

# Spirituality in healthcare

Identifying, exploring and integrating into care provision  
what matters most to a patient with advanced illness

Jacqueline van Meurs





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Jacqueline Maria Josepha van Meurs

## **Colophon**

The work presented in this thesis was carried out at the Radboud university medical center, department of Anesthesiology, Pain and Palliative Medicine

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*Man is not destroyed by suffering;  
he is destroyed by suffering without meaning*

**Victor Emil Frankl**  
(freely quoted)

# Table of contents

Prologue		13
Chapter 1	General introduction	15
<b>PART I</b>	<b>Current practice of nurses and physicians in identifying and exploring the spiritual dimension of patients with advanced cancer</b>	<b>29</b>
Chapter 2	Nurses exploring the spirituality of their patients with cancer: participant observation on a medical oncology ward	31
Chapter 3	Oncologist responses to advanced cancer patients' lived illness experiences and effects: an applied conversation analysis study	49
<b>PART II</b>	<b>Increasing the competence of nurses and physicians in identifying and exploring the spiritual dimension of patients with advanced illness</b>	<b>69</b>
Chapter 4	Identifying, exploring and integrating the spiritual dimension in proactive care planning: a mixed methods evaluation of a communication training intervention for multidisciplinary palliative care teams	71
Chapter 5	Effectiveness of meaning-centred coaching on the job of oncology nurses on spiritual care competences: a participatory action research approach	97
<b>PART III</b>	<b>The role of spiritual caregivers in increasing the integration of spiritual care by healthcare providers</b>	<b>123</b>
Chapter 6	Role-perceptions of Dutch spiritual caregivers in implementing multidisciplinary spiritual care: A national survey	125

Chapter 7	General Conclusions & Discussion. Recommendations for clinical practice, education, research, policy makersand scientific organisations	149
Chapter 8	Summary	166
	Nederlandse Samenvatting	170
	Data management	175
	Dankwoord	176
	Curriculum vitae	180
	Publication list	184
	PhD Portfolio	186



## Prologue: what this patient is most concerned about...

In 2010, I started working as a spiritual care consultant within the palliative care team of the hospital where I'm employed. One afternoon, I had an appointment with one of the physicians on this team. On entering his room, he was making notes in the electronic medical record (EMR) and said: "Do you know what this patient is most concerned about? That he no longer can drive his caravan to the Cevennes in France. All my colleagues kind of laughed that I noted this as his main concern. But this is exactly it!"

I was positively impressed that a physician gave the meaning of being ill such a prominent place in his clinical management and subsequently in the EMR, so that the whole team was aware of this important observation.

When I expressed my surprise to this physician, he then continued: "Many years ago, when my father learnt that I wanted to become a doctor, he said to me: 'Son, the most important tool a doctor has is a chair to sit with his patient.' That's what he said: a chair! And he even was a surgeon!" In the years after, he had learned for himself that patients feel more openness to tell what is on their minds when a physician sits down for a moment rather than remaining standing by the bed of a patient and asking: 'How are you today?'

Attention to what matters most to a patient was integrated into his daily care delivery. This physician had put me on a trail. Would it be possible to extend this sensitiveness to the spiritual dimension to other health care providers in the clinic or outpatient clinics? And what could be my role?

It would be another three years before I started coaching health care providers in exploring the spiritual dimension through the Mount Vernon Cancer Network's three questions, the first of which is, 'How do you make sense of what is happening to you?'.

Since 2010, I worked with many healthcare providers on integrated attention to 'spiritual care' in daily healthcare provision, especially for critically ill and palliative patients. Four years of research related to this dissertation have substantiated and deepened what has already emerged from practice: caring for how patients make sense of what is happening to them, or paying attention to the spiritual dimension of critically ill and palliative patients, is not only possible but desirable for both patients and their caregivers. Furthermore, it is also found possible to provide this care both proactively and integrated into daily care delivery.



# CHAPTER

General introduction

# 1

# 1. Spirituality in healthcare

## 1.1. Towards a contemporary understanding of spirituality in healthcare

Developments in evidence-based medicine in the 20th century brought about a tremendous development in the diagnosis and treatment of patients, but also a marginalization of what once was the foundation of health care: spirituality. [1] However, in recent decades, notably from within the care of seriously ill patients, there has been significantly more attention to spirituality in healthcare. In 1998, the WHO mentioned spirituality as an important dimension of quality of life. [2] The first article on extending the biopsychosocial model into a biopsychosocial-spiritual model of care was published in 2002. [3] In that same year, the WHO defined palliative care as care on four dimensions: the somatic, psychological, social and the spiritual. [4] Thus, the WHO emphasised the importance of integrating also the spiritual dimension into the whole of healthcare provision, at least for the seriously ill or palliative patients. A similar impetus was also given in the United States in 2009 at a conference on improving the quality of spiritual care as a dimension on palliative care, referred to as the 'Consensus Conference'. [5] The participants not only affirmed the importance of an interdisciplinary approach, but also reached consensus on the definition of spirituality in healthcare as *'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.'* [5]. Today, spirituality in healthcare is referred to as multidimensional and consisting of existential challenges, value-based considerations and attitudes, and religious considerations and foundations. [6]

Although the word 'spiritual' is increasingly used in the medical field, it is still often associated by healthcare providers with 'heavy' or even a 'weasel word'. [7-9] Not surprising, given the fact that medical dictionary definitions, for example, are: "An awareness of the metaphysical, the religious, or the sublime", [10] and "something that in ecclesiastical law belongs to the church or to a cleric as such" or "sensitivity or attachment to religious values". [11] Also, the spiritual dimension is referred to as 'being hidden because it underlies the physical, psychological and social sphere and is not always directly visible, accessible or talked about'. [12] (p. 6)

## 2. The role of nurses, physicians & spiritual caregivers in providing spiritual care

Spiritual care has been much underreported in literature and in the care provided by physicians and nurses. However, developments have been ongoing. When it



comes to the care of seriously ill patients, reference is often made to Dame Cicely Saunders (1918 – 2005), nurse, social worker and physician and founder of modern palliative care. [13] [14] She also founded the concept of ‘total pain’, or the approach to pain that encompasses all elements of a person’s physical, psychological, social, spiritual, and practical struggles’. [15] With regard to spiritual care, Saunders realized that both care provider and patient more and more live in secularized societies and often have no (longer) language at their disposal for the meaning of illness, life, dying and death. Therefore, she stresses the importance of “concerned listening” and, as a professional, providing room for the search for meaning, so that: “patients and families can reach out in trust towards what they see as true and find courage and acceptance of what is happening to them.” [13]

### **2.1. Nurses and their role in providing spiritual care**

As a discipline, nurses in particular have repeatedly pointed out the importance of paying attention to psychosocial and spiritual care or to a holistic approach to patient care, in addition to just somatic care. [16] (p. 211 - 217) [17] [18] [19] Already in 2008, an instrument (the Spiritual Care Competence Scale, or SCCS), was validated to assess nurses’ competences in providing spiritual care. [20] Nurses often consider themselves (somewhat) competent in terms of this care. [21] [22] However, it is still largely unknown whether they have the skills and do integrate this into their daily work. Also not known is how patients seek attention to spiritual issues in their contacts with nurses. This was the situation when I started the studies for this thesis. [23]

### **2.3. Physicians and their role in providing spiritual care**

Attention to what concerns the patient most is also important in the physician-patient relationship. Consequently, statement documents of international medical societies include the importance of spiritual care. [24] [25] Many physicians, like nurses, are willing to provide spiritual care, but also mention reluctance and obstacles to this such as lack of time, insufficient training or that it is not part of their job. [21] [8] They often tend to associate spiritual care with religion and therefore consider it to have no role within medicine. [7] [16] (p. 177) Moreover, they assume patients will bring up spiritual issues if they wish, not realizing that in a clinical setting many patients don’t feel free to say what is on their mind. [26] [27] [28] [29] Patients find it valuable that physicians pay attention to what matters most to them. [30] [31] [32] [33] [34] [35] [36] At the moment I started the research for my thesis, which was inspired on the work of Joep van de Geer [37], it was hardly explored whether and how physicians during their daily healthcare provision pay attention to spiritual issues of their patients.

### **2.4. Spiritual caregivers and their role in providing spiritual care**

While nurses and physicians are generalists, hospital chaplains or spiritual caregivers

are experts in providing spiritual care. [5] [38] [39] [40] Most healthcare institutions have a spiritual care (or chaplaincy) service to meet spiritual support for patients and their proxies. [41] Their work is diverse. Often they participate in patient care teams and also undertake work in health care ethics, policy and research, the design and leading of rituals and within education and training. [42] [43] However, spiritual caregivers are often insufficiently visible in their organisations and their contributions are lacking awareness of their colleague caregivers. [39] [44] [45]

Spiritual caregivers sometimes indicate that the spiritual dimension of care is primarily their domain. [46] Moreover, because of their 'duty of confidentiality', which has its origins in the confessional secrecy of clergy, part of the spiritual caregivers are reluctant to share information about patients, even when they are jointly caring for a patient as part of a team. [47] (p. 66-87) Besides, the understanding of the work of spiritual caregivers by other healthcare providers and patients is often limited or strongly associated with religion, end of life care and dying. [48] [41] [49] This limited vision also negatively affects the number of referrals by nurses and physicians to such professionals. [50] [51] [40]

## **2.5. Team collaboration in spiritual care today**

Good care for serious ill and palliative patients requires an interdisciplinary approach. [52] However, when it comes to providing spiritual care within a team, it is often insufficiently clear who should provide this care and in what way. Often, the spiritual caregiver is designated as the primary responsible person. [39]

# **3. Spiritual care in the Netherlands**

## **3.1. Palliative care as the impetus for spiritual care**

The Netherlands is one of the most secularised countries in the world and there is a mostly informal, personal approach to death and dying. [53] [54] [55] [56] Here, spirituality has long been neglected or only received attention in an implicit way in healthcare. [57] However, in the past decades, there has been an increased attention to spiritual care in healthcare, especially regarding seriously ill and/or palliative patients. A national palliative care programme in the late 1990s has been the impetus for its increase; healthcare providers, policymakers, and researchers felt challenged to give spiritual care a prominent place within patient care, education and research. [57] In 2006, two palliative care professors, Zuurmond and Vissers, pointed out the inextricable link between spiritual care and other clinical care, education and research and called to action. [57]

### 3.2. A national guideline for multidisciplinary spiritual care

The productive collaboration of politics and science in improving palliative care also boosted spiritual care practice. This resulted in 2010 in the first national guideline [58] for multidisciplinary spiritual care as part of palliative care, followed in 2018 by the current guideline 'Existential and Spiritual Aspects of Palliative Care', now also translated into English. [12] The in the Netherlands mostly used description and definition of spirituality (within health care) are developed within palliative care (shown in box 1).

