that health care professionals in Dutch hospitals display a combination of a dominant curative attitude with a lack of PC knowledge, being unfamiliar with SC diagnostic tools. In addition chaplains realized that the tension between their own language and the common medical language forms a barrier for the development of SC. Since almost all participating chaplains gained new knowledge about health care research procedures and organizational aspects of quality improvement, this could indicate that a lack of knowledge on these subjects could be characteristic for the profession.

The stimulating cooperation with the hospital based PC teams, the willingness to improve end-of-life care, the need for training, the positive attitude of physicians and nurses towards improvement of SC create possibilities for implementation of the SC guideline, as well as possibilities for chaplaincy to develop a more research-based integration of chaplaincy in the multidisciplinary team.

For project-based improvement of SC in hospitals using implementation of a guideline, a clear mandate and ownership, departments' bottom-up commitment, chaplains' attitudes of authenticity, visibility, and personal commitment to the team are critical success factors. Presenting SC as connected to health care professionals' motivation, not as an additional task was a critical success factor in the training. And, last but not least: time is a critical success factor. The chaplains reported their own training and preparation to be essential for this demanding, time consuming quality improvement project.

According to the chaplains, training health care professionals in SC as an implementation strategy for the SC guideline was a fruitful endeavor. Although implementation of guidelines is a well-tested

method for improving patient care,(25) until now it was not an obvious activity for chaplains in the Netherlands. Working as a group in a multicenter trial - including 8 of the 27 non-university training hospitals in the Netherlands - these chaplains actually started an implementation process, collected essential new practical knowledge for a strategy to improve SC within the national PC program, and enhanced the profile of chaplaincy as a specialized, research-based health care profession.(26) The project created national visibility and was awarded twice.

By exploring training methods in an action-research design, the chaplains developed a more systematic approach, and they contributed to research-based answers to the needs of their colleagues in the multidisciplinary team. Thus, this study meets many of the needs of health care professionals, identified in a worldwide survey by Selman and colleagues : understanding of SC (who/what/where), staff education, understanding of spiritual needs and distress, SC for nonreligious people and people of different faiths, and conceptualizations and definitions of spirituality/the spiritual dimension.(27)

The study shows reports of empowered health care professionals, improved understanding among chaplains, nurses, and physicians, enhanced participation in performing multidisciplinary SC, and indications of improved patient care.

Although the study protocol was limited to PC in hospitals, the chaplains' group agreed that this training needs to be developed further, and it is transferable to nursing homes, hospice, and home care, as well as to forms of acute and chronic care.

Because of the explorative character of this study our results are indicative, and generate rather than confirm hypotheses. Finally, the sample of chaplains is subject to selection bias. The inclusion procedure selected those chaplaincy teams that were willing to work on the implementation of the SC guideline, expecting it to create opportunities to improve patient care and chaplains' professional profiles. Therefore, this group of chaplains probably represents a group of pioneers.

The conclusion of this study is that from a chaplaincy perspective, chaplain-led, multidisciplinary spiritual care training is a feasible method to start implementation of SC methods in hospitals, as described in the multidisciplinary guideline. Positive effects such as lowering barriers to spiritual care, increasing health care professionals' competences, and increasing health care chaplains' profile are possible.

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General discussion



Chapter 8. General discussion

This final chapter addresses our primary research question: ‘What training do primary health care professionals (physicians, nurses) need to use hermeneutical diagnostic tools for multidisciplinary spiritual care and to integrate these tools in their professional practice, with the expert support of health care chaplains?’

First, we summarize the findings based on our research questions. The final **Conclusions** for the primary research question will be followed by a **Discussion** and an overview of the **Strengths and limitations** of this study.

Because this practical research project began six years ago, in 2011, it is important to address **Where we are now?** prior to closing with the **Implications** of our conclusions for additional development in practice, spiritual care training, research, and policy making in this area.

Conclusions

Multidisciplinary spiritual care in palliative care in the Netherlands in 2012.

Chapter 2 described ‘the baseline for developing multidisciplinary spiritual care in the Netherlands in 2012’, which was the beginning of this research project. We concluded that there was a partially completed infrastructure for developing spiritual care in the Dutch health care system at the time. Groups of dedicated chaplains in the Netherlands who were motivated to engage in the local and national development of spiritual care had been trained in the ‘Masterclass on spirituality and health care chaplaincy in palliative care,’ beginning in 2007; other health care professionals also started to attend the masterclass, which developed into a programme for multidisciplinary groups and changed its name to the ‘Masterclass on spirituality in palliative care’ in 2012.

In 2102, the challenge was to propose a spiritual care project in palliative care as an example of good practice, which could then be used and implemented in the Improvement programme for palliative care from 2012-2016.(1) At that time, there was no project that was 'mature' enough for inclusion.

Hospitals in the Netherlands were pioneering and searching for structure and organization in hospital palliative care between 2012 and 2017.

To answer our second research question 'How have teaching hospitals in the Netherlands structured and organized inpatient palliative care, and the component of spiritual care?' Based on the findings from 9 of the 28 teaching hospitals, we integrate our findings for this question in Chapter 7 with the results from a questionnaire that was designed by Galesloot et al.(2), which allowed us to contribute questions about the delivery and organization of spiritual care, as well as a recent publication by Brinkman-Stoppelenburg et al.(3), which provides a representative description.

At the beginning of our research project, 10 of the 28 teaching hospitals were interested in participating in this study and met the inclusion criterion as they had some type of palliative care improvement programme or a Palliative Consultation Team. The co-researchers in the participating hospitals reported a large variation in the staffing, setup, structure, and financial support for the palliative care (consultation) teams, and four of the eight were able to build a fruitful cooperation with these teams to conduct the study according to the protocol. They noticed a predominantly curative attitude among the health care professionals in their hospitals that was combined with a lack of knowledge about palliative care, which often resulted in failing to recognize when patients' were at the beginning of the palliative or even dying phase. Those hospitals did not use diagnostic tools for spiritual care, and only three of the eight co-researchers reported the use of the distress thermometer for the

detection of psychosocial distress.(4) This tool was not approved by the Dutch Association of Health care Chaplains (VGVZ).

Because the 2013 publication by Galesloot et al.(2) is only available in Dutch, we summarize the findings for the items that we provided on the delivery and organization of spiritual care. The response rate for the questionnaire was 62% (57 of the 92 approached hospitals). In 51 hospitals, there was a health care chaplain for more complex spiritual needs. For the responsibility of the spiritual care policy, 44 facilities reported that the chaplain, 7 hospitals reported that the medical discipline, 10 reported that the nursing discipline, and 9 hospitals reported that a manager was responsible. Screening for spiritual needs was completed by nurses in 44 hospitals, physicians in 28 hospitals, and chaplains in 20 facilities; one organization reported that this duty was performed by a volunteer and another was performed by a case-manager. In approximately 50% of the hospitals, there was some spiritual care training as part of a broader training programme (16 hospitals) or as a distinct module. In 14% of the hospitals, the Guideline had been translated into a local protocol for spiritual care, and it was integrated into a policy document on spiritual and/or chaplaincy care in two hospitals.

The publication by Brinkman et al.(3) is based on responses to a questionnaire from 74 of the 92 hospitals in the Netherlands about the disciplines that are represented in the palliative care consultation teams, the procedures that teams follow, the number of consultations and team meetings as well as quality assurance procedures. Although Brinkman et al. observed an increase in the number of palliative consultation teams (39>77%) in 2015 and reported 65% of health care chaplains (spiritual caregivers) were part of those teams, there are still misconceptions in situations when palliative care consultation teams are contacted too late. Misconceptions include thinking that 'palliative care is only appropriate for patients nearing death' or that 'involving palliative care professionals can be conceived by patients as a sign that there is no hope left'. The Dis-

tress Thermometer was the most commonly used instrument by both generalists and specialists in palliative care (4).

As such, our 2012 conclusion that there was a specific infrastructure for spiritual care in Dutch health care was premature. In the section ‘Where are we now?’, we reflect on the current situation (2017).

In Dutch hospitals, diagnostic tools for spiritual care were not structurally implemented in palliative care

We can conclude that diagnostic tools for spiritual care have not structurally been implemented in Dutch health care. Chapter 4 addressed the research question ‘What diagnostic tools for spiritual care theoretically correspond to the multidisciplinary guideline, the needs of patients and proxies, the needs of health care professionals and their professional tasks and standards, and, from the primary health care professionals’ perspective, are suitable for practical application?’. We found that although there were more tools available in the international research literature that theoretically corresponded to the Guideline, the experts in the invitational research conference limited the training models in the pilots to a.) symbolic listening according to Erhard Weiher, (5) b.) translating the three screening questions that were developed by the Mount Vernon Cancer Network (MVCN), (6) and c.) the Dutch spiritual care model, Ars Moriendi(7), because these were the three models that were included and translated in the Guideline.

Our findings for the effects of spiritual care training reported in Chapter 5, based on patient-reported outcomes, were combined with the reports of the co-researchers about the positive impressions of and improved referrals to chaplaincy in Chapter 7, and provided indirect evidence that suggests that the trained diagnostic tools correspond with the needs of patients and proxies. However, it is not possible to determine how they correspond with patients’ and proxies’ spiritual needs based on these findings.

For professionals' needs and practical application of the diagnostic tools, the findings that were reported in Chapter 6 suggest that the training was more effective for nurses than physicians. However, based on the reports from the co-researchers in Chapter 7, it is not possible to conclude that these tools are less useful for physician's practice. Although our findings provide indirect evidence that indicates that the advised tools correspond with the needs of nurses rather than the needs of physicians, this was not supported in the interviews that Van der Werf conducted with 10 physicians who had participated in 3 different pilots at three different sites. (8) According to her report, the training did not sufficiently correspond with physicians' training needs.

Based on the reports from the co-researchers that were discussed in Chapter 7, our hypothesis is that the model that is the most suitable for practical application is a combination of MVCN and symbolic listening. Additional research is needed to understand why *Ars Moriendi* received less attention in the training that was conducted by the chaplains.

Using two sessions for spiritual care training and detailed participants' case descriptions will allow chaplains to support primary caregivers in clinical practice.

Our fourth research question, 'How do chaplains concretise spiritual care training for primary caregivers in clinical practice?', is reported in Chapter 7.

We concluded that implementing spiritual care in hospitals can be successful if it is based on: two training sessions with 90 minutes each (group size 8-20), and includes participants' detailed personal case descriptions in the second session to illustrate and practice the models and diagnostic tools in the training in multidisciplinary groups.

Monodisciplinary training may be more practical, or easier to organize, and adjustable to specific learning needs. However, for multidisciplinary training, the co-researchers reported that the quali-

ty of training was improved by the participation of physicians, as this eliminated mutual stereotypes, and provided opportunities for influencing work processes. In multidisciplinary staff training, it is possible to make collaborative choices about implementing specific models/diagnostic tools for referral and multidisciplinary communication in (electronic) patients' reports.

