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## Learning spiritual care in Dutch hospitals

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# 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 20<sup>th</sup> 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.’

		<b>Doctors and nurses</b>	<b>Medical social workers, psychologists</b>	<b>Health care chaplains</b>	
	<i>Primary focus, access and frame of reference</i>	<i>Somatic</i>	<i>Psychosocial</i>	<i>Spiritual</i>	
<b>A</b>	<b>Attention</b> <i>(always)</i>	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening	Listening, supporting, recognizing, screening, interpreting	Representing and connecting
<b>B</b>	<b>Counselling</b> <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	
<b>C</b>	<b>Crisis intervention</b> <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.'<sup>(32)</sup> 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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