#### **Quality Framework for Palliative Care Netherlands (2017)**

*Spirituality plays an important role in how people deal with disease or frailty, how they experience inner peace and acquire insights into what has value in their lives. Confrontation with death and physical, psychological and/or social limitations have an influence on how purpose and meaning are experienced, and often lead to a re-evaluation of one's life story. This may lead to enrichment, but it may also be accompanied by spiritual distress. The time and space needed by an individual to face the reality of the diagnosis and to relate it to what has meaning and value in his life, varies. This process leads some to growth and transformation, others to existential crisis and despair, and most to a combination of both. [59]*

#### **European Association for Palliative Care (EAPC) consensus based definition (2010), also used in the Dutch guideline Existential and Spiritual Aspects of Palliative Care (2018)**

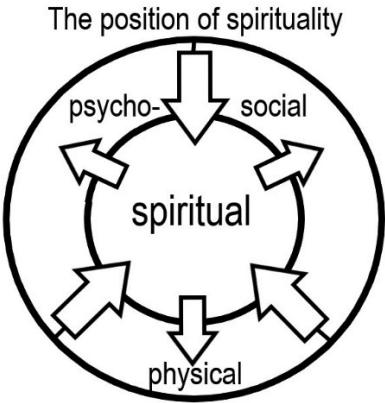
*Spirituality (or: a sense of meaning and purpose) is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. [60]*

#### *BOX 1. Defining spirituality in health care in The Netherlands*

In line with the World Health Organisation (WHO), the Dutch guideline interprets spirituality as a dimension intrinsically related to all humans, and inseparable from other dimensions of health care (Figure 1): 'This figure illustrates that spirituality is a hidden, intimate, unifying 'foundational layer': the personal 'inner perspective' of the physical, psychological and social dimensions of human existence'[12] (p. 6) [61] (p. 55)

While the first guideline was entirely consensus-based, the 2018 guideline also has many references to evidence-based research (p. 69 ff.), and has been authorised by several associations of physicians, nurses and other healthcare providers including the Dutch Association of Spiritual Caregivers (VGVZ) and the Netherlands Patients Federation. (p. 81)

The challenge for healthcare providers and palliative care teams is to implement this guideline in daily care of critically ill and palliative patients. The guideline should also be implemented within education and research.



**Figure 1.** The position of spirituality as reflected in: IKNL “Existential and Spiritual Aspects of Palliative Care. Dutch national guideline.” Version 2.0. (2018)

The guideline proposes an A-B-C model within multidisciplinary care; attention (In Dutch: Aandacht) and accompaniment (in Dutch: Begeleiding) of spiritual issues is expected from each healthcare provider dealing with seriously ill or palliative patients while in spiritual or existential crisis interventions (In Dutch: Crisis) the support of an expert in this care is requested. (Box 2.)

	<i>physician and nurse</i>	<i>Spiritual caregiver</i>
<i>Primary focus</i>	somatic	spiritual
<i>Access and reference frame</i>		
<b>A. Attention</b> <i>always</i>	identify, listen, support, refer	identify, listen, explore and interpret
<b>B. Accompaniment</b> <i>with patient’s permission</i>	identify, explore/assess, refer	identify, explore, interpret/ appraise, counsel & follow (up) patient’s search process
<b>C. Crisis intervention</b> <i>if indicated</i>	identify, refer	identify, explore, interpret/ appraise, treat and/or referral

**BOX 2.** ABC model. Adapted from: IKNL “Existential and Spiritual Aspects of Palliative Care. Dutch national guideline.” Version 2.0. (2018)

The guideline highlights three different tools that can be helpful to explore the patients’ existential/spiritual state: the questions of the Mount Vernon Cancer Network, the FICA model, the Layers of Meaning and the Ars Moriendi model. (Box 3.)

### Three tools to explore spiritual aspects of palliative care

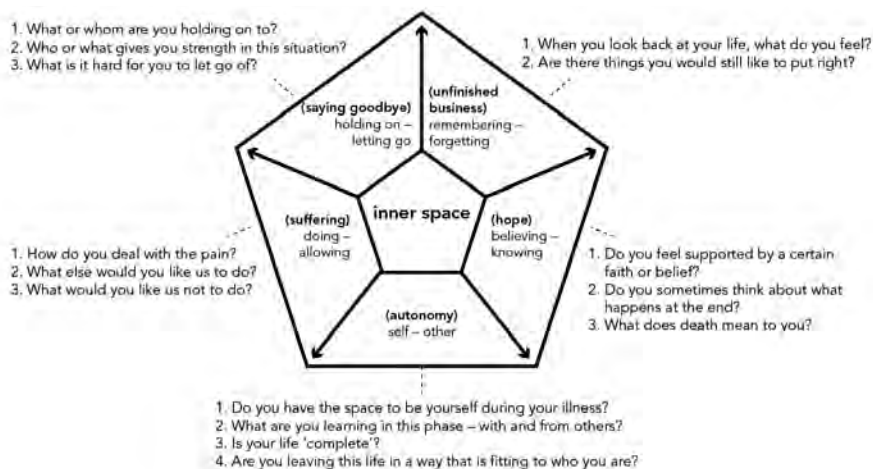
Three cue questions of the Mount Vernon Cancer Network (MVCN) spirituality assessment tool  
Developed by MVCN Spiritual support steering group/ Stevenage (UK)

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?

This tool has not been validated.

The Ars Moriendi model – developed by Leget C (The Netherlands)

Validated ( Haufe M. et al. 2022 )



Four layers of meaning – developed by Weiher E (Germany)

Layers of meaning Statements that patients make rarely mean just one thing; they often contain several layers of meaning. The layer of meaning pertaining to the existential/spiritual dimension often underlies an expression that on the surface appears to be of a physical or psychosocial nature. (Weiher 2004, 2007, 2009):

- **Factually** : here the meaning is about a factual and objectively verifiable state of affairs
- **Emotionally** : here the meaning is related to thoughts, images, feelings and emotions
- **Biographical** : here the meaning is about a person's social context and says something about their identity
- **Spiritual** : here it is about what moves people most deeply, what inspires them and gives their life meaning; this is often connected with ordinary everyday things in life

### The FICA Spiritual History Tool ©

FICA is a spirituality assessment tool - © U.S. Cancer Pain Relief Committee

Ref: Borneman, T et al (2010);

FICA briefly addresses this dimension of palliative care in several concise areas of concern. FICA has been translated into Dutch but has not yet been validated.

*BOX 3. Three tools to explore spiritual aspects of palliative care; Ref: IKNL "Existential and Spiritual Aspects of Palliative Care. Dutch national guideline." Version 2.0. (2018)*

### **3.3. Education of nurses and physicians in spiritual care provision guided by the guideline 'Existential and Spiritual Aspects of Palliative care'**

Currently, the curricula of both initial and advanced medical courses in the Netherlands pay ample attention to communication. [62] [63] [64]. Moreover, there is concern for 'patient cues' within clinical reasoning. [65] However, dedicated attention to spiritual issues of patients, including the serious ill, is not part of the medical curricula and specific training interventions related to spiritual issues are scarce. [66] [6] The Dutch guideline 'Existential and Spiritual Aspects of Palliative care' mandates that all clinicians, involved in care for the serious ill, address spiritual concerns of their patients. Research shows that in cases where healthcare professionals were trained to discuss these issues, they became more competent to meet their patients' spiritual needs. [67] [7]

A training intervention in teaching hospitals in the Netherlands integrated recommendations from the aforementioned Dutch national guideline with promising results. [37] They also showed that, of the three tools mentioned in this guideline (Box 3), physicians and nurses found the Mount Vernon Cancer Network tool to be the most practical and compatible in the daily practice of providing care. [37] (p. 186) The training courses within this study were conducted by spiritual caregivers. When starting the studies for my thesis, it was unknown how Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals in the Netherlands, and how they address this role. In the same period in which I performed the studies of my thesis, also another Dutch researcher studied what palliative care physicians, nurses, and social workers understand about what chaplains do. [49]

## **4. Research questions and outline of the thesis**

The Dutch National Guideline Existential and Spiritual Aspects of Palliative Care provides tools and recommendations regarding (A) attention to, (B) accompaniment of and (C) intervention in crisis situations when it comes to patients' spiritual concerns. In this thesis, in line with the recommendations in this guideline, I aimed to answer the five research questions as outlined below.