Our findings indicate that physicians' training needs warrant more attention; thus, health care chaplains should familiarize themselves with physicians' daily practices. Further, reflection on one's own spirituality or confrontation with end-of-life-care is not possible in the limited time that is in general available for training professionals in hospitals.

Spiritual care training improves the quality of care that is perceived by patients, and influences health care professionals' attitudes and competencies.

For our final research question on 'the effects of spiritual care training', our quantitative studies that were reported in Chapters 5 and 6 suggest that within the limited time that is available in hospitals for training health care professionals, it is possible to decrease barriers to spiritual care, enhance physicians' and nurses' spiritual care competencies, and improve the quality of care as perceived by patients in palliative trajectories. Measuring the effects of spiritual care training for multidisciplinary teams using the Spiritual Care Competence Scale (SCCS)(9) was successful because it allowed us to measure differences in time and between groups. No participants criticized the questionnaire as less applicable to physicians; thus, we conclude that this tool, which was originally developed to evaluate nursing education in spiritual care, may also be suitable for evaluating medical education in spiritual care.(10) A formal validation study is in preparation.

We believe that the decreased impact of the training on physicians is because the health care chaplains as trainers/co-researchers are more familiar with nursing practices than with physicians' daily

practices, and, therefore, could not adjust their training methods to physicians' training needs.

Based on the qualitative study, there were four primary effects on the chaplains: a.) new knowledge about and experience with research using an action-research approach, b) an improved understanding of the professional practice of nurses and physicians, c) renewed self-consciousness, and d) a better profile of chaplaincy in the participating hospitals.

Spiritual care training as part of a quality improvement project can have sustainable effects

In Chapter 3, 'Effects of spiritual care training on patients and health care professionals: a systematic review', we report the results from a systematic review that was performed in 2016-2017 that focused on effective training methods for spiritual care. We found diverse outcome measures, with a tendency towards competence-based measures.

Based on the qualitative synthesis, we concluded that improving spiritual care, or implementing a spiritual care standard, is optimal when it is designed as a quality improvement project. This type of project can follow a plan-do-check-act cycle that begins with (1) an initial audit to identify the barriers in the health care setting where this improvement is targeted; (2) formulating a spiritual care policy that is based on available national standards (plan); (3) providing training to decrease the identified barriers and provide the spiritual care as formulated in the policy (do); (4) evaluating the effects of the training as well as the policy (check); and (5) adjusting the training and/or policy based on the recommendations (act).

For this systematic review, we used methods that were commonly used in the medical field. Although the Cochrane paradigm is dominant in medical research and is suitable for reviewing the literature on standardized medical/therapeutic interventions, it may not be the most appropriate method for reviewing the research literature on spirituality and/or spiritual care. Improving or implementing

spiritual care is a complex social intervention; therefore, we recommend the Campbell method for future systematic reviews. This method is designed to ‘to inform policymakers, practitioners, researchers, and other interested parties about the extent, quality, and findings of the available research evidence on the effectiveness of social programmes, policies, or practices. Thus, suitable topics include the synthesis of research that investigates the effects of deliberate, organized social interventions intended to bring about change on some set of targeted outcomes that represents improvement in the conditions the intervention is designed to address for a population experiencing those conditions’.(11) Campbell reviews summarize both the best evidence available about the effects of the focal intervention(s), and the evidence that provides credible estimates of those effects, which may provide a better synthesis in the multidisciplinary field of spiritual care, where there is an intersection for the paradigms of science and humanities.

Concise training programmes for spiritual care in palliative care are effective in improving the quality of care in hospitals, decreasing spiritual care barriers, having positive effects on spiritual care competencies, improving multidisciplinary work, and enhancing the profile of chaplains.

As the final conclusion to our primary research question, ‘What training do primary health care professionals (physicians, nurses) need to use hermeneutical diagnostic tools for multidisciplinary spiritual care and to integrate these tools in their professional practice, with the expert support of health care chaplains?’, we believe the following critical factors for success are essential for the successful implementation of the spiritual care guideline:

1. At the local level, it is essential to have at least one (preferably two, depending on the chaplaincy team staffing) dedicated chaplain(s) who has additional training in spiritual care, and a clear mandate from the supervising physician, nursing director, and management related to responsibility for the spiritual care policy of the organization;

2. At the national level, it is important to provide an e-learning module or interactive learning environment for the theory of spiritual care based on the Guideline;
3. Space in hospitals' education plans for wards in which patients are treated in curative as well as palliative trajectories. Our findings suggest that two sessions of 90 minutes each (or three of 60 minutes) result in a significant improvement in the quality of care. Because our findings suggest that chaplains' knowledge of physicians' practices is too limited to detect an effect on physicians, we suggest that these trainings should be conducted in pairs: a chaplain with a dedicated physician or nurse.

General discussion

In this study, we wanted the participating chaplains to train health care professionals to use the diagnostic tools for spiritual care in such a way that patients' expressions of spiritual needs and resources could be *interpreted* and addressed based on the patients' verbal and non-verbal communication, with the health care professionals attempting to *understand* the *meaning* of the patient's experiences. This type of interpretive use of diagnostic tools is typical of chaplaincy and is called 'hermeneutical' use of diagnostic tools. Using diagnostic tools for spiritual care in the medical process of diagnosing, i.e., as a process of *determining* the disease or condition that *explains* a person's symptoms and signs, may reduce patients' complex, nuanced, existential experiences to merely a series of ticks in a box.(12)

Although the chaplains who were interviewed reported inter- and intra-group differences in physicians' and nurses' reflective skills, they did not report a trend to reduce spiritual care to a tick-box mentality. It is possible that the past resistance that chaplains expressed related to diagnostic tools for chaplaincy care led to a fear that training physicians and nurses to use spiritual care diagnostic tools would medicalize spirituality. Based on our findings, this is a serious bias in chaplains, which could be overcome with intense

communication and cooperation between physicians and chaplains in patient care. Gijsberts' noted, in the General Discussion of her thesis, that in the nursing home she visited for her ethnographic study, '*and probably in many other Dutch nursing homes*', there was a spiritual counsellor who did not collaborate with the multidisciplinary team for residents' spiritual issues at the end of life', (13) and illustrates the need to intensify multidisciplinary and interdisciplinary forms of cooperation between chaplains, nurses, and physicians to develop spiritual care that adheres to the standards that are formulated in the guideline.

Another aspect of the 'hermeneutical' use of diagnostic tools in spiritual care could be the lack of a common language between the medical, psychosocial, and spiritual disciplines in Dutch health care, which still needs to be developed. (14) Spiritual needs are often expressed in metaphorical language, and more research is needed to determine whether the 'hermeneutical reporting' of spiritual needs is viable or if it demands a systematic taxonomy.

Spiritual care is a multidisciplinary activity, and our study design sought to explore and bridge the gap between different practices, research perspectives, and methodologies from medical (including nursing) science and the humanities (including theology). We believe that the strength of this study lies not only in the attempt to connect both research traditions but also in connecting clinicians (nurses, physicians, chaplains, and managers) to develop a multidisciplinary practice of spiritual care with a combination of implementation, education, and research that seeks to improve the quality of care.

The combination of international input (15), a multicentre design instead of the one-site study by Vlasblom et al., (16) patient-reported outcomes, and a team approach to improvements in the quality of care (17) is unique in chaplaincy studies in the Netherlands. This study allowed chaplains who were not able to conduct their own local research projects to participate in a pre-designed research pro-

ject and to collaborate to contribute to improving quality of care and developing a more research-based chaplaincy.

As we concluded in Chapter 3, the most effective spiritual care training studies were performed in specialized palliative care settings, as a component of a quality improvement programme. Our study indicates that it is possible to generate comparable effects in hospitals. However, we believe that our study would have been more effective had we specifically included the implementation of a spiritual care policy in our aims and methods.

Another strength of our study design was to examine ‘attention to life issues, existential and spiritual distress,’ as a patient-reported primary outcome, because it is the basic attitude that the Guideline promotes to patients and proxies who are in distress, and to every patient and proxy who is confronted with a life-limiting condition.

For implementing spiritual care in hospitals, our sample size, with 8 of the 27 teaching hospitals, provided a substantial impulse at the national level.

We believe that the small patient sample is a limitation that could be expected in an explorative study. Because this study explored and tested training methods for spiritual care and did not evaluate a spiritual intervention among patients who were in spiritual distress, we did not assess the content of patients’ spiritual needs.

From an action-research perspective, an important limitation (and a missed opportunity) is that the study design only included physicians and nurses as participants in the training, as they were not included as participants and co-researchers in the collaborative action-research process.

Where are we now?

We completed our summary of the baseline in 2012 with the observation that there was no project that was ‘mature’ enough to be included in the national improvement programme at that time.

However, we note that the new programme for developing palliative care in the Netherlands, *Palliantie*(18), is now partially complete (2015-2020) and includes a small but growing number of projects that are specifically aimed at developing spiritual care.

To increase alignment with evidence-based practice, the Spiritual Care Guideline from 2010 is now being revised under the authority of the Dutch Comprehensive Cancer Centre (Integraal Kankercentrum Nederland, IKNL) by a taskforce of multidisciplinary representatives from several medical professional organizations, including nursing, psychology, chaplaincy and patient organizations, all of whom will be asked to authorize the final concept.

The quality framework for palliative care(19) is being developed by a broader group of representatives from professional organizations under the authority of the Comprehensive Cancer Centre and the multidisciplinary professional organization for professionals in palliative care, *Palliactief*. This framework acknowledges that the provision of spiritual care as an essential dimension of palliative care from the patient's perspectives.

Currently, the two projects that explicitly address the spiritual dimension in the national programme, *Palliantie*, are: testing a new four-dimensional version of the Utrecht Symptom Diary that integrates the *Ars Moriendi* model, and a training and implementation project that includes an electronic training and implementation toolkit that is based on the revised Guideline for spiritual care.

The first account of a systematic implementation of a spiritual care diagnostic tool sought to continue spiritual care in the chain of care in the Netherlands and was published this year by van Meurs et al.(20) This is an example of a quality improvement programme that is based on pre-formulated goals for providing multidisciplinary spiritual care, including e training and support for health care professionals from the expert health care chaplain or spiritual care provider, and assessing the policy's results.

Internationally, there are validated tools for spiritual care and research in this field that are available in multiple languages. Health

care professionals and researchers are connected with the World Health Organization through global networks, such as the Global Network for Spirituality & Health (GNSAH).(21) Finally, the EAPC Taskforce on spiritual care has been invited by the EAPC Board to become a more structural component of the EAPC as a permanent Reference Group with long-term aims and goals.

At the time that this thesis was completed, in 2017, we conclude that health care chaplaincy is developing into a more evidence-based profession,(22,23) and at a national level, there is more awareness of the importance of spiritual care in palliative care in the Netherlands.(24,25) We believe that the combination of these developments creates new opportunities in hospitals and other health care organizations for integrating health care chaplains' expertise in multidisciplinary teams.

Implications for medical practice

a. patients/general public:

We recommend additional implementation of the revised spiritual care guideline based on the outcomes that were described in Chapter 5, where we discuss the importance of health care professionals' attention to life issues, existential and spiritual distress (on a 0-10 scale: 8.5 (1.6) 7.2 (2.9), and the effects of spiritual care training on the quality of care as reported by palliative patients.

b. physicians and nurses:

Based on the outcomes that were described in Chapter 6, which discusses the effects of training on barriers to providing spiritual care and the spiritual care competencies of physicians and nurses, we recommend additional implementation of diagnostic tools in hospitals consistent with the Guideline to improve the reporting and planning of spiritual care.

c. health care chaplains:

Based on interviews with the chaplains who participated in our study

(discussed in Chapter 7), in which chaplains stated that the specialized training was essential for preparing for this quality improvement project on spiritual care and that implementing the guideline had not been a priority, we recommend that spiritual care training be included as a component in a quality improvement project. Second, the qualitative synthesis in Chapter 3 concludes that the effects of spiritual care training were the best when this training was a component of an audited quality improvement project. Thus, we agree with Vissers, Van der Zande and Van Meurs(25,26), and recommend a sub-specialty within chaplaincy: a spiritual consultant for palliative care who has the explicit task of developing a spiritual care policy. For an organization in the Dutch health care system, a spiritual care policy should be created from the patient's perspective and safeguard a continuum of care between hospitals, other health care institutions, and home care.

Patients/general public	Attend to the spiritual dimension and communicate this dimension using patient information tools.
Physicians and nurses	Implement the guideline on spiritual care and use diagnostic tools in primary care and hospitals based on the Guideline to improve reporting and planning of spiritual care.
Health care chaplains	- Introduce spiritual care training as a component of a quality improvement project. - Develop a sub-specialism within chaplaincy: a spiritual consultant (for PC) with the explicit task of developing a spiritual care policy.

Table 1. Summary of recommendations for medical practice

Implications for training in spiritual care

a. patients:

Based on reports by Ford et al.(27) and Tait & Hodges (28), which were mentioned in Chapter 3, we recommend exploring the possibility of patients' participating in training modules for spiritual care.

b. physicians and nurses:

- i. additional operationalization of training methods for professionals using *Ars Moriendi*

Based on the chaplains reports that were described in Chapter 7, the *Ars Moriendi* model was used the least in the pilot training; thus, we conclude that chaplains need practical training methods to instruct physicians and nurses operationalizing the model in daily practice. Therefore, we recommend additional operationalization of training methods that are suitable for specialists who instruct other health care professionals.

- ii. additional exploration of physician's training needs, and the strengths and limitations of mono-disciplinary / multidisciplinary spiritual care training

Chapter 7 suggests that the decreased impact on the training of physicians occurred because the health care chaplains (as trainers/co-researchers) were more familiar with nursing than physicians' daily practices and could not adjust their training methods to physicians' specific training needs. We recommend exploring physicians' spiritual care training needs and testing the effectiveness of specific training methods in both mono-disciplinary and multidisciplinary courses.

- iii. develop special retreats for reflecting on one's own spirituality and confrontation with EoL care

In Chapter 7, we report that chaplains explained that a lack of time forced them to only mention the relevance of reflecting on one's own spirituality and experiences in confronting end-of-life care. In Chapter 3, we describe examples of a spiritual care policy that includes stimulating self-care and reflection.

c. health care chaplains:

Because the findings that were reported in Chapter 7 suggest that chaplains' knowledge of physicians' daily practice is too limited to result in a significant effect, we suggest training multidisciplinary teams in pairs: a chaplain with a dedicated physician or nurse. We also recommend exploring additional training methods for improving spiritual care and methods that secure training results as a component of a more extended spiritual care policy.

Patients/general public	Explore possibilities for patients' participation in spiritual care training modules.
Physicians and nurses	<ul style="list-style-type: none"> - Further operationalize the training methods that are suitable for specialists who instruct other health care professionals. - Explore physicians' spiritual care training needs and test the effectiveness of specific training methods in both mono-disciplinary and multidisciplinary courses. - Develop special retreats for reflecting on one's own spirituality and confrontation with EoL care.
Health care chaplains	<ul style="list-style-type: none"> - Train multidisciplinary teams in pairs: a chaplain with a dedicated physician or nurse. - Further explore training methods for improving spiritual care. - Explore methods to secure training results as a component of a more extended spiritual care policy.

Table 2. Summary of recommendations for spiritual care training

Implications for research on spiritual care

a. patients:

In this study, we report quantitative results on patients' spiritual attitudes, interests, and needs. Chapter 7 highlights two independent patient-reported outcome measures that should be improved: health care professionals' attention to patients' spiritual and existential needs, and a significant improvement in patients' sleeping patterns. Additional research is needed to analyse the relationship between health care professionals improved attention to patients' spiritual needs and a decrease in sleeping problems. However, to better understand the content of spiritual needs, we need more research strategies that are implemented 'with' patients instead of 'for' or 'on' patients; therefore, it is important to use rigorous action-research methodologies and qualitative methods. We also recommend additional research on the effects of specific spiritual interventions on spiritual distress.

b. medical practice:

In our study, the chaplains participated as co-researchers. However, because spiritual care is a multidisciplinary activity, future studies that use action-research methods should include physicians, nurses,

nursing directors, health care management, health care chaplains, and patients as co-researchers.

c. use Campbell systematic review methods:

For systematic reviews on training and developing spiritual care policy, we recommend the Campbell review guidelines because they are more appropriate for social interventions that are intended to influence methods for education and improving policies and practices.

d. health care chaplains:

Our study was the first explorative study in this area in the Netherlands; thus, it is not possible to develop quality indicators for spiritual care training. Therefore, we recommend further research on effective methods for spiritual care training for nurses and/or physicians that is administered by chaplains. Based on our results, we conclude that the action-research method is effective for pre-formulated outcome measures as well as for the profile of chaplaincy as a more research-based profession. However, a more fundamental, theoretical analysis should determine whether critical action-research methods correspond with chaplaincy.

Patients/general public	<ul style="list-style-type: none"> - Analyse the relationship between improved health care, professionals' attention to patients' spiritual needs and decreases in sleeping problems. - Develop mixed-methods action-research methodologies in collaboration with patients. - Test the effects of specific spiritual interventions on spiritual distress.
Medical practice	<ul style="list-style-type: none"> - Include physicians, nurses, nursing directors, health care management, health care chaplains, and patients as co-researchers in action-research methodologies.
Systematic reviews	Use Campbell systematic review methods.
Health care chaplains	<ul style="list-style-type: none"> - Develop quality indicators for spiritual care training that are based on research on effective training methods for spiritual care with nurses and/or physicians. - Theoretically analyse critical action-research methods for chaplaincy.

Table 3. Summary of recommendations for spiritual care research

Implications for policy

a. patients/general public:

Based on the positive effects on the quality of care, which was described in Chapter 5, we recommend additional implementation of the revised multidisciplinary Guideline for spiritual care.

b. physicians and nurses/health care management:

To disseminate the knowledge that is concentrated in the revised Guideline on spiritual care in the Dutch health care system, we recommend adding spiritual consultants to IKNL Palliative care Consultation Teams (PCTs) and to the hospital PCTs that have recently been developed based on oncology standards (SONCOS). We recommend developing a local spiritual care policy that is based on the implementation plan that will be included in the revised Guideline for spiritual care.

c. health care chaplains/VGVZ:

Based on the findings that were reported in Chapter 5, 6 and 7, we support recent developments towards a more evidence-based chaplaincy.

d. EAPC Spiritual Care Taskforce/Reference Group:

We recommend using the Dutch *Palliantie* matrix for the future EU project, *Improvement of multidisciplinary SC in PC by training primary caregivers* (action research, education, implementation).

Patients/general public	Further implementation of the revised multidisciplinary Guideline for spiritual care.
Physicians and nurses/health care management	Add spiritual consultants to IKNL Palliative Care Consultation Teams (PCTs) and the hospital PCTs. Develop a local spiritual care policy.
Health care chaplains/VGVZ	Continue developing a more evidence-based chaplaincy.
EAPC Spiritual Care Taskforce/Reference Group	Consider using the Dutch <i>Palliantie</i> matrix for the future EU project, Improvements of multidisciplinary SC in PC by training primary caregivers.

Table 4. Summary of Recommendations for policy making

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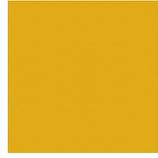
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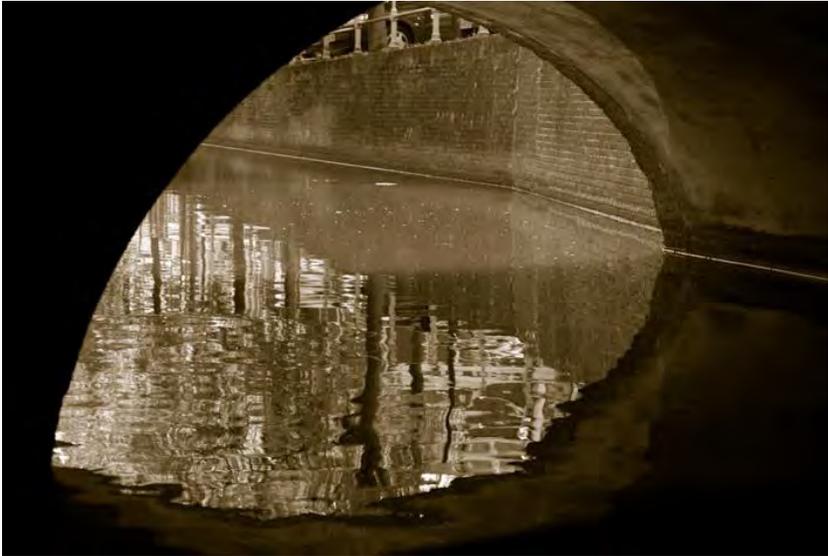
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Epilogue. Blessed with talents



Epilogue. Blessed with talents

Position

In the Prologue, I briefly explained my personal position and perspective as a health care professional and researcher and described the genesis of my research questions. In this epilogue, I reflect on my experiences in this research process from a theological perspective. As a healthcare chaplain and ordained minister, my spiritual and theological position is a part of my professional frame of reference. Thus, it should be continuously reflected on as part of my expertise as a health care chaplain, without interfering with my hermeneutic competences of observing and interpreting the spiritual positions of patients and those who are close to them, or – when I work in the multidisciplinary team – the spiritual positions of medical, nursing, or other colleagues.

My classical education as a theologian from the Faculty of Theology at Utrecht University and the Seminary of the Covenant of Free Evangelical Churches (*Bond van Vrije Evangelische Gemeenten*) provided a solid grounding, with a basic knowledge of Latin, biblical Hebrew and Greek for biblical theology, and knowledge and skills in philosophical, historical and social sciences. It allowed me to address some of the puzzling evangelical fundamentalist convictions that I had been confronted with as an adolescent in my local church. Most of the curriculum was designed to be useful for serving a local church community. However, the curriculum was also designed to teach me to identify and oppose dehumanizing tendencies in society and culture and to contribute to an open dialogue that is based on the Judeo-Christian tradition. As such, the curriculum also provided an initial training as a health care chaplain. This curriculum and active participation in the ecumenical working group, *Uterque*, shaped me into an ecumenical theologian.