### **PART I**

To get more insights in how healthcare professionals in daily practice pay attention to spiritual issues of their patients, we addressed the following two research questions:

1. Do nurses, during their care for hospitalized patients with cancer, recognize and use opportunities to talk about spirituality? (chapter 2)

2. Do medical oncologists, during their daily consultations, identify and explore lived illness experiences raised by their patients with advanced cancer? And if they do, by which means do they do it and (how) does this influences patients' responses? (chapter 3)

## **PART II**

Based on the findings of part I, we performed two intervention studies to increase health care professionals' signalling and exploring spiritual issues of their patients:

3. What are the effects of an interactive communication training intervention for palliative care teams in identifying and exploring the spiritual dimension and integrating it in patients' care plans? (chapter 4)
4. What are the effects of coaching on the job of oncology nurses on their self-assessed spiritual care competences and job satisfaction? (chapter 5)

## **PART III**

To explore what Dutch spiritual caregivers, being the 'specialists' in spiritual care, have and aim to have in supporting other the 'generalists' in this care, being other health care professionals, in integrating spiritual care into their daily health care provision, we performed a survey study:

5. How do Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals in the Netherlands, and how do they address this role? (chapter 6)

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# **PART I**

## **CURRENT PRACTICE OF NURSES AND PHYSICIANS IN IDENTIFYING AND EXPLORING THE SPIRITUAL DIMENSION OF PATIENTS WITH ADVANCED CANCER**





# CHAPTER

# 2

## Nurses exploring the spirituality of their patients with cancer: participant observation on a medical oncology ward

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## Abstract

### Background

Attention for spirituality should be an integral part of professionals' caregiving. Particularly, nurses caring for patients with cancer might have opportunities to give attention to this dimension.

### Objective

The aim of this study was to gain insight in the way and extent to which nurses during daily caregiving observe and explore spiritual issues of hospitalized patients with cancer.

### Methods

We performed an ethnographic study with participant observation. Data were collected in 2015 during 4 shifts at the medical oncology department of a university hospital. The researcher, a spiritual care provider (chaplain) wearing the same kind of uniform as the nurses, observed the nurses, participated in their actions, and interviewed them after the shift.

### Results

Although the patients did send many implicit and explicit messages concerning spiritual issues, the nurses did not explore them. If noticed, 3 barriers for exploring spiritual issues were mentioned by the nurses: lack of time, conflict with their mindset, and being reserved to talk about such issues.

### Conclusions

During their daily caregiving to patients with a life-threatening illness, nurses have many opportunities to explore spiritual issues, but they do not often recognize them. If they do, they tend not to explore the spiritual issues.

### Implications for Practice

Communication training for nurses is necessary to develop skills for exploring the spiritual dimension in patients with cancer. In such training, attention to the misconception that such a conversation requires a lot of time and for recognizing signals from patients inviting an exploration of their concerns is necessary.



## Background

Paying attention to physical, social, psychological, and spiritual care needs is considered important for patients' health, well-being, and recovery. This is reflected in healthcare policy at European and global levels.<sup>1</sup> The definition of palliative care by the World Health Organization specifically includes spirituality.<sup>2</sup> In Dutch healthcare settings, "spirituality" and "spiritual care" are discussed significantly more often in the last decade,<sup>3</sup> and recently, a clinical practice guideline for spiritual care in palliative patients has been published.<sup>4</sup> According to this guideline, attention to the spiritual dimension should be an integral part of the care provided by all healthcare providers, including nurses. However, in the Netherlands, as in other western countries, attention to this dimension is not an everyday practice.<sup>5,6</sup>

Nurses may, during their daily caregiving tasks, observe implicit or explicit signals from patients to share spiritual issues.<sup>7</sup> Patients with cancer can experience uncertainty regarding prognosis and deteriorating health, which can cause spiritual distress.<sup>8</sup> Facilitating factors for such distress are, for example, cancer recurrence, unrelieved physical pain, or regret of unhealthy behaviours in the past. These might reveal emotions, such as anxiety, panic, or depressed mood,<sup>4</sup> resulting in thoughts such as "My life is meaningless," "I am so alone," or "What if all that I believe is not true?".<sup>9,10</sup> Even during a stable illness period, the patient with cancer may have time to consider all that has befallen him/her and where it may lead, which can also cause spiritual distress.<sup>4</sup> As an aid for nurses to explore the spiritual dimension during their daily caregiving, the Dutch Spiritual Care Guideline<sup>4</sup> lists 3 simple questions. These questions, derived from the Mount Vernon Cancer Network (MVCN)<sup>11</sup> are as follows:

- (1) "Is there at this time anything in particular that you are concerned about?"
- (2) "Where did you previously find support in difficult situations? (Family? World view? Music?)"
- (3) "Who would you like to have near you? From whom would you like to have support?"

Through asking these questions, patients are invited to tell in their own words what they are most concerned about, and what, in this period and in the past, are their sources of strength. The answers also help to distinguish whether professional counseling might be indicated. It is currently unclear whether nurses are willing and have the skills to integrate these questions into their daily work. Also not known is how patients seek attention to spiritual issues in their contacts with nurses. For these reasons, we decided to study whether nurses, during their care for hospitalized

patients with cancer, recognize and use opportunities to talk about spirituality and whether they apply the 3 guiding questions of the Dutch Spiritual Care Guideline.

## Methodology

### 2

#### Design

We performed an ethnographic observation study, meaning that the nurses, in their interaction and conversation with the patient, were studied systematically. This was combined with short interviews to reflect on the observations.<sup>12</sup> The researcher (J.v.M.) is also a healthcare provider (chaplain) and therefore regularly present at and familiar with the oncology ward of the hospital where the study took place. She is trained and skilled in exploring and mapping patients' spiritual dimension, as a consultant to spiritual care rather than as a traditional chaplain.<sup>13</sup> Rather than searching for predetermined or defined behaviours, she observed and listened in an open and inquisitive manner during the observation, while paying special attention to how, when, and whether nurses addressed the spiritual dimension with their patients. She also observed whether the 3 questions of the Dutch Spiritual Care Guideline for screening the spiritual dimension were used. At the end of the shifts, each observed nurse was interviewed by the researcher.

#### Initial Situation

Several months before the participant observation, an article was distributed among all nurses of the oncology ward on exploring the spiritual dimension of patients with cancer through the 3 questions of the Dutch guideline. During this period, implementation of the 3 questions was discussed during each of the weekly patient discussions the researcher attended. At the start of the participant observation, all nurses were aware of the existence of the 3 questions and the following definition of spirituality: "the dynamic of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred."<sup>14,15</sup>

#### Setting and Participants

The research was carried out at the medical oncology ward of an academic medical hospital of 700 beds in the southeastern part of the Netherlands. We used purposive sampling. Of the 40 nurses working at the department, who had all received the article on exploring the spiritual dimension and attended several weekly patient discussions about this topic, 4 nurses were selected, taking care that women and men, young and old, having shorter and longer years of experience, and being specialized in oncology

or not were represented. After being informed about the concepts being studied, all 4 accepted the invitation to be observed. Patients were informed about the observation by the researcher and nurse together at the start of the shift. The researcher introduced herself as being a researcher in the field of spiritual care and that she observed whether and how nurses give attention to this dimension. She told that, at any moment, they could ask for additional information, and they were told that they could refuse the researcher's further presence at any time. All patients gave verbal permission for the observation. Three patients asked for additional information about the research, which they received. The researcher, like the nurse, wore a white uniform. Through simple actions such as getting a glass of water, bringing the weighing chair, and opening and closing the curtain around the bed, the researcher participated in the actions of the nurses she observed. Patients sometimes asked the researcher questions or made comments in presence of the nurse. When the researcher interpreted these as an unfolding of the spiritual dimension and the nurse did not react on this herself, she sometimes integrated the 3 questions of the Dutch guideline in a conversation with the patient. In addition, the researcher forwarded the questions she received from the patients to the nurse, either on the spot or in the interview at the end of the shift.

### **Data Collection**

The participant observation took place while accompanying the nurses during complete shifts. All observations and interviews were conducted in January 2015. Explanations to, and consent from, the nurses were given and obtained verbally beforehand. Starting from the research question, the observations and interviews were guided by the following subquestions:

1. In what (care) situations do nurses and hospitalized patients with cancer start to talk about spiritual issues?
2. Do nurses, in these cases, apply the 3 MVCN questions,<sup>11</sup> as suggested by the Dutch Spiritual Care Guideline?
3. What facilitating factors and barriers do nurses encounter that contribute to starting, or refraining from, conversations about spiritual issues?

Answers to subquestions 1 and 2 were obtained by means of participant observation and were, at the beginning of the shift, again openly presented to the nurses as the focus of the observation. The last subquestion (3) was studied by means of participant observation combined with the interview afterward. This interview included the following questions and themes:

- Did you discuss or explore the spiritual dimension?
- If so, in what way?

- If not, what were the reasons?
- If the researcher had noticed unused opportunities to talk about spiritual issues, the nurse was asked whether he/she had recognized these situations.

2

All field data collected were anonymized, that is, saved in a way not traceable to any person. During the observation, the researcher took notes: dialogues and situations were sometimes recorded on the spot and other times less visibly in the hallway or nurses' office. These observations and dialogues are described in Tables 1 to 7. The interviews were audiotaped and transcribed. The observations and written interpretations based on the interviews, as well as the observation, were handed to the nurses, asking them whether they recognized the description derived from the observation (member check).