I believe that this type of education in the humanities, which develops competencies that are based on philosophical or theological traditions *outside of* the health care system, that make health care chaplains' unique contributions to patients and the healthcare system possible and constitute a specific *proprium* of the profession. I also note that an education that *only* occurs outside of the health care system is no longer enough.

In this epilogue, I provide a theological reflection on my research project in a personal, spiritual elaboration of the first topic in Leget's(1) *Ars Moriendi*: autonomy, the dynamic tension between oneself and the others, or the Other – or, as Leget formulated in his latest book: who am I and what do I really want?

Who am I: A creature blessed with talents

For the question 'who am I?', Leget follows Ricoeur in discerning three relations that in combination constitute the 'self' as an ongoing process in time: the relation between me and myself, the relation between myself and the others, and the relation between myself and the institutions. In separate sections, he describes each dynamic tension in his *Ars Moriendi model* from a personal, Roman Catholic perspective. My personal religious perspective is that of an ecumenical protestant health care chaplain, who was ordained in the free evangelical church.

I see myself as part of a reality that was created by God, as expressed in Psalm 139:

¹³ *For it was you who formed my inward parts;
you knit me together in my mother's womb.*

¹⁴ *I praise you, for I am fearfully and wonderfully made.
Wonderful are your works;
that I know very well.*

A creature bestowed, as any other creature, with the spiritual gifts that Paul described in his first letter to the Corinthians:

Now there are varieties of gifts, but the same Spirit; and there are varieties of services, but the same Lord; and there are varieties of activities, but it is the same God who activates all of them in everyone. To each is given the manifestation of the Spirit for the common good. (1 Cor. 12:4-6)

As soon as I decided to study theology, the parable of the talents became important (Matth. 25:14-30) for my personal inspiration. Matthew places this parable in Jesus's last long speech, in which he announces his death and exhorts his disciples to continue to expect, and actively contribute to, the coming of the Kingdom of God. The life task we have been given, to exploit the talents we have received in the service of the community, has remained constant, both in the work of a preacher in a local community and in the position of health care chaplain. In a professional sense, the task for the community is reflected in the VGVZ professional standard, which states that health care chaplains are expected to contribute at the micro, meso, and macro levels.

Personally, participating in the national and international developments in palliative care that were described in the Prologue, made the words in Ecclesiastes, *For everything there is a season, and a time for every matter under heaven* (Ecclesiastes 3:1), feel very appropriate. I felt blessed living at that moment in time, surrounded by colleagues, friends, and mentors who inspired and showed me how to 'surf on the waves of this incoming tide'.

Being aware of the New Testament distinction between χρόνος (*chronos*, the duration of time) and κάιρος (*kairos*, a specific moment in time)(2) I viewed it as my personal, spiritual, and professional responsibility to act in this *kairos*, using all of the talents that God gave me, to the utmost of my abilities, as a health care chaplain. I believed that it was essential in this *kairos* for a chaplain to move beyond the comfort zone of qualitative research, and to go the second mile (Matthew 5:41), because modern palliative care requires that health care chaplains include quantitative methods in their re-

search projects to present transparent reports of their contributions to improving the quality of care.

What do I really want: Recognizing patients' spiritual resources and health care professionals' spiritual gifts, building a sustainable health care system for the common good together

During a forum discussion on the quality standard for palliative care at the Dutch National Congress on Palliative Care, in 2017, I suggested that attention to spirituality in health care was important for the quality of care for patients and their closest, as well as for caregivers. Dehumanizing tendencies in health care damage not only the patient but also the caregiver. There is a well-known Dutch saying, 'Anything that receives attention will grow,' which is reflected in the growing attention to spirituality, person-centred health care, or compassion, as examples of converging counter-movements of dehumanizing tendencies. My conviction is that it is not only health care chaplains who can provide the attention that I have confirmed in my research. Doctors, nursing staff and other paramedics bring professional and personal talents to the multidisciplinary team, which I personally experience as both challenging and supportive.

In the Prologue, I called doctors and nurses the 'priests and priestesses in the temple of health care.' I agree with Abraham Joshua Heschel, who, speaking in 1964 to the American Medical Association in San Francisco, California, referred to doctors as priests.⁽³⁾ In 2017, I would like to paraphrase his words, adding nurses to this metaphor.

Life is a mystery, the reflection of God's presence in His self-imposed absence. ... His chief commandment is, 'Choose life' (Deuteronomy 30:19). The doctor and the nurse are God's partners in the struggle between life and death. Religion is medicine in the form of a prayer; medicine or nursing is prayer in the form of a deed. From the perspective of the love of God, the work

of healing and the work of religion are one. The body is a sanctuary, the doctor and the nurse are priests.

In 1964, Heschel was speaking in a religious context; my dissertation appears in a secularized context in which there is renewed attention to spirituality, for example, in the health care sector. In the Dutch Guideline, spiritual care is presented as everybody's responsibility, as a multidisciplinary activity, with doctors and nurses playing a fundamental role and health care chaplains as the specialists who are responsible for complex care needs, training, and – in consultation with other disciplines – for the spiritual care policy.

With my research results I hope to contribute to new connections between doctors, nursing staff, other paramedical disciplines and health care chaplains, so that together we can provide a secure and reliable safety net for patients and those who are close to them when they are confronted with illness, loss, and death.

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Summary



Summary

Background

After the decline of the pillarization of Dutch society, a period in which healthcare was organized along confessional/denominational lines, spirituality became neglected or implicit for decades in the Dutch healthcare system. During the modernisation of healthcare in the 1960s, the development of professional language concerning chaplaincy and psychosocial care in a secularising society created a blind spot for this fundamental dimension of care. In the Netherlands, palliative care was boosted by a national programme challenging healthcare providers, policymakers and researchers to reassess and allocate the spiritual dimension to the biopsychosocial model in health care. Inspired by this national policy and personal leadership the Agora Taskforce on ethics and spiritual care initiated the development of the first Dutch, consensus-based national guideline for multidisciplinary spiritual care as part of palliative care, the Guideline Spiritual care in palliative care (*Richtlijn Spirituele zorg*), summarized in Chapter 1. The publication of this guideline led to the adjustment of the professional standard of healthcare chaplaincy in the Netherlands, including the concept of spirituality in medical care, which was not used before in this standard. It also inspired the authors to invite experts on spiritual care in palliative care from different countries to join the initiative for a European Taskforce on Spiritual Care, as described in Chapter 2.

The combination of specific educational programs on the spiritual dimension in health care and broad international contacts inspired the author to undertake an action-research study to explore possibilities for health care chaplains in Dutch general hospitals to contribute to palliative care improvement programmes. This thesis reports the results of this mixed-methods study using quantitative and qualitative methods, in which a pilot training on spiritual care in palliative care was tested by trained hospital chaplains in eight Dutch non-university teaching hospitals. The effects on patients and health

care professionals (physicians and nurses) was measured via questionnaires followed by quantitative analysis. Semi-structured interviews were held with the hospital chaplains who performed the intervention in order to analyse their experiences.

Research questions

The main research question as described in Chapter 1 was: ‘What is necessary for training primary health care professionals (physicians, nurses) in the hermeneutical use of diagnostic tools for multidisciplinary spiritual care, so that they can integrate this into their professional practice with the expert support of health care chaplains?’

Secondary research questions were:

1. What is the baseline situation for the development of multidisciplinary spiritual care in palliative care in the Netherlands in the year 2012?
2. How have teaching hospitals in the Netherland structured and organized palliative care, and spiritual care as part of that, for inpatients?
3. Which diagnostic tools for spiritual care
 - a. theoretically correspond to the multidisciplinary guideline,
 - b. correspond with the needs of patients and proxies,
 - c. correspond with the needs of health care professionals and their professional tasks and standards,
 - d. are, from the primary health care professionals’ perspective, suitable for practical application?
4. How are chaplains able to concretise spiritual care training for primary caregivers in clinical practice?
5. What is the effect of this training on:
 - a. patients?
 - b. participating health care professionals?
 - c. chaplains?

Context and set-up

In Chapter 2 we describe the context for the development of multi-disciplinary spiritual care in the Netherlands in 2012, at the start of this research project. The conclusion is that in the Dutch health care system at the time a specific infrastructure for the development of spiritual care was almost complete. Groups of dedicated chaplains in the Netherlands, motivated to engage in local and national development of spiritual care, had from 2007 onwards been trained in the 'Masterclass on spirituality and health care chaplaincy in palliative care'. Other health care professionals, such as nurses, physicians, art and music therapists, also started to attend the masterclass, which developed the programme for multidisciplinary groups and in 2012 changed its name to 'Masterclass on spirituality in palliative care'. The need for training and implementation methods discussed in these groups, combined with personal experience as a project leader pioneering and searching for structure and organization of hospital palliative care in a teaching hospital, inspired the author to develop a multicenter action research project in teaching hospitals in the Netherlands.

At the start of the project, 10 out of the 28 teaching hospitals in the Netherlands showed interest in participating, and met the inclusion criterion of having some form of palliative care improvement programme or Palliative Consultation Team.

Although in the international research literature there were more tools available that theoretically correspond to the Guideline spiritual care in palliative care (further: the Guideline), the experts in an invitational research conference in 2013 limited the models to be trained in the pilots to: a) symbolic listening according to Erhard Weiher, b) the translation of the three screening questions developed by the Mount Vernon Cancer Network (MVCN), and c) the Dutch *Ars Moriendi* spiritual care model developed by Carlo Leget. This selection corresponded to the three models included and translated in the Guideline. At this conference further requirements for the pilot training in spiritual care in palliative care were discussed. The

target group had to consist of multidisciplinary clinical teams of departments were patients in both palliative and curative trajectories are treated. The main competencies to be trained were: recognizing, referring, self-reflexivity, and open attitude toward patient spirituality, in two lessons of 90-120 minutes.

Systematic review

Chapter 3, reports of a systematic review of the literature on spiritual care training methods, and their effects on patients and health care professionals, we found a diversity in outcome measures, with a tendency towards competence-based measures. On the basis of the qualitative synthesis we conclude that improving spiritual care, or implementing a spiritual care standard, is optimal when it is designed as a quality improvement project.

Intervention, participants and measures

The spiritual care training intervention was delivered nine times in seven hospitals from February 2014 to February 2015, and 374 healthcare professionals were scheduled in groups for one or two lessons during working hours given by the healthcare chaplains, using standard slides for presentation and selected teaching methods. In accordance with the action research approach, there were local variations in the training within the preliminary set of requirements of the study protocol as described in Chapter 4.