### Ethical Considerations

The study was performed within the Dutch law and Good Clinical Practice guidelines. Because the study concerned observation of routine care, or the way nurses usually interact with patients, no permission of the medical ethical committee was required.

**Table 1.** Feeling "Me" Again

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*A young woman sees to it strictly that her chemotherapy does not incur any delay. The nurse (n4) is irritated by this, feels hurried on and played out against the doctor. The spiritual care provider suggests the nurse she asks this woman about her concerns, why she is putting such pressure on time. The nurse sits with the woman and asks. The woman explains that in the hospital she is just another patient, surrounded by other people with their illnesses and their stories. Here she is just a woman with cancer. She makes no effort to hide her illness, does not wear a wig. "But at home, at home I put on my wig, my lipstick and return to my life. I am 'me' again. I can barely wait. However hard you people try; my feeling is I am shut in here. Confined. I do try my best to make something of it. But that uncertainty is there too and I don't want to be occupied with only that, but that's hard in here."*

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To guarantee anonymity, patient characteristics including quotes were adjusted to prevent recognition of the patient, and all nurses were mentioned or quoted alike and as a woman.

### Data Analysis

Initially, the data were read and reread for familiarization. We inductively identified and indexed themes and categories. Afterward, all the data relevant to each category were discussed with 2 other researchers (M.G. and Y.E.) until consensus was reached. The key point about this process was inclusiveness; categories were added to reflect as many of the nuances in the data as possible rather than reducing data and so

moving toward hypotheses or propositions.<sup>16</sup> The consolidated criteria for reporting qualitative research, that is, a checklist for explicit and comprehensive reporting of qualitative studies, was used.<sup>17</sup>

## Findings

Four nurses were observed, 3 women and 1 man. Of these four, three had acquired the oncology specialization. The care the nurses provided took place in rooms for 4, 2, or 1 bed(s). The observation was conducted 3 times during a day shift and 1 time during an evening shift. At the start of their shift, each nurse confirmed being familiar with the 3 questions of the Dutch spiritual guideline as possible questions for exploring the spiritual dimension and to have taken note of the 3 subquestions of the study. After each observed shift, the nurse was interviewed. When asked whether situations had occurred during the shift that had offered a clear entry or even an explicit invitation to explore or have a conversation about meaning, each nurse initially indicated not having recognized such situations. However, once the researcher offered examples she had observed that day and had herself even acted on a few times with or without the help of the 3 questions of the Dutch guideline, each of the nurses agreed to having recognized several of such occasions.

**Table 2.** Airsoft

*Although the nurse (n2) informed the spiritual care provider at the start of her shift that she was ready for the “challenge” of entering into a meaningful conversation with this young, somewhat “tough” young woman, it did not happen during her shift. The woman was lying in bed all day, slept a lot, and, when awake, was busy with her laptop. The spiritual care provider then at the end of the day decided to ask this woman what she was concerned about. [Is there at this time anything in particular that you are concerned about?] She was lying on the bed at the time with her laptop on her lap and headphones on her head. She immediately took off her headphones and invited the researcher to watch photos and videos about Airsoft, a battle simulation game using replicas of existing weapons. She also showed her the leg that had received surgery and reported: “My hip joint was not optimal but when I had surgery on my leg I knew: what I want most, working with the Army, is not going to happen.” She then talked about the group of boys and girls of which she was part: “some I have known since kindergarten, others from high school.” [Where did you previously find support in difficult situations?] Several of them received training at the Army. Engaging in Airsoft together approximated her desire to take part in combat units the most. “Next week I will undergo two more treatments. Two girlfriends will accompany me to the hospital. We will spend the night at relatives in Nijmegen and the next day I get the second treatment.” [Who would you like to have near you for support?] [Who would you like to have near you? From whom would you like to have support?]*

The nurses proceeded by pointing out all sorts of barriers that often kept them from entering into a conversation. During these observations and the interviews, in which



the observer and the nurse reflected on these observations, we concluded that no new barriers or deductive factors arose during the fourth interview.

**Table 3.** Faith as Major Support

*In the morning, the spiritual care provider asks a patient the 3 questions of the Dutch guideline. The nurse (n2) nudges her afterward saying: "I heard the three questions!" [Is there at this time anything in particular that you are concerned about?] The patient tells how he was given a diagnosis of cancer during the summer. This came after his divorce and soon after he lost his job as well: "Life can be harsh, yes. But what concerns me too are all these refugees and wars. Can we not live with more love rather than violence?"*  
*[Where did you previously find support in difficult situations?] "My faith, that has been a major support. And the people of our church. I sing in the church choir, that has helped me tremendously. But there is an anger in me too. Why does God allow this to happen? There is that as well!"*  
*[Who would you like to have near you? From whom would you like to have support?] "My brother. He is always there. He takes me to the hospital and he picks me up. Our relationship has only grown tighter since I am divorced and have cancer. He's always there for me, in every conversation with the doctor. We're very close."*

The barriers derived from observation and interviews could be subdivided into three main themes: lack of time, mindset, and reserve.

## Barriers

### ***Lack of time***

Three of the 4 nurses indicated that there was little or no time to have a conversation about spirituality. All thought such a conversation would take a lot of their time.

I guess I cannot start such a conversation knowing I have to be on my way again. That is the dilemma sometimes; knowing things are waiting for me and then I will not inquire further.

According to the nurses, the afternoon usually offered more space and time for such conversations than the morning:

You should not try and do that in the rush of your work. (...) that to me is the professionalism of a nurse, that you plan to integrate that, as part of your care, later in the day. (n2)

**Table 4.** Going home today

*While he was having blood samples taken, the spiritual care provider asked a patient why it was so important to him to be able to get home today. [Is there at this time anything in particular that you are concerned about?] He explained that, a day before, it was exactly 1 year since his mother passed away. "My mother was much more than a grandmother to my children, she helped raise them. She was my best friend. I miss her dearly." [Where did you previously find support in difficult situations?] Together with his children, he had had a statuette made, which they would place at her grave 1 year after her passing. Because of the therapy, he could not be present. Because of the bad weather the previous, day they had postponed it. It was now to take place this evening, and he wanted to be there. "If I would have to get back to the hospital afterwards then that's OK. But for now I first want to get home. Take part in the remembrance of her demise." [Who would you like to have near you? From whom would you like to have support?] After our talk he says: "I sat with a psychologist in a room here once. Then I thought: I won't do that again. But here, like this, at the bedside; then I find: it's good to tell my story."*

**Table 5.** Yesterday I Was in the Disco

*While speaking with a patient: The first situation involves a young woman who, in front of the nurse (n1), says: "Pretty weird, one day you're at the disco and the next day you're so whacked." The nurse does not respond. The same woman then turns to the spiritual care provider saying, "Are you familiar with that, that people who get cancer want to go over everything?" The researcher directs the question back to the nurse who answers "no, not weird at all. Many people do," and asks whether he can measure the patient's blood pressure.*

**Table 6.** A Priest From Africa

*Image: At the start of the shift, the nurse (n1) tells the spiritual care provider that she wishes to "offer support" to a patient coming from an African country because "this man hardly asks for anything and that concerns me." The nurse knows that his church has "something important" coming up shortly and that he is "a priest." The patient wears a T-shirt that day, bearing in big letters: "God created me for a reason." During the day, the nurse discusses with the man neither about the date on which "something important" is to happen nor about his faith nor about the words on his T-shirt.*

**Mindset**

The interviews revealed that the nurses' mindset also represented a limiting factor. They expressed how they spent a substantial part of their time completing and inquiring in service of checklists and scoring lists; during their shifts, this needed to have their full attention ("you will be held accountable through these lists" [n3]). This made it difficult to be able to hear a patient's question or comment as an unfolding of the spiritual dimension or as an entry or invitation to a conversation about spirituality. Most of the time, they carried a computer in which to directly insert scores. Watching patients and listening to them have, to a substantial degree, given way to keeping track of scores:

Not my clinical eye but the MEWS [Modified Early Warning Score] has to tell me how the patient is doing. Talking about this, this nurse realizes:

“that I often primarily ask closed questions.” (n3)

Another barrier was that, because of personal circumstances or an incident, their mindset did not allow for a conversation about meaning:

It also depends on how I am going into my shift. Sometimes it has to do with me personally. (...) There are days when I am “doing my tasks” mostly and other days when I feel I have a bit more to give.(n3)

Another nurse said:

Sometimes I just do not succeed. Then I am already full (...) It has also happened; someone had passed away in a room. And then there was a new patient. But my feeling was that that room still belongs to that other patient. Then I could not start a conversation. That was actually like I did something really nasty. But I did not have the headspace yet. (...) I think with every patient, every room, you have to switch again (...) our admissions, our experiences of one to the other, are very quick. (n4)

### ***Reserve***

Apart from lack of time and mindset, nurses mentioned a number of factors pointing to reluctance to engage in a conversation about meaning. All 4 nurses indicated that intruding on the privacy of the patient represented 1 such factor. Speaking about meaning, according to them, was difficult to reconcile with the possibility that fellow patients and others might be listening in. Considerations that the conversation could be overheard by a third party could be a reason not to enter into the conversation. Two nurses stressed specifically that they experienced this as an impeding factor to address the spiritual dimension. In addition, all 4 nurses indicated that talking about meaning might be stressful to patients. Not every patient has a need for this, they said. They also wanted to avoid that different nurses would start a conversation with the same patient about his concerns:

You should be careful not to over ask people. (n2)

The nurses expressed as well that, because much work needed to be done during a shift, they often had to set other priorities. The personality of the patient also could contribute to reservedness in the nurse with regard to entering into a conversation:

When you don’t connect with people then I also do not feel like asking about it. Or when people are really bothersome. When you feel there is no rapport. (n2)



Patients were also said to choose to start a conversation with a certain nurse and not the other.

....that some people also know: with you I get along. So with you I like to share my story. (n3)

Finally, the nurses indicated in the interviews that it could be demanding for themselves as well to frequently have such conversations:

You cannot keep this up with all people, every day, at this rate for it demands a lot of you because you have to reveal a lot about yourself too. (n2)

Sometimes, nurses deliberately let moments pass that presented possibilities for conversation:

You don't always feel like it, you see. (n2)

### **Conducive Factors**

In the end, situations were presented to the nurses in which talks about spirituality during their shifts actually had taken place. The reactions that followed identified several factors conducive to conversations about spirituality: suggestions from the spiritual care provider, observation of the spiritual care provider, a renewed viewing of the situation, and continuity of care.

#### ***Suggestions from the spiritual care provider***

On occasion, the researcher, upon explicit request of the relevant nurse, pointed to a clear effort a patient had made to engage in a conversation about meaning. The nurses knew the researcher first and foremost as spiritual care providers. They interpreted being shown instances and opportunities for entering conversations as suggestions from the discipline of spiritual care. These suggestions seemed helpful for engaging in a conversation. In the interview, looking back to this conversation (Table 1), the nurse in question was asked whether this exploration brought her or the patient anything:

Yes, it makes a difference. Especially that the woman showed her vulnerability; what motivated her to act in such away. (...) Now that I know what caused her to be so on top of the therapy, then that offers an explanation. (n4)

Another nurse remarked, after a similar encouragement to explore and the resulting conversation:

You also get useful information from there. Also just to be able to better care for your patients. Small pieces of personal information also enable you to develop a certain connection with someone. It also ensures that you can support people in another way. I now like knowing that this man is expecting his second child and does not know what the future holds for him and whether or not he is going to be able to see it. It gives me a lot of information on him. (n3)

This nurse spontaneously made notes in the electronic patient file after her conversation with the patient:

Sure! But to me it's not just about that information but also about him being able to be here as the person he is. (n3)

**Table 7.** Spinning Mind

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*Nursing action: The nurse (n3) has scheduled for the afternoon that a patient's line of tube feeding should be rinsed out/ flushed with water. Because the patient will eventually have to be able to do so herself, she wants to "practice" with the patient at a less busy time. That afternoon, she sits at the bedside of the patient, noting that the screw on the spray appears worn, rotating with no grip. The patient reacts saying: "Well, how appropriate to my own condition. My mind spins madly on ever since I lost my grip on things." The nurse does not respond to this remark by the patient but continues with the operation and explanation.*

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***Observation of the spiritual care provider***

The researcher occasionally had short conversations with the patients; whenever possible, she used the 3 questions from the MVCN (see Tables 2-4). In the interviews, nurses indicated that they had heard these conversations, either completely or in part. During the interview, a nurse informs the researcher that she had already observed her before this in her work as a spiritual care provider: I have often seen you talking to patients; I then did not stand close, but now my idea has been confirmed: people quickly feel like they can share their story with you. I then try to analyze what that is; that interests me. (...) I admire that. (n3)

***Situational appraisal***

During the interviews, the researcher discussed several situations (Tables 5Y7) with the nurses, which might have been an opening to (further) explore the spiritual

dimension but where this exploration did not occur. By analyzing these situations, they recognized opportunities that they had not noticed during their service. Opportunities presented themselves while speaking with patients, through visual images/objects and during nursing actions. This first situation (Table 5) contains an explicit invitation to talk by a young woman. The nurse responded in the interview: “Yes, that’s right. Now that I hear you say it. I did not pick up on that (...)” (n1)

The researcher recalled with the nurse (situation, Table 6) that she had not given attention to the spiritual dimension the entire day, although she had intended otherwise at the start of her shift. Nurse: “I think you’re right. I now wonder: why did I not do that? I can say well, I was busy with other things, which is the easiest way out. But I guess what you’re telling me now about this patient, for me did not carry that charge.” (n1)

The researcher assesses a situation (Table 7) with the nurse where, during a simple nursing act, a patient tells her that she experiences a restless mind. Reviewing this together, the nurse informed the researcher that “What I notice about you: you are very observant, to what you see in people, and you respond to that. And that way you create an entry with people. And what I observe in myself, now that I walk with you: I actually ask closed questions pretty often. I notice: you often let the story come from the people themselves. That’s a big difference.” (n3)

### ***Continuity of care***

The interviews showed that providing care to the same patients on consecutive days promotes intimacy between nurses and patients and facilitates conversation, also on the spiritual dimension. In the words of one of them: “Then you can keep an extra eye on this one this day, on that one the following, and that other one the next day.” Especially in terms of this dimension. I would really like to see that more attention was paid to continuity of care on all dimensions!” (n2)

## **Discussion**

During the participant observations in an oncology ward, there were no (care) situations where nurses explored spirituality with patients. Multiple situations occurred in which patients gave nurses explicit or implicit signals to discuss existential issues. In most cases, nurses seemed not to have spontaneously recognized these signals. However, when the researcher mentioned the situations during feedback, they acknowledged all of them. Accompanying the nurses, the researcher detected signals that patients often offered as an opening to engage in a conversation about

what preoccupied them the most. Because the nurses did not, several times, she then asked the 3 questions of the Dutch Spiritual guideline.<sup>4</sup> Besides, patients shared their concerns spontaneously to the researcher during moments of silent presence. Nurses indicated that they experienced 3 barriers that made them not to engage in this type of conversation: lack of time, a mindset unattuned to exploring, and reluctance to burden patients or others, including themselves, with exploring the spiritual dimension. Similar results were found in a survey among physicians in academic hospitals in the Netherlands.<sup>18</sup>

In line with Balboni et al,<sup>6</sup> the nurses observed in our study proved to be sympathetic to discussing spiritual issues. However, this attitude was different from the actual spiritual care they rendered.<sup>5</sup> Molzahn and Shields<sup>7</sup> also mentioned that it is not clear why nurses are reticent to discuss spiritual issues with people for whom they provide care, despite evidence of the positive effects of spirituality on well-being. According to Molzahn and Shields,<sup>7</sup> nurses providing spiritual care are expected to be able to use language of human experience (such as the formulation of the 3 questions), to understand language belonging to institutionalized religions, and to be sensitive to the “unspokenness” that pertains to the mystery and the mysticism inherent in spirituality. McSherry and Ross<sup>8</sup> state that, in nursing, there is a need for the concept of spirituality to be developed in a meaningful and rigorous manner. Our observation indicates that nursing practice offers multiple opportunities to explore or identify the spiritual dimension of patients. The mindset of the nurse at the bedside differs from that of the spiritual care provider. A patient’s comment, “Is it strange that people who get cancer want to evaluate their entire life?”, was heard by the nurse as a question to which an answer was expected and by the researcher as an unfolding of what concerned this woman in her illness. In daily nursing practice, where much time and effort go to measuring physical aspects, creating time and space for “the unfolding of the clients’ tale” is a challenge.<sup>19</sup> Lack of skills pertaining to the spiritual dimension may require an interdisciplinary approach if it is to take a full role in daily practice in the care provided to patients, in addition to the more common focus on the somatic, psychological, and social dimensions.<sup>20</sup>

### **Strengths and Weaknesses**

Our results are based on observations of daily oncology practice, which provided insights in what takes place. A limitation of the study is that it was conducted in only 1 department of only 1 hospital in the Netherlands. In addition, only a limited number of nurses were observed. Yet, this number was sufficient to reveal multiple opportunities in nursing practice to explore the spiritual dimension. To guarantee anonymity of the nurses, gender was not reported in the results section. This implies that gender-sensitive examination of the data was not possible. That the researcher

also worked at that ward as a spiritual care provider may have influenced observing objectively. However, it also made the nurses feel at ease in the presence of the researcher, which made the situation more natural.

## Conclusions and Recommendations

Hospitalized patients provide many opportunities to nurses to explore the spiritual dimensions, but because of a diversity of reasons, nurses do not tend to recognize them. To close this gap, nurses should be trained to allow them to naturally, and in a way commensurate with their work, explore the spiritual dimension of patients and to identify a need for specialist counseling or crisis intervention. This certainly applies to the care of patients with cancer, in whom the experience of a life-threatening illness and the uncertainty regarding diagnosis and of facing death can cause spiritual distress.

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# CHAPTER

# 3

## Oncologist responses to advanced cancer patients' lived illness experiences and effects: an applied conversation analysis study

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## Abstract

### Background

An advanced cancer patient's life is often disturbed by fear of cancer recurrence, cancer progress, approaching suffering, and fear of dying. Consequently, the role of the medical oncologist is not only to provide best quality anti-cancer treatment, but also to address the impact of disease and treatment on a patient's life, the lived illness experience. We aimed to gain insights into whether and how medical oncologists working at an outpatient clinic identify and explore lived illness experiences raised by patients with advanced cancer, and how this influences patients' responses.

### Methods

Conversation Analysis was applied to analyse 16 verbatim transcribed audio-recorded consultations.