The aim of the intervention was a) to improve healthcare professionals' attention to patients' expressions of spiritual needs, and not to implement one specific tool for spiritual interventions but to raise healthcare professionals' competencies in supporting patients on this dimension, b) to raise the quality of care as perceived by palliative patients on the wards that participated in the training, and c) to gain practical knowledge about the barriers to and critical success factors for training spiritual care and the implementation of the spiritual care guideline. The core skills for doctors and nurses to be trained were: screening/assessing spiritual needs, counselling pa-

tients (matching their own professional role), and referring patients to specialists in cases of crisis. Multidisciplinary training was mandatory.

The hospitals were selected on the basis of three inclusion criteria: being a member of the association of tertiary medical teaching hospitals (*Stichting Topklinische Ziekenhuizen*), being actively involved in advancing palliative care by having a specialist consultation team or implementing palliative care quality improvement programmes, and having a dedicated trained healthcare chaplain specialized in spiritual care in palliative care.

The intervention and control wards were selected by the local co-researchers, i.e., the dedicated chaplains; as the instructors, the chaplains were responsible for the spiritual care training for palliative care. The criteria for the intervention wards required the chaplain to be connected to the ward, the ward to be willing to facilitate and encourage staff to follow the training, and to be willing to facilitate patient interviews.

The physician responsible for each patient was asked to assess the patients' advanced clinical conditions as well as the indicators for supportive or palliative care. The physicians were asked, "Would it surprise you if this patient died in the next 12 months?". When the answer was negative, the patient was asked to participate, was given written information about the study, and was included in the study after giving informed consent in writing. The patients included were asked to complete the questionnaire independently. If necessary, the questionnaire was read at their bedside by a specialist palliative care nurse or a ward nurse from another department with additional palliative care training.

As co-researchers the participating chaplains were responsible for conducting the study locally according to the protocol: planning and carrying out the training in the intervention wards of the participating hospitals, including the participating health care professionals in the study of the effects on barriers and competencies regarding spiritual care, selecting control wards, and - in cooperation

with the local spiritual care consultation teams - organizing the process of selecting palliative patients for the purpose of studying the effects of the training on the quality of care. To assess the acquired practical knowledge of the co-researchers, 20 semi-structured interviews were conducted during the project: nine interviews at eight sites before the training (at one site, two separate pilots were conducted with different chaplains as the trainers) between 9 December 2013, and 18 March 2015 (duration 50-85", average 55"). The participants received the questions beforehand.

Findings

In Chapters 5 and 6 we report the effects of the spiritual care training on patient reported outcomes and health care professionals' competencies. The findings suggest that within the limited time available in hospitals for training health care professionals, it is possible to lower barriers to spiritual care, enhance physicians' and nurses' spiritual care competencies, and improve the quality of care as perceived by patients in palliative trajectories. Measuring the effects of spiritual care training for multidisciplinary teams by means of the Spiritual Care Competence Scale (SCCS) was successful in that it enabled us to measure differences in time and between groups.

We found a sustainable effect (after 1 and 6 months) on nurses, but a lower impact of the training on physicians. This may be explained by the fact that as trainers/co-researchers the health care chaplains are more familiar with nursing practice than with the daily practice of physicians, and hence were less able to adjust their training methods to physicians' training needs.

In Chapter 7 we report the findings of our qualitative study concerning the research question 'how can chaplains concretise spiritual care training for primary caregivers in clinical practice?', on the basis of the semi-structured interviews with the health care chaplains. The conclusion is that the implementation of spiritual care in hospitals can be expected to be successful if it is based on two training sessions in multidisciplinary groups of 90 minutes each (group size 8-20),

with participants' detailed personal case descriptions used in the second session to illustrate and practice the models and diagnostic tools trained, in multidisciplinary groups.

Monodisciplinary training seems more practical, or easier to organize, and adjustable to specific learning needs. However, the advantages of multidisciplinary training tip the balance: co-researchers reported that the quality of the training was improved by the participation of physicians in trainings for nurses and vice versa, as this helped eliminating of mutual stereotypes, and provided opportunities for influencing working processes. Furthermore, in multidisciplinary staff training it is possible to make joint choices about the implementation of specific models/diagnostic tools for referral, and about multidisciplinary communication in patients' reports.

Our findings indicate that for adequate training more notice should be taken of physicians' training needs, which means that health care chaplains need to familiarize themselves more with physicians' daily practice. Further, reflection on one's own spirituality or confrontation with end-of-life-care is hardly possible within the limited time available for training professionals in hospitals.

Our qualitative study has shown four main effects on the chaplains: a) new knowledge about and experience with research in an action-research approach, b) improved understanding of the professional practice of nurses and physicians, c) renewed self-consciousness, and d) a better profile of chaplaincy in the participating hospitals.

The co-researchers in the participating hospitals reported a large variation in staffing, set-up, structure, and financial support of palliative care consultation teams, and four out of eight chaplains were able to build a fruitful cooperation with these teams in performing the study according to the study protocol. They observed a predominantly curative attitude among health care professionals in their hospitals, combined with a lack of knowledge about palliative care, which resulted in often failing to recognize patients' being in the beginning of the palliative or even dying phase. In those hospitals

no diagnostic tools for spiritual care were used, and only three out of eight co-researchers reported the use of the ‘distress thermometer’ for the detection of psychosocial distress. We conclude that at this moment diagnostic tools for spiritual care have not structurally been implemented in Dutch health care.

Conclusion

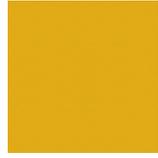
In Chapter 8 the main research question is answered. The conclusion is that concise training programs for spiritual care in palliative care are effective in improving quality of care in hospitals, decreasing spiritual care barriers, having positive effects on spiritual care competencies, improving multidisciplinary working, and enhancing the profile of chaplains.

We consider the following critical success factors essential for a successful implementation of the spiritual care guideline.

First: at the local level, the availability of at least one (preferably two, depending on the staffing of the chaplaincy team) dedicated chaplain with additional training in spiritual care, and a clear mandate from the supervising physician, nursing director, and management concerning responsibility for the spiritual care policy of the organization.

Second: preferably at national level, the availability of an e-learning module or interactive learning environment for the theory of spiritual care based on the Guideline.

Third: simply some room in hospitals’ education plans for wards where patients are treated in curative as well as palliative trajectories. Our findings suggest that with two sessions of 90 minutes each (or three 60’ sessions) significant improvement in the quality of care may be expected. Since our findings indicate that chaplains’ knowledge of physicians’ practice is too limited to have a significant effect on physicians, we suggest performing these trainings in pairs: a chaplain together with a dedicated physician or nurse.



Samenvatting



Samenvatting

Achtergrond

Na het verdwijnen van de verzuiling in de Nederlandse maatschappij, waarin de gezondheidszorg georganiseerd was langs confessionele lijnen, raakte de aandacht voor spiritualiteit tientallen jaren verwaarloosd binnen het Nederlandse zorgsysteem. Tijdens de modernisering van de gezondheidszorg in de zestiger jaren van de twintigste eeuw ontwikkelde het professioneel taalgebruik ten aanzien van geestelijke en psychosociale zorg in de gezondheidszorg zich binnen de context van een drie-dimensioneel zorgmodel: het bio-psycho-sociale model. Vanaf het moment dat palliatieve zorg in Nederland onderdeel werd van nationaal beleid voor de reguliere zorg, stonden instellingen voor gezondheidszorg, beleidsmakers en onderzoekers voor de uitdaging om dit complexe begrip opnieuw te definiëren. Nationaal beleid en persoonlijke initiatieven op het gebied van onderzoek en onderwijs (onder andere de Masterclass spiritualiteit en geestelijke verzorging in de palliatieve zorg) kwamen samen in een inspirerend proces dat uitmondde in de eerste Nederlandse, consensus-based richtlijn voor multidisciplinaire spirituele zorg binnen de palliatieve zorg: de *Richtlijn Spirituele zorg*, samengevat in hoofdstuk 1. Het verschijnen van deze richtlijn leidde tot het opnemen van het begrip spiritualiteit in de beroepsstandaard voor geestelijke verzorging van de Vereniging Geestelijke VerZorgers in Nederland (VGVZ), en het initiatief tot een Europese Taskforce on Spiritual Care, beschreven in hoofdstuk 2.

De combinatie van onderwijs en internationale contacten inspireerde de auteur tot het opzetten van een actieonderzoek, met als doel te verkennen hoe geestelijk verzorgers in Nederlandse algemene ziekenhuizen kunnen bijdragen aan het verbeteren van de aandacht voor spirituele zorg in de palliatieve zorg. De resultaten van dit mixed methods-onderzoek, waarin de effecten zijn gemeten van een scholing spirituele zorg in de palliatieve zorg in acht Nederlandse topklinische opleidingsziekenhuizen, verzorgd door gespecialiseerde

geestelijk verzorgers, worden in deze dissertatie beschreven. De effecten op patiënten en professionele hulpverleners werden gemeten via vragenlijsten, die met kwantitatieve methoden werden geanalyseerd (hoofdstuk 5 en 6). Semigestructureerde interviews vonden plaats met de geestelijk verzorgers die de interventie uitvoerden om hun ervaringen te verzamelen en te analyseren (hoofdstuk 7).

Onderzoeksvragen

De hoofdvraag in het onderzoek, beschreven in hoofdstuk 1, was: Waaraan dient scholing in het hermeneutisch gebruik van diagnostische instrumenten ten behoeve van multidisciplinaire spirituele zorg te voldoen opdat primaire zorgverleners (artsen, verpleegkundigen, verzorgenden) ondersteund door geestelijk verzorgers (als experts) dit tot een geïntegreerd onderdeel van hun praktijk kunnen maken?

Deelvragen waren: 1) Wat is de uitgangssituatie voor de ontwikkeling van multidisciplinaire spirituele zorg in de palliatieve zorg in Nederland anno 2012? 2) Op welke wijze hebben topklinische ziekenhuizen in Nederland palliatieve zorg en spirituele zorg, voor zover onderdeel daarvan, intern gestructureerd en georganiseerd? 3) Welke diagnostische instrumenten sluiten theoretisch aan bij de Richtlijn Spirituele Zorg, sluiten aan bij de behoeften van patiënten en naasten en sluiten aan bij de behoeften van zorgverleners en hun professionele taken en beroepsstandaarden en zijn in de ogen van primaire zorgverleners geschikt voor praktische toepassing? 4) Hoe kunnen geestelijk verzorgers in de klinische praktijk scholing in spirituele zorg aan primaire zorgverleners concretiseren? 5) Wat is het rendement van deze scholing?