### Results

We identified 37 fragments in which patients expressed a lived experience from 11 of the 16 consultations. We found differing responses from different oncologists. Patients continued talking about their lived experiences if the listener produced a continuer such as humming or tried to capture the experience in their own words. In contrast, a response with optimistic talking or the presentation of medical evidence prevented patients from further unfolding the experience. In consultations in which the lived illness experience was most extensively unfolded, medical oncologists and patients could constantly see each other's facial expressions.

### Conclusions

When a patient with advanced cancer spontaneously introduces a lived illness experience, it helps to identify and explore it when the medical oncologist produces a continuer or tries to capture this experience in their own words. Our findings can be implemented in training sessions, followed by frequent reinforcement in daily care.

## Background

In recent decades, life expectancy of patients with advanced cancer has increased significantly as a result of innovations in diagnostics and treatments. However, their life is often disturbed by fear of cancer recurrence, cancer progress, approaching suffering, and fear of dying. [2] [3]

Consequently, the role of the medical oncologist is not only to provide best quality anti-cancer treatment, but also to address the impact of the disease and its treatment on a patient's life, the lived illness experience. [1] [4] [5] Considering the uniqueness of patients' illness experiences, medical oncologists should, as stated in the WHO definition of palliative care, not only pay attention to the somatic, but also to the social, psychological and spiritual aspects of being ill. [6] [7] Knowing what matters most to the patient is a prerequisite for successful personalized care, [8] [9] [5] and patients and their proxies confronted with a life-threatening disease highly value attention given by healthcare providers'. [10] [11]

For several reasons, lived illness experiences are underexplored. Patients with advanced cancer, even in the last months of life, often find it difficult to acknowledge that they will not be cured, which hampers open communication. [12] Moreover, not all patients are capable of explicitly articulating what is on their mind. [10] Often, attention for their experiences and concerns is asked implicitly, and recognizing these signals can be challenging. [13] [14] Even though clinicians receive communication training during their education and specialisation, training in signalling and exploring lived illness experiences is scarce. [15] [1] Moreover, clinicians consider responding to patients' lived illness experiences, if signalled, time-consuming, [16] even though it has shown that it doesn't increase consultation length. [17]

A recent review covering deficiencies in the current state of communication between medical oncologists and patients living with serious illness concluded that it is one of the most important ways that clinicians influence patient-centred care. [18] A JAMA consensus conference paper highlighted the need for research to improve quality of communication between health care professionals and patients living with serious illness. [19] However, there is a lack of insights in what happens in usual medical oncologists – patient conversations concerning lived illness experiences. Therefore, we explored whether and how medical oncologists, during their daily consultations, identify and explore lived illness experiences raised by their patients with advanced cancer.

## Methods

### Participants and procedure

This observational study took place at a university medical centre in the Netherlands. Between January and March 2019, outpatient consultations with medical oncologists and patients with advanced cancer with the outcome of a scan communicated were observed and audio-recorded by JvM, who previously worked with participating oncologists as a spiritual caregiver. In addition, field notes were made on non-verbal communication, including drawings depicting positions of physician, patient, relative and computer screen.

3

The oncologists were informed about the research project orally and by email. Patients with advanced cancer were approached by a nurse. They received information about the study, the voluntary nature of participation, and were able to ask questions. Participants gave their written informed consent. An exclusion criterion was a patient aged under 18. Data collection was stopped when central trends were identified and confirmed in further analysis.

### Design

We chose to analyse the data according to ‘applied conversation analysis’, an applied form of the classical method of conversation analysis (CA). CA explores the organization of naturally occurring talk, like medical consultation, and focusses on what the interlocutors are doing when talking, for example activities like turn-taking or self-repair of what has been said. [20] [21] Within CA, the researcher does not intervene in the interactions and is only present for the technical execution of the recording. [21] In classical CA, the analysis of data is done through “unmotivated viewing”, or “by approaching the data with nothing special in mind”. [22] Applied CA however, provides room for a more practical approach towards a direct question or problem. [23] The applied approach was used as this study aimed to gain insights into whether and how the medical oncologists, during their daily consultations, identify and explore lived illness experiences raised by their patients.

### Data analysis

Characteristics of patients and oncologists (supplemental material) were collated using descriptive statistics. The COREQ checklist for observational research guided the reporting.

### Building collection

Audio-recordings of the consultations were listened to by three researchers (ABW, JvM, YE) several times, transcribed verbatim, and the transcriptions were read and

re-read. Two researchers (JvM, & ABW) independently searched the transcripts for fragments in which the patient raised a lived illness experience, such as being happy or worried ('*I am very happy because I was worrying a bit....*'), or by talking about fears ('it is tense though') or hope ('*I hope I can still make it*'). A collection of these fragments was critically read by and discussed with a team of experts consisting of a medical oncologist, a patient diagnosed with incurable cancer, a general practitioner, and a spiritual caregiver. [24] On agreement, stretches of this collection were re-transcribed according to Jeffersonian transcription conventions (Table 1) to capture details such as laughter, overlapping talk, length of silences, inhalations and exhalations, sound stretches, faster and slower speech etc. [24]

**Table 1.** Jeffersonian transcription conventions

(.)	Short, untimed pause
(1.4)	Timed pause
hh	Exhalation
.hh	Inhalation
(word)	Unclear hearing
((comment))	Transcriber's comment
w[ord	Overlapping onset
wor]d	Cut-off word
wor-	Faster speech rate
>word<	Slower speech rate
↓word	Markedly lower pitch
↑word	Markedly higher pitch
word=	Latching, rush into next turn or segment
<u>word</u>	Prominent stress
WORD	Higher volume than surrounding talk
wo:rd	Lengthening of segment
.	Falling intonation
,	Level or slight rise intonation
?	High rising intonation

### **Data sessions**

Analytic credibility was provided by studying these CA transcripts in *data sessions* in which linguists and CA experts and two GPs, an internist-oncologist, a spiritual caregiver and a patient participated. [25] The analysis always started with the patient's lived illness experience, and then the oncologist's response followed by that of the patient. One of the oncologists with expertise in research gave feedback on the findings.

### ***Ethical considerations***

The study was performed according to the Dutch law and Good Clinical Practice guidelines. [26, 27] The Medical Review Ethics Committee region Arnhem-Nijmegen concluded this study was not subject to the Medical Research Involving Human Subjects Act (case number CMO:2018-4992/date 28 December 2018). In addition to the written consent previously given, all patients and their family caregivers also gave verbal informed consent prior to the observations and audio-recordings. All data were stored and analysed anonymized.

## **Results**

Sixteen outpatient consultations with ten medical oncologists and 16 patients were observed and recorded. There were three refusals to participate: one oncologist refused and two patients were unwilling to participate. The ten oncologists (seven women) had work experience ranging from 2 to 35 years. The treatment involved different types of cancer: breast, ovary, skin, salivary gland, soft tissue, head/neck, thyroid, bladder, kidney, and prostate. Details of the consultations are shown in Figure 1.

We identified 37 fragments in which patients expressed a lived experience, from 11 of the 16 consultations. In 13 fragments the response of the oncologist invited the patient to talk about their lived illness experience further, while in 24 fragments the response of the oncologist prevented him or her from doing so.

Oncologist responses that encouraged patients to tell more about these experiences were: producing a continuer such as humming, or trying to capture the raised lived illness experience. Oncologists responses with optimistic talk or presenting medical evidence did not result in inviting patients to further unfold their experience.

In four of the 21 fragments in which oncologist responses stopped further unfolding, the patient came back to it later. And twice, a patient did not elaborate further on their lived illness experience after the oncologist tried to put this experience into his own words; in both cases, this response was immediately followed by a presentation of medical evidence. The main types of responses are presented below.

Almost all oncologists were seated in front of their computer during the consultations (position 1). At some point, most oncologists turned the computer screen to show the scan image to the patient and relative (position 2). In three consultations the screen and keyboard were pushed aside and not used at all (position 3).

Patients elaborate on their lived illness experience

In 13 of the 37 fragments, patients elaborated on their lived illness experience. This was preceded by oncologist responses such as trying to capture the lived illness experience of the patient in their own words, producing a continuer like a single short word such as ‘yes’, making an exclamation like ‘oh dear’, or humming.

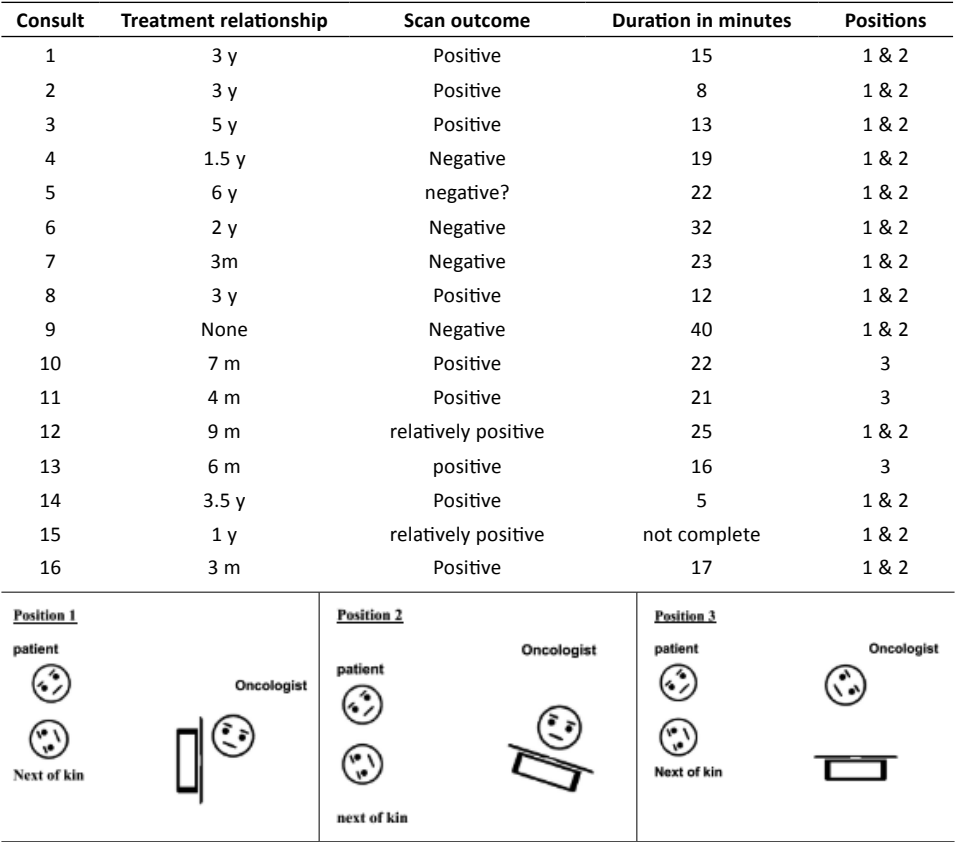


Figure 1. Consultation characteristics

Oncologist produces continuers

An example of an oncologist producing continuers in response to a patient’s raised lived illness experience can be found in Table 2. The husband also participated in this example. The oncologist was seated in front of the computer, making notes.