Context en opzet

In hoofdstuk 2 wordt de context beschreven aan het begin van dit onderzoeksproject ten aanzien van de ontwikkeling van de multidisciplinaire spirituele zorg in Nederland. De conclusie in 2012 is dat op dat moment een specifieke infrastructuur voor de ontwikkeling van spirituele zorg in de Nederlandse gezondheidszorg bijna zijn

beslag had gekregen. Vanaf 2007 werden groepen betrokken geestelijk verzorgers, die bij wilden dragen aan de ontwikkeling van spirituele zorg op lokaal en nationaal niveau, getraind in de 'Masterclass spiritualiteit en geestelijke verzorging in de palliatieve zorg'. Andere professionals in de gezondheidszorg, zoals verpleegkundigen, artsen, beeldend- en muziektherapeuten, begonnen de masterclass ook te volgen, zodat het programma verder werd uitgebouwd voor multidisciplinaire groepen en de naam in 2012 veranderd werd in 'Masterclass spiritualiteit in palliatieve zorg'. De behoefte aan scholing en implementatiemethoden zoals die in deze groepen naar voren kwam, gecombineerd met de persoonlijke ervaring als projectleider palliatieve zorg in het eigen ziekenhuis (Medisch Centrum Leeuwarden), vormden de aanzet tot het opzetten van een multicenter actie-onderzoek in topklinische ziekenhuizen in Nederland.

Bij de start van het project toonden 10 van de 28 topklinische ziekenhuizen in Nederland belangstelling voor deelname aan het project. Als inclusiecriteria gold het hebben van een lopend kwaliteitsprogramma palliatieve zorg of een palliatief consultatie team.

Hoewel in de internationale onderzoeksliteratuur meer instrumenten en handvatten werden genoemd die theoretisch in de Richtlijn spirituele zorg (verder: de Richtlijn) zouden passen, beperkten de experts in een invitational research conference in 2013 de modellen die in de proefcursussen getraind zouden worden tot de drie modellen die in de Richtlijn in vertaalde vorm zijn opgenomen: a) luisteren in lagen volgens Erhard Weiher, b) de vertaling van de drie screeningvragen ontwikkeld door het Mount Vernon Cancer Network (MVCN), en c) het Nederlandse Ars Moriendi model voor spirituele zorg van Carlo Leget. Op deze conferentie werden ook verdere vereisten voor de proeftraining Spirituele zorg binnen palliatieve zorg in de deelnemende ziekenhuizen besproken. De doelgroep werd geformuleerd als multidisciplinaire klinische teams van afdelingen waar patiënten behandeld werden in zowel palliatieve als curatieve trajecten. Als belangrijkste in twee sessies van 90-120 minuten

te scholen competenties werden genoemd: het onderkennen van spirituele behoeften, doorverwijzen, zelfreflectie, en een open houding tegenover de spiritualiteit van de patiënt.

Systematisch literatuuronderzoek

Hoofdstuk 3 biedt een systematisch overzicht van de literatuur betreffende trainingmethoden in spirituele zorg en de effecten daarvan op patiënten en professionals in de gezondheidszorg en wordt een verscheidenheid aan voornamelijk competentiegerichte uitkomstmaten beschreven. Op basis van de kwalitatieve synthese is de conclusie dat verbetering van spirituele zorg, of het implementeren van een standaard daarvoor, optimaal is indien het opgezet is als een project voor kwaliteitsverbetering.

Interventie, deelnemers en resultaten

De interventie 'training in spirituele zorg' werd tussen februari 2014 en februari 2015 negen keer gegeven in zeven ziekenhuizen; 374 professionele zorgverleners werden groepsgewijs ingeroosterd voor een of twee lessen tijdens werktijden, gegeven door aan de afdeling verbonden en getrainde geestelijk verzorgers, met behulp van een gestandaardiseerde presentatie en enkele standaard werkvormen. In overeenstemming met de actie-onderzoek-opzet varieerde de training per ziekenhuis, binnen de vereisten van het afgesproken onderzoeksprotocol als beschreven in hoofdstuk 4.

Het doel van de interventie was: a) het verbeteren van de aandacht bij professionele zorgverleners voor spirituele behoeften van patiënten, (niet één specifiek instrument voor spirituele interventies te implementeren, maar gericht op de verbetering van de competenties van artsen en verpleegkundigen op deze dimensie), b) het verbeteren van de kwaliteit van zorg zoals ervaren door palliatieve patiënten op de afdelingen waar de training werd gegeven, en c) het vergaren van praktische kennis over de belemmeringen en kritische succesfactoren bij het trainen van spirituele zorg en de implementatie van de Richtlijn. De te trainen kernvaardigheden waren:

het herkennen en verkennen van spirituele behoeften, het begeleiden van patiënten (passend bij de eigen professionele rol), en doorverwijzen in geval van crisis. Multidisciplinaire scholing was verplicht.

De ziekenhuizen werden geselecteerd op basis van drie inclusie criteria: lidmaatschap van de *Stichting Topklinische Ziekenhuizen*, actief bezig zijn met het verbeteren van palliatieve zorg via een gespecialiseerd consultatieteam of de implementatie van programma's voor het verbeteren van de kwaliteit van palliatieve zorg, en de aanwezigheid van een betrokken, gekwalificeerde geestelijk verzorger gespecialiseerd in spirituele zorg binnen palliatieve zorg.

De interventie en controle-afdelingen werden geselecteerd door de betrokken geestelijk verzorgers, als de co-onderzoekers in elk ziekenhuis; als docenten waren de geestelijk verzorgers verantwoordelijk voor de training in spirituele zorg binnen palliatieve zorg. Als selectiecriteria voor de interventie-afdelingen golden dat de geestelijk verzorger daar aan verbonden moest zijn, dat de afdeling bereid was om het behandelteam de mogelijkheid te bieden en aan te moedigen om de training te volgen, en dat interviews met patiënten gehouden mochten worden op de afdeling.

De voor de afdeling verantwoordelijke arts werd gevraagd de medische situatie te beschrijven en de indicaties voor ondersteunende of palliatieve zorg in te schatten. Aan de artsen werd gevraagd 'Zou u verrast zijn als deze patiënt binnen een jaar overleed?'. Als het antwoord nee was werd de patiënt gevraagd mee te doen aan het onderzoek, kreeg hij/zij schriftelijke informatie, en werd na het geven van de toestemmingsverklaring ('informed consent') opgenomen in het onderzoek. De deelnemende patiënten werd gevraagd om de vragenlijst zelfstandig in te vullen; indien nodig werden de vragen aan hun bed voorgelezen door een verpleegkundige gespecialiseerd in palliatieve zorg, of een verpleegkundige van een andere afdeling met extra scholing in palliatieve zorg.

Als co-onderzoekers waren de deelnemende geestelijk verzorgers verantwoordelijk voor de uitvoering van het onderzoek volgens het protocol: het plannen en uitvoeren van de training op de

interventieafdelingen, het betrekken van de deelnemende artsen en verplegers in het onderzoek naar de effecten op barrières en competenties betreffende spirituele zorg, het selecteren van controleafdelingen, en - in samenwerking met de consultatieteams voor palliatieve zorg in het betreffende ziekenhuis - het organiseren van het proces van de selectie van palliatieve patiënten voor het onderzoek naar de effecten op de kwaliteit van de zorg. Om de praktische kennis van de co-onderzoekers in kaart te brengen werden gedurende het project 20 semi-gestructureerde interviews afgenomen: negen interviews in acht ziekenhuizen voorafgaand aan de training (in één ziekenhuis werden twee verschillende proefprojecten uitgevoerd met verschillende geestelijk verzorgers als trainers) tussen 9 december 2013 en 18 maart 2015 (duur 50-85, gemiddeld 55 minuten). De deelnemers kregen de vragen van tevoren toegezonden.

Resultaten

In de hoofdstukken 5 en 6 worden de effecten van de training spirituele zorg beschreven op de kwaliteit van zorg zoals die door patiënten is ervaren (patient reported outcomes), en op de competenties van geschoolde artsen en verpleegkundigen. De resultaten geven aan dat het met een korte scholing het mogelijk is om de belemmeringen voor spirituele zorg te verminderen, de competenties van artsen en verplegers op dit gebied te verbeteren, en de kwaliteit van zorg zoals ervaren door palliatieve patiënten te verhogen. De Spiritual Care Competence Scale (SCCS) bleek toepasbaar voor het meten van het effect van de scholing spirituele zorg bij multidisciplinaire groepen, de SCCS stelde in staat verschillen zowel door de tijd als tussen artsen en verpleegkundigen te meten.

De resultaten toonden een blijvend effect (na 1 en 6 maanden) bij verpleegkundigen maar onvoldoende impact van de training op artsen, een verschil dat verklaard kan worden uit het feit dat de geestelijke verzorgers als trainers meer vertrouwd zijn met de praktijk van de verpleegkundigen dan met het dagelijks werk van artsen,

en dus hun trainingsmethoden minder goed konden afstemmen op de behoeften van artsen.

In hoofdstuk 7 worden de resultaten beschreven van het kwalitatieve onderzoek, op basis van de semi-gestructureerde interviews met de geestelijke verzorgers, naar de vraag: Hoe kunnen geestelijk verzorgers in de klinische praktijk scholing in spirituele zorg aan primaire zorgverleners concretiseren? De conclusie luidt dat de richtlijn spirituele zorg in ziekenhuizen effectief kan worden geïmplementeerd als deze is gebaseerd op twee lessen van elk 90 minuten (groepsgrootte 8-20), in multidisciplinaire groepen, waarbij in de tweede sessie de gedetailleerde casusbeschrijvingen van de deelnemers aan bod komen als voorbeelden en oefenmateriaal voor de aangeleerde modellen, instrumenten en handvatten.

Monodisciplinaire training lijkt praktischer of gemakkelijker te organiseren, en aan te passen aan specifieke leerbehoeften. Echter, als voordelen van multidisciplinaire scholing meldden de co-onderzoekers dat de kwaliteit van de scholing aan kwaliteit won als zowel artsen als verpleegkundigen deelnamen aan een training, omdat dit bijdroeg aan het wegnemen van wederzijdse stereotypen en het mogelijkheden schiep om de werkprocessen aan te passen. Multidisciplinaire training biedt het team de gelegenheid tot het maken van gezamenlijke keuzes betreffende de implementatie van specifieke modellen/instrumenten en handvatten voor verkenning, voor multidisciplinaire communicatie in (elektronische) patiëntendossiers en verwijzing naar geestelijke verzorging of andere disciplines.

De resultaten geven aan dat bij de ontwikkeling van scholing spirituele zorg meer rekening moet worden gehouden met de scholingsbehoeften van artsen., Om dat te kunnen doen moeten geestelijk verzorgers meer vertrouwd raken met de dagelijkse praktijk van het werk van de arts. Overigens is er nauwelijks reflectie op de eigen spiritualiteit of confrontatie met levenseinde zorg mogelijk binnen de beperkte tijd die in ziekenhuizen aan de scholing van artsen en verpleegkundigen kan worden besteed.

Het kwalitatieve onderzoek wijst op vier hoofdeffecten bij de geestelijk verzorgers: a) nieuwe kennis over en ervaring met onderzoek in de vorm van een actie-onderzoek, b) beter inzicht in de beroepspraktijk van verpleegkundigen en artsen, c) hernieuwd zelfbewustzijn van de geestelijk verzorger, d) een beter profiel van geestelijke verzorging in de deelnemende ziekenhuizen.