In line 3 of Table 2, the patient raises an experience relevant to her illness: ‘I’m very happy because I was worrying a bit....’ She then uses emphasis to make clear that it is

important to her that the oncologist listens (*'and that IS'* line 3 and 4) and by inserting that she will speak more clearly (line 5). She then talks about an acquaintance who recently died of colon cancer. The oncologist does not interrupt but uses continuers: 'yes' (line 7, line. 11, line 14) and an evaluative 'oh my' (line 9).

Then (line 12) the patient shows the connection between her acquaintance's story and her own illness by saying: *'and he had colon cancer but then even for you it's a bit worrying.'* (line 12 and 13) and: *'you know, I've had breast cancer so..'* (line 15). The oncologist then formulates how she interprets the patients' story so far [28]: *'yes and he'll have had metastasis of the colon cancer in his lungs?'* (line 17 and 18). The patient and next of kin confirm this formulation three times with a 'yes' (line 20) and the patient rephrases her worrying: *'so, then you start to think'*. Again, the oncologist produces a continuer ('yes') whereupon the patient unfolds her lived illness experience by elaborating on her 'worrying': *'and he passed away last week so, we went to the funeral and so on, and that's really been lingering in my head, I must say.'* (lines 25 – 27)

### **Oncologist tries to capture the lived illness experience in own words**

When an oncologist responded to a raised lived illness experience by trying to capture this experience in his or her own words, the patient also elaborated on this experience. An example of this is shown in Table 3. In this consultation the husband also participated; the computer screen and keyboard were pushed aside. (Figure 1. Position 3)

Prior to the start of this extract, the medical oncologist had announced 'good news' from the scan. In lines 1-4 of Table 3, the husband and the patient welcome this news respectively with: *'Yes, yes, super'* and *'yes, super good'*. Subsequently, in line 7, the patient articulates an experience relevant to her illness: *'Boy, I had not dared to hope'*. The oncologist does not respond immediately but as the patient does not elaborate further, the oncologist tries to capture her '*not dared to hope*' in his own words by saying: *'No, it's always worrying, that you (...) I did say that the chance that it would respond of course was bigger than with the [name drug].'* (lines 9 – 14). After the patient, in line 15-16, confirms what the oncologist has outlined (*'Yes, that's right'*), she continues by talking more about her lived illness experience: *'but I thought, yeah, and the blood values of course have been the whole time extremely good'*. Again the oncologist responds by capturing in his own words the patient's experience: *'still always wait and [see]...'* (line 20) He adds an open 'but' which is immediately taken up by the patient and complemented by a further elaboration on her lived illness experience: *'But I thought, yeah, what is it doing inside there'* (line 22). The oncologist then produces a continuer ('yes' in line 23) and the patient elaborates further: *'...and that's what I was a bit afraid of'*.



**Table 2.** Oncologist producing continuers

1. O: so in that respect I was very happy when I eh (.)
2. saw the scan;
3. P: I'm very happy because I was worrying a bit and that
4. IS;
5. oh I'll speak a bit more clearly;
6. •h that's in fact also because we have an acquaintance;
7. O: yes,
8. P: who recently died of lung cancer;
9. O: oh my,
10. P: and he had metastases he had;
11. O: yes;
12. P: and he had colon cancer but then even for you it's: a
13. bit worrying
14. O: yes;
15. P: [>you know<] I've had breast cancer so:
16. N: [(yes exactly)]
17. O: yes and he'll have had metastasis of the colon cancer in=
18. [his lungs ]
19. N: [yes yes exactly]
20. P: [yes yes yes; ]
21. N: that was the case=
22. P: =so then you [start] to think
23. O: [yes;]
24. y↑es;
25. P: and he passed away last week so •h (0.3) we went to the
26. funeral and so on and that's- (0.5) really been lingering in my head
27. I must [say;]

**Table 3.** Oncologist tries to capture the lived illness experience

1. N: yes yes;
2. (0.3) SUp̄er
3. P: yes super good;
4. [((laughs))]
5. A: [yes: ]
6. and uh [( ) ]
7. P: [boy] I had'nt dared to hope;
8. (0.4) ((sniffs))
9. A: (0.7) no: it's always worrying;
10. that [you:]
11. P: [yes ]
12. A: I did say that the CHANCE;
13. (0.2) that it would respond [of]course was bigger than with the
14. (name drug)
15. P: [yes]
16. [that's] right;
17. A: [but ]
18. P: but I [thought yes: (.) and the blood ] values of course have been
19. >the whole time< extremely good;
20. A: [ still always wait and ]...
21. yes;
22. P: but I thought yes what is it doing inside there,
23. A: yes;
24. P: (0.5) and that's what I was a >bit afraid of<;

Patients do not elaborate on their lived illness experience

In 24 of the 37 fragments, patients did not elaborate on their raised lived illness experience. Two forms of oncologist response preceded this: presenting medical evidence like findings drawn from statistics, radiographs or scans, or by talking optimistically like ‘*Well, this all looks good*’. We found some overlap between these two forms of response: when presenting medical evidence, the discussion often was a moment of optimism. In four extracts in which the raised lived illness experience was not elaborated on, the patient did not withdraw it, but repeated it in (slightly) different terms.

Oncologist presents medical evidence

Table 4 gives an example of an oncologist presenting medical evidence as a response to a raised lived illness experience of a patient. The patient’s husband was also present. The patient had recently been diagnosed with advanced cancer for which there was no effective treatment. The oncologist was seated in front of the computer and made notes. Prior to this extract, the oncologist had tried to end the conversation, suggesting calling the patient the following Wednesday. The patient snivels and raises a thought relevant to her illness: ‘*And how, how long do I still have? It won’t be long, it won’t be long anymore I think*’ (Table 4, line 2-4). In her response, the oncologist presents medical evidence beginning with: ‘*No, that’s what I think too*’ (line 5), followed by: ‘*But I really think that if I thought that we with immunotherapy, that it really could beautifully lengthen it, I would start tomorrow. But I think that we that, because ... we can’t do that*’ (line 7 – 12). The oncologist continues her reasoning for not giving immunotherapy, based on medical evidence. The patient’s lived illness experience regarding ‘*how long do I still have?*’ does not further unfold.

Table 4. Oncologist presents medical evidence

1.	P:	((sniffs))
2.		(2.5) ((cries)) and how (.) how long do I still have, ((cries))
3.		(2.0) ((cries)) it won’t be <u>long</u> , ((cries))
4.		(3.9) ((cries)) it won’t be long anymore I think ((cries))
5.	A:	<u>no</u> that’s what I think too;
6.	P:	((sniffs))
7.	A:	(3.2) but I re- <u>really</u> think that if I <u>thought</u> that we with
8.		immunotherapy, that it <u>really</u> (.4) could <u>beautifully</u> lengthen it,
9.		I would start <u>tomorrow</u> ;
10.		(2.5) but I think that we tha-
11.		((coughs))
12.		because (.) we can’t <u>do</u> that;

### Oncologist talks optimistically

Another response restraining patients from elaborating on their lived illness experience was optimistic talk by the oncologist, as can be seen in Table 5. In the consultation from which this fragment is taken, the patient's wife was also present. The oncologist was seated in front of the computer and made notes. A few months before this consultation, a new treatment had been started that proved effective. Prior to this fragment, the patient told the oncologist about a new study he had read about.

In line 1-6 of Table 5 the oncologist resumes his previous answer, using words that point to the future: *'trying'*, *'to administer'*, *'in a study'* and *'hopefully'*. The patient responds by raising an experience relevant to his illness: *'Well, I hope I'll make it'* (line 7). The patient repeats this experience twice more, in slightly different words: *'yes, well as long as this is good'* (line 11) and *'ahem, if it works well, but in the meantime....'* (line 16-17).

The oncologist responds repeatedly by talking optimistically: *'Well, this looks, so far, all looks good, so that, that's right?'* (line 8 - 10), *'now it's starting to work'* (line 12), *'so we'll keep all options[open]'* (line 19). In line 20, the patient aligns with the oncologist by briefly describing what he has understood: *'a lot is happening still'*. The doctor confirms his summary by once again repeating that all options will remain: *'exactly, exactly, we'll keep all options open'* and responds once again by optimistically discussing future options (lines 25 - 29). The patient now repeats his lived illness experience: *'we'll wait for them and I hope I'll still make it; so eh ...'* (line 35 - 36). In his response the oncologist asks the patient to move on to a next topic by saying: *'Yes. Okay. And briefly back to eh, the order of the day'*.