De co-onderzoekers meldden een grote variatie in bezetting, opzet, structuur en financiële ondersteuning van de (consultatie-)teams voor palliatieve zorg in de deelnemende ziekenhuizen. Vier van de acht waren in staat een vruchtbare samenwerking met deze teams op te bouwen bij het uitvoeren van het onderzoek volgens het protocol. De co-onderzoekers troffen een hoofdzakelijk curatieve instelling bij de zorgverleners in hun ziekenhuizen, gecombineerd met een gebrek aan kennis van palliatieve zorg, wat resulteert in het vaak niet onderkennen dat een patiënt zich in de palliatieve of zelfs het begin van de stervensfase bevond. In deze ziekenhuizen werden geen instrumenten of handvatten voor spirituele zorg gebruikt, en slechts drie van de acht co-onderzoekers meldden het gebruik van de 'lastmeter' om psychosociale nood te detecteren. We concluderen dat tot op heden instrumenten of handvatten voor spirituele zorg nog niet structureel in de Nederlandse gezondheidszorg zijn geïmplementeerd.

Conclusie

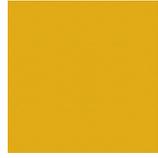
In hoofdstuk 8 wordt het antwoord op de hoofdvraag van het onderzoek gegeven. De conclusie is dat kortlopende trainingsprogramma's voor spirituele zorg in de palliatieve zorg effectief zijn voor wat betreft het verbeteren van de kwaliteit van zorg in ziekenhuizen, het verminderen van belemmeringen voor spirituele zorg en positieve effecten heeft op de competenties van zorgverleners ten aanzien van spirituele zorg, op het multidisciplinair werken, en op het profiel van de geestelijk verzorgers.

Naar onze mening zijn de volgende drie factoren cruciaal voor een succesvolle implementatie van de Richtlijn Spirituele Zorg:

Ten eerste, op nationaal niveau de beschikbaarheid van een e-learning module of interactieve leeromgeving voor de theorie van spirituele zorg, op basis van de Richtlijn.

Ten tweede, op plaatselijk niveau de beschikbaarheid van minstens één (liefst twee, afhankelijk van de bezetting van het team) betrokken geestelijk verzorger(s) met aanvullende scholing in spirituele zorg en een duidelijk mandaat van het medisch en verpleegkundig management en van de directie aan de geestelijke verzorging, met betrekking tot de verantwoordelijkheid voor het spiritueel zorgbeleid in de organisatie.

Ten derde, ruimte in het opleidingsplan van ziekenhuizen voor verpleegafdelingen waar patiënten worden behandeld in zowel curatieve als palliatieve trajecten. De resultaten geven aan dat met twee sessies van elk 90 minuten (of drie van 60 minuten) een significante verbetering van de kwaliteit van zorg mag worden verwacht. Aangezien het onderzoek ook aan het licht bracht dat de kennis bij geestelijk verzorgers van de dagelijkse praktijk van artsen te beperkt is om de scholing een duidelijk effect te laten hebben, adviseren wij om deze trainingen in tweetallen te geven: door een geestelijk verzorger samen met een betrokken arts of verpleegkundige.



Dankwoord en Curriculum Vitae



Dankwoord

Dit proefschrift is voortgekomen uit de wens om een goede geestelijk verzorger te worden en te blijven. Het vak verandert in hoog tempo. Toen ik, met mijn predikants- en jeugdwerkervaring, vlak voor de eeuwwisseling de context van de gezondheidszorg verkende als beginnend geestelijk verzorger hoorde wetenschappelijk onderzoek daar nauwelijks bij. De collega's die mij introduceerden in het vakgebied en ik vonden het vanzelfsprekend dat we academisch geschoold waren, maar dat van ons verwacht mocht worden dat wetenschappelijk onderzoek een onderdeel van onze dagelijkse praktijk zou zijn, kwam toen niet in ons op. Anneke Haijntink was een locatiemanager bij Noorderbreedte ouderenzorg en zij was de eerste die mij er van bewust maakte hoe onlogisch dat eigenlijk was. Anneke was één van de vele collega's, managers, artsen, verpleegkundigen, verzorgenden, paramedici, vrijwilligers met wie ik heb mogen samenwerken en die mij mede hebben gevormd als geestelijk verzorger. Zonder hun inspiratie en zonder het vertrouwen en de levenslessen van de bewoners, cliënten, patiënten en hun naasten voor wie ik een tijdelijke reisgezel mocht zijn, zou ik niet de geestelijk verzorger zijn die ik geworden ben.

'Met praktijkgericht onderzoek in de palliatieve zorg kunnen we de kwaliteit van zorg in onze organisatie verbeteren', die boodschap probeerde ik te slijten bij Martin Kirchner, destijds regiomanager in Noorderbreedte. 'Goed idee, kom maar met een voorstel, ga maar doen.', was de reactie die ik niet verwacht had, maar mij voor het eerst liet nadenken over de mogelijkheid om wetenschappelijk onderzoek een onderdeel van mijn werk te laten zijn. Het bleek toen niet haalbaar, een paar jaar later mocht ik jouw relatie met Marjan Lieuwes, één van de bovengenoemde inspirerende collega's inzegenen. Weet Martin, dat jij met jouw uitdaging om zelf onderzoek te gaan doen mij gezegend hebt.

Mijn collega geestelijk verzorgers in de vakgroep geestelijke verzorging in de ouderenzorg, aan wie ik schatplichtig ben als het gaat om mijn eerste vorming als geestelijk verzorger, noemde ik hierboven al als groep, met name wil ik noemen: Gerda van Brug mijn eerste collega in Nieuw Mellens, Grietje-Willy van Bochove-Wildschut mijn tweede collega en veilig maatje op die basisplek, Gerda Wiersma, Fons van der Meulen, Ben van Remmerden. Ieder op haar en zijn eigen manier met een passie voor mensen en een passie voor het vak.

Er ontstonden verschillende werkgroepen palliatieve zorg met verschillende taken, maar er kwam in de regio pas echt beweging toen Wil Hoek netwerkcoördinator werd en de ervaring die ze in alle netwerken palliatieve zorg in Groningen en Fryslân opdeed ook met ons deelde. Wil, jij ging als het ware met mij mee van de ouderenzorg naar de ziekenhuiszorg, met al jouw ervaring van hoe jij werkprocessen en bestuursprocessen aan elkaar wist te knopen. Want in het Medisch Centrum Leeuwarden (MCL) bleek de kennismaking met directeur Maria Schonewille achteraf cruciaal voor de bijdrage die ik met dit proefschrift heb kunnen leveren. Toen Maria hoorde dat ik betrokken was geweest bij verschillende projecten rond palliatieve zorg, was zij het die mij direct vroeg om samen met Andrea van Zijl van het Oncologisch Centrum de palliatieve zorg in het MCL te gaan ontwikkelen. Dank, dus voor de kansen die jij mij daarmee geboden hebt en voor de manier waarop jij mijn betrokken opdrachtgever bleef en mij bijstuurde later in mijn positie als projectleider. Ik heb veel van je geleerd, jij hebt veel betekend voor het MCL.

Het was het idee van Ben om mij helemaal naar het MCL te halen toen bleek dat de vraag om de palliatieve zorg in het ziekenhuis te verbeteren niet iets voor 'een taak erbij' bleek, maar een echte projectleider vereiste. Samen met Andrea en Wil en internist oncoloog Edward Fiets vormden we de kern van een groep mensen die zich sterk wilde maken voor de verbetering van de palliatieve zorg in het ziekenhuis. Vanaf 2008 werd Nynke Planting mijn maatje in het

pionieren en de opbouw van het Palliatief Advies Team (PAT), jij werd het gezicht van het PAT op de werkvloer. Eerst alleen, met een paar uurtjes, later samen met Annette Keuning, inmiddels met Ineke Wijnja en Sibbelina Visser. We hebben successen en frustraties gedeeld de afgelopen jaren, het gaat misschien niet zo snel meer als in het begin, maar we staan er als PAT veel sterker voor dan enkele jaren geleden. Edward heeft gezelschap gekregen van pijnspecialist Anneke Krul, longarts oncoloog Femke van Vollenhove en klinisch geriater Marjolijn Blaauw. Nog steeds kunnen we een beroep doen op de deskundigheid van Christa Rolf, de Friese huisarts consulent palliatieve zorg, specialist ouderengeneeskunde Daan Kruizinga en thuiszorgverpleegkundigen Janet Visser en Roelant Muis. Het was een voorrecht om als projectleider aan de ontwikkeling van dit team te mogen bijdragen en het als een vaste structuur over te kunnen dragen aan Rob van Boxtel.

Kort na de start als projectleider vonden de ontmoetingen plaats die ik mijn proloog beschreven heb in 2006. De ontdekking samen met Marijke Wulp dat er in het eerste Richtlijnenboek voor de praktijk van de palliatieve zorg geen hoofdstuk aan de spirituele dimensie was gewijd. Marijke, jij hielp me op weg om de vragen die ik vanuit de praktijk had aan de juiste instanties en personen te stellen. Mijn soms ongeremde enthousiasme wist jij aan te vullen met jouw kennis van landelijke structuren en strategisch inzicht. Je bracht me in contact met Carolina van den Akker van het Integraal Kankercentrum Noord Oost (IKNO nu: IKNL), die het belang zag om de spirituele dimensie te gaan onderscheiden van psychosociale zorg en hielp om de eerste Masterclass te organiseren. De cursus Teaching the Teachers in de palliatieve zorg werd gegeven door Ruthmarijke Smeding en Frans Baar. Ruthmarijke, zonder jou was de masterclass er nooit gekomen. Ik heb veel te danken aan jouw expertise, gedrevenheid, steun en advies. Frans, zonder jou was de masterclass er inmiddels niet meer geweest. Jouw toewijding en tomeloze inzet vanuit de Leerhuizen Palliatieve Zorg Rotterdam hebben het mogelijk gemaakt dat het van een monodisciplinaire

scholing voor geestelijk verzorgers (1.0) kon uitgroeien tot een multidisciplinaire scholing voor alle bij de palliatieve zorg betrokken disciplines (2.0). En we zijn nog niet klaar, we zullen op weg gaan naar de masterclass 3.0. Dank voor jullie beider vriendschap.

De Masterclass spiritualiteit (en geestelijke verzorging) in de palliatieve zorg bracht me in contact met zoveel inspirerende mensen, docenten en collega's, het is ondoenlijk om ze allemaal te noemen. Erhard Weiher, lieber Freund, du bist für mich und viele Kollegen und Kolleginnen wirklich der Meister in unserem Masterclass. Marinus van den Berg, pionier in ons vakgebied als het gaat om de aandacht voor zingeving en spiritualiteit in de palliatieve zorg. Saskia Teunissen, Yvette van der Linden, Martin Walton. Carlo Legget, vanaf de eerste Masterclass hernieuwde onze vriendschap zich en bleek onze samenwerking ons naar onverwachte plekken te kunnen brengen. Samen met Marijke begonnen we ons inspirerende avontuur in de European Association for Palliative Care. Mij kennende vroeg je mij als vriend ernstig of ik zeker wist dat ik dat wilde: promotieonderzoek, of dat wel bij mij paste? Wij ontdekten samen dat de relatie hoogleraar - promovendus, uitstekend in onze vriendschap bleek te passen. Hetty Zock, de eerste masterclass in 2007 kon je geen bijdrage leveren omdat het samenviel met jouw eigen oratie, in de tweede masterclass datzelfde jaar gingen we de discussie aan: zingeving of spiritualiteit. Twee jaar later was je bereid om mijn promotor te worden: je moet geweten hebben hoeveel geduld je met me zou moeten hebben voordat mijn enthousiaste breedsprakigheid zich zou kunnen voegen in het nauwkeurige discours van wetenschappelijk onderzoek. Dank voor jouw geduld, jouw snelle reacties op al mijn stukken en nauwgezette feedback. Dank ook voor jouw vriendschap.