**Table 5.** Oncologist talks optimistically

1. A: [so] we eh: we are eh: with our nuclear colleagues we are •h
2. tryin' to b- a combination of those two substances eh: to
3. (0.4) eh: (.) administer;
4. (0.6) •pt in a in a study;
5. P: yes:yes;
6. A: >yes that that, hg we can [hopefully in the-]
7. P: [well I hope I'll ] make it;
8. A: •h well,
9. (0.5) this looks- so far all looks good so that: that's
10. right?
11. P: yes: [well as long as this ] is good,
12. A: [now it's starting to work,]
13. P: yes well well!;
14. A: •h it can be that eh: that eh this treatment,
15. eh: (.) it will work for (0.3) one and a half years [he so that eh: if it]
16. P: [h↓m: if it ]
17. works well but [in the meantime]
18. A: [if it works well;]
19. (0.5) so we'll keep' [all options: ]
20. P: [a lot is happening] still;
21. A: exactly;
22. exactly;
23. [op- we'll] keep all options open,
24. N: [yes;; ]
25. A: •h and eh: they'r indeed many new treatments coming up;
26. the psma is one of them,
27. but: also one is coming one •h one treatment with olaparib (.) one
28. different (0.2) new (0.5) drug which maybe is just as good
29. and maybe even better than that psma-therapie,
30. P: hmm,
31. A: so a lot of new things are coming up so;
32. •h
33. P: yesyes;
34. A: that's eh;
35. P: We'll wait for them and I hope I'll still make it;
36. so eh: he,
37. A: yes;
38. •h okay;
39. and briefly (0.4) back to eh: the order of the day [>because we:<]
40. P: [yes ]

## Discussion

This study provides insights into whether and how medical oncologists at an outpatient clinic identify and explore lived illness experiences raised by patients with incurable cancer. We note two forms of oncologists' responses to these experiences that encouraged patients to elaborate on them: by producing 'continuers' or by trying to capture the patients' experience in their own words. Patients did not elaborate on their experiences in cases where oncologists responded with optimistic talk or presented medical evidence.

In most of the observed consultations, patients raised lived illness experiences. This is in line with previous studies that showed that patients on the oncology ward directly or indirectly express what mostly concerns them. [13] Weiner et al. denote listening to what matters as efficient healthcare provision '*because it uncovers the actual underlying issues that account for the presenting problem*'. [29] Overlooking the patient's life context may even result in inappropriate and costly care. [17]

However, oncologists often find it challenging to talk to patients about their illness, life and death. [1] [30] For patients, a hospital is often an environment in which it can be a challenge to share their concerns, experiences and questions; [31] they follow their doctors' optimistic talk, although they often regret this later. [32] [33]

Interestingly, in those conversations where the patient elaborated most on the lived illness experience, the computer screen and keyboard were pushed aside. Earlier research shows that physicians' simultaneous use of a computer and speech compromises communication skills, [34] and that the computer is often a distracting source of information. [35] Moreover, when attention was paid to the lived illness experience, the consultations did not take any longer than those where no attention was paid, which is in line with previous findings. [17]

### **Study strengths and limitations**

This is the first study to examine, during live outpatient consultations, whether and how patients' lived illness experiences occur, how medical oncologists respond, and the effects. The multidisciplinary approach to the analysis resulted in a wide range of relevant viewpoints. The CA analysis proved valuable in capturing the real time interaction of patient-oncologist consultations.

However, all interviews were recorded at the same university medical centre, from one team of oncologists. Also, the fact both oncologists and patients were informed about the subject of the study may have caused bias.

Although nearly forty extracts were included, these originated from eleven of the sixteen consultations, conducted by nine oncologists. Differences between oncologists regarding sex, age and experience were not included in our analyses. Although earlier research did not find any significant influence of those variables on communication outcomes, [36] we do recommend including such characteristics in future studies. Furthermore, for each patient, we only recorded one of a series of consultations, not knowing what had already been discussed at these other consultations, which limits its generalisability. Moreover, our analyses did not capture how conversations created conditions to actually express lived illness experiences.


Lastly, although video recordings would have made it possible to also fully include non-verbal communication in the analyses, audio recordings were chosen in order to prevent patients from feeling uncomfortable.

### **Clinical implications**

According to CanMEDS (Canadian Medical Education Directions for Specialists), the most widely accepted and applied physician competency framework in the world, being a ‘communicator’ is one of the 8 core skills of physicians. [37] However, research shows that there are many shortcomings and pitfalls in the daily communication between physicians and patients. [18] We believe our findings make a valuable contribution to bridging the gap between reluctance of both oncologists and patients when discussing illness, life and death. Our findings are not complex, and easily applicable. It requires medical oncologists to be more alert to raised lived illness experiences of patients and to actively listen to patients who spontaneously introduce these issues. Yet, it is difficult to change established practice, and ‘culture eats strategy for breakfast’. Addressing and integrating the lived illness experience in consultations does not have to take extra time, and may even contribute to more efficient consultations. [17]. However, paying attention to and acquiring (more) competence in exploring the lived experiences may demand training sessions with, for example, simulation patients or coaching on the job. [36] Moreover, we recommend ‘frequent reinforcement’, for example during patient handovers or case discussions. [29]

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## Additional file 1. COREQ checklist.

**COREQ (Consolidated criteria for REporting Qualitative research) Checklist**

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	4
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1 and 4
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	4
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	6
Non-participation	13	How many people refused to participate or dropped out? Reasons?	6
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	appendix 1
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	4
Field notes	20	Were field notes made during and/or after the inter view or focus group?	4
Duration	21	What was the duration of the inter views or focus group?	appendix 1
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	N/A
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	5
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Box 1 – 4
Data and findings consistent	30	Was there consistency between the data presented and the findings?	N/A
Clarity of major themes	31	Were major themes clearly presented in the findings?	6 – 7
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.





# **PART II**

**INCREASING THE COMPETENCE OF NURSES  
AND PHYSICIANS IN IDENTIFYING AND  
EXPLORING THE SPIRITUAL DIMENSION OF  
PATIENTS WITH ADVANCED ILLNESS**





# CHAPTER

# 4

Identifying, exploring and  
integrating the spiritual dimension  
in proactive care planning:  
a mixed methods evaluation  
of a communication training  
intervention for multidisciplinary  
palliative care teams

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Joep van de Geer

Kris Vissers

Carlo Leget

Yvonne Engels

\* contributed equally

## Abstract

### Background

Patients receiving palliative care value attention given to their spiritual needs. However, these needs often remain unexplored as healthcare professionals lack the skills to identify and explore them and to integrate this information into care plans.

### Aim

To evaluate the effects of an interactive communication training intervention for palliative care teams in order to identify and explore the spiritual dimension and integrate it in patients' care plans.

### Design

A mixed methods pre-post study, including self-assessment questionnaires, evaluation of videos with simulated consultations (applied competence) and medical record review (implementation).

### Setting/participants

Three palliative care teams including nurses (N = 21), physicians (N = 14) and spiritual caregivers (N = 3).

### Results

The questionnaires showed an improvement on 'Patient and family-centred communication' of the End-of-life professional caregiver survey (+0.37,  $p < 0.01$ ; the 8-item S-EOLC (+0.54,  $p < 0.01$ ) and regarding the Spiritual Care Competence Scale, on the three subscales used (+0.27,  $p < 0.01$ , +0.29,  $p < 0.01$  and +0.32,  $p < 0.01$ ). Video evaluations showed increased attention being paid to patient's aims and needs. The medical record review showed an increase in anticipation on the non-somatic dimension (OR: 2.2, 95% CI: 1.2–4.3,  $p < 0.05$ ) and, using the Mount Vernon Cancer Network assessment tool, addressing spiritual issues (OR: 10.9, 95% CI: 3.7–39.5,  $p < 0.001$ ).

### Conclusions

Our training intervention resulted in increased palliative care professionals' competence in identifying and exploring patients' spiritual issues, and their integration in multidimensional proactive palliative care plans. The intervention directly addresses patients' spiritual concerns and adds value to their palliative care plans.



## Introduction

Palliative care patients' confrontations with deteriorating health, future uncertainties, and facing death all can raise spiritual issues.<sup>1-3</sup> Leading international organisations rank addressing this spiritual dimension among the most important of all care interventions.<sup>4-6</sup> Spirituality can be defined as the dynamic dimension of human life that relates to the way persons experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.<sup>7</sup>

During patient – healthcare professional contacts, patients continuously give signals of their search for meaning and about their spiritual concerns.<sup>8,9</sup> As their content and meaning can only be identified by multidimensional exploration,<sup>10</sup> these concerns' often remain unrecognised, and thus remain unexplored.<sup>3,8,11,12</sup> Even when noticed, healthcare professionals are frequently unclear about which next steps should be taken.<sup>10</sup> Essentially, patient signals about their concerns are often overlooked as they fall outside the familiar 'clinical reasoning' frame of reference.<sup>13</sup> Patients appreciate healthcare professionals' attention to their spiritual needs,<sup>14-18</sup> and become more empowered to adapt and selfmanage than in cases where attention is only given to their physical needs.<sup>17</sup> Moreover, addressing spiritual issues is important for proactive