De start van het onderzoek werd mogelijk gemaakt door een subsidie van het IKNL. Mijn begeleidingscommissie breidde zich uit met Kris Vissers: gedreven pijnspecialist en hoogleraar palliatieve zorg. Kris, je noemde 4 contra indicaties om met mij een promotietraject in te gaan, maar je stelde jouw toewijding en jouw vriend-

schap er tegenover. Je hebt mij uitgedaagd om de brug te slaan naar de taal van de medische wetenschap, vanuit de diepe overtuiging dat wij het aan onze patiënten verplicht zijn om de samenwerking tussen artsen en geestelijk verzorgers te verbeteren. Ik dank je voor jouw tomeloze energie en het vertrouwen dat je in mij stelde. Jan Willem Uringa werd aangenomen om een deel van mijn klinische taken over te nemen en bleek niet alleen talentvolle collega en onderzoeker, maar ook een maatje, die op dat moment beter overzag waar ik mee bezig was dan ikzelf. Als leidinggevende kwam je in de gelegenheid om mij daarbij op de rails te houden. Daar ben ik je heel dankbaar voor, zonder goede structuur en ondersteuning had ik absoluut kunnen stranden in dit avontuur.

Jelle Prins maakte de begeleidingscommissie compleet, als eerste decaan van de MCL Academie gaf je aan ‘een praktische ondersteuningsstructuur voor onderzoekers’ te willen opbouwen. Ik vond het prachtig klinken, maar je hebt het waar gemaakt! Als hoofdaanvrager bij de Fondswerving, ons reguliere voortgangsoverleg en in de facilitering. Die facilitering kwam via de kanjers van het Kennis- en Informatie Centrum: Ingeborg van Dusseldorp, informatiespecialist die een stevig fundament legde voor onze systematische review. Olga van Dijk, Alies van der Wal en Hellma Zoutsma, ‘artikel niet te vinden’ bestaat niet voor jullie, nooit deed ik tevergeefs een beroep op jullie! Via Nic Veeger, epidemioloog, de man die geduldig uitlegde dat mijn protocol nog gedetailleerder uitgewerkt moest worden voordat ik mocht beginnen. Nic, de man die de grootste database in mijn onderzoek analyseerbaar moest maken en mij bij de uiteindelijke analyses hielp. Ik had nooit gedacht dat ik als geestelijk verzorger ooit zou zeggen ‘dat er een zekere schoonheid schuilt in een kloppende kwantitatieve database’. Dank voor dat inzicht en jouw geduld. Via Foppe Jorna, mijn diep Friese research assistent, die de structuur voor de databases bouwde, de patiënten gegevens analyseerde met SPSS en de eerste hoopvolle resultaten liet zien. Via ook Richtsje Andela, die de analyse overnam toen ik zonder assistent verder moest, en mij vlot trok toen ik vastgelopen was. En

via Lammie de Vries, die de vragenlijsten voor zorgverleners digitaliseerde, toestuurde naar die 387 artsen en verpleegkundigen en na meerdere herinneringen alle resultaten verwerkte per meting en per ziekenhuis.

Marieke de Groot, steun en toeverlaat bij drie artikelen, met jouw enthousiasme, inhoudelijke kennis over spiritualiteit in de palliatieve zorg en onderzoekservaring, wist je grote hobbels weer tot normale proporties terug te brengen. Voordat ik bij jou praktisch terecht kon was je al één van de vrienden en vriendinnen die ik op de diverse nationale congressen en Europese congressen palliatieve zorg leerde kennen. Ze zijn wederom niet allemaal te noemen, drie dan: Saskia Teunissen en Jaap Gootjes, die mij vanaf het moment dat ik aangaf aan dit traject te beginnen met grote betrokkenheid kritisch ondersteunden en Jet van Esch, die net als ik gewoon wil dat de zorg beter wordt en niet voor onderzoek geboren meent te zijn. Zet hem op Jet!

Twee masterstudenten geestelijke verzorging van de RUG hebben als mede-onderzoekers bijgedragen aan dit project: Roland Pennaertz die de eerste systematische review deed en Susanne Lub, die de analyse van de eerste ronde interviews voor haar rekening nam. Dank voor al het werk en jullie inzet, ik heb van jullie geleerd. En een masterstudent geneeskunde meldde zich aan, welke geestelijk verzorger heeft zo'n voorrecht? Merijn van der Werf, ooit collega medisch maatschappelijk werker in het MCL, inmiddels bijna huisarts, 'wetenschap hoort er nu eenmaal bij' verzochtte jij tijdens jouw stage. Het was voor mij een wezenlijke aanvulling om samen onderzoek te doen met een dokter in opleiding en het is een groot genoegen om samen met jou de masterclass te mogen leiden.

Sietske Blok, Suzanne Landman, Taeke Hoekstra, Mirjam van 't Hul en onze eigen kinderen Daan, Roel en Anna waren degenen die de papieren vragenlijsten verwerkten tot cijfertjes in analyseerbare databases of de interviews met de geestelijk verzorgers uittypten.

De geestelijk verzorgers, de co-researchers, de pilotdocenten, jullie waren bereid om je te laten meeslepen in dit veeleisende avontuur waarbij we onze praktijk en onderzoek samen brachten. Moesten langs wetenschapscommissies, afdelingen, managers, jouw eigen invulling geven aan de scholing, data verzamelen bij zorgverleners en patiënten. In het laatste resultaat artikel dat geaccepteerd is bij het Journal of Health Care Chaplaincy schreef ik over jullie: ‘Because of the explorative character of this study our results are indicative, and generate rather than confirm hypotheses. Finally, the sample of chaplains is subject to selection bias. The inclusion procedure selected those chaplaincy teams that were willing to work on the implementation of the SC guideline, expecting it to create opportunities to improve patient care and chaplains’ professional profiles. Therefore, this group of chaplains probably represents a group of pioneers.’ Als onderzoeker toon je met zulke zinnen je bescheidenheid, maar als collega wil ik jullie bedanken en eren met dat laatste woord: pioniers, want dat zijn jullie! Met ere genoemd: René van Doremalen, Bert de Haar, Desiree van der Hijden, Annemieke Kelder, Dick Luijmes, Rinske Nijendijk, Nienke Overvliet, Ruud Roefs, Simone Visser, Ruurd van de Water en Henri Wolterink.

En via hen de verpleegkundigen die de vragenlijsten bij de patiënten hebben afgenomen, niet al jullie namen zijn mij bekend, maar ik noem onze eigen palliatief verpleegkundig consulenten: Nynke Planting en Ineke Wijnja.

Ik dank de patiënten, en hun familieleden die bereid waren hun kostbare energie in hun laatste levensfase te besteden aan een vragenlijst over hun aandoening(en), symptomen en spirituele interesses, attitudes en behoeften. Velen van u gaven aan dat de vragenlijst aanleiding gaf tot een diepgaander reflectie op wat belangrijk voor u is. Enkelen gaven aan op de hoogte gebracht te willen worden van de resultaten. Ik ga mijn uiterste best doen of ik u of uw familie kan achterhalen.

Dank ook aan alle zorgverleners die gemotiveerd waren om zich te laten scholen en de vragenlijsten in te vullen, dank aan alle

managers die dit project meegedragen hebben en zonder enige vergoeding de tijd van hun team ter beschikking hebben gesteld voor de scholing.

Dank ook aan mijn collega's van de staf geestelijk verzorging in het MCL, ik heb jullie hierboven al genoemd, behalve onze jongste aanwinst Taeke, en nostra segretaria sempre felice Eline Alkema, voor het meewerken, voor de enthousiaste belangstelling, voor jullie geduld, voor alles wat jullie moeste opvangen als ik weer eens aan het 'buiten spelen' was. Dit is klaar, er komt mogelijk meer rust in de tent.

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Bijna tot slot, dank ook aan mijn sparringpartners tijdens de proefpromotie: mijn paranyfen Marijke Wulp en Jan Willem Uringa, jullie rol in dit traject is hierboven al beschreven. Verder Eva Ouwehand, vakgenote, promovenda, kloosterzuster tijdens onze schrijfweek in Doetinchem, zet hem op! En de overige promovende sparringpartners: Nico van der Leer, Charlotte Gaasterland, Everlien de Graaf en Akke-Nynke van der Meer.

Dan, mijn thuisbasis. Daan, ik heb genoten van jouw hulp bij het voorbereiden van de presentaties van de kwantitatieve resultaten, zonder jouw hulp had ik de prijs voor het beste wetenschappelijk onderzoek van 2015 in het MCL niet gewonnen. Dat geldt ook

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Dit onderzoek is in 2014 onderscheiden met de eerste Onderzoeksbijdrage van de Vereniging Geestelijk VerZorgers en in 2015 met de Auletiusprijs voor het beste wetenschappelijk onderzoek in 2015 van het Medisch Centrum Leeuwarden.

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Curriculum vitae

Jacob (Joep) van de Geer was born on 13 July 1959 in Zaandam, Netherlands.

After his secondary education at the 'Reformatorisch college Blaise Pascal' in Zaandam, he obtained his bachelor degree in theology at Utrecht University in 1985, and his master of divinity in 1988 at the Seminary of the Alliance of Free Evangelical Churches (Bond van Vrije Evangelische Gemeenten) in the Netherlands, affiliated with the Theological Faculty of Utrecht University.

Within the Alliance he worked as a minister in the Free Evangelical Congregation in Franeker between 1990 and 1998 and combined this work as a national trainer in the Alliance for youth chaplaincy between 1993 and 1999.

From 1990 he worked as a health care chaplain for psychogeriatric and chronic somatic patients, in ambulatory elderly care and nursing homes in and around Leeuwarden. From 2004 he has been working as health care chaplain at the Medical Centre Leeuwarden, where he was project manager for palliative care from 2005 until 2015.

In 2007 Joep van de Geer started the 'Masterclass on spirituality and health care chaplaincy in palliative care' which from 2012 was continued as a multidisciplinary training programme under the name 'Masterclass on spirituality in palliative care'.

Van de Geer is co-chair of the Taskforce on Spiritual Care of the European Association for Palliative Care, which he initiated in 2009 together with Carlo Leget and Marijke Wulp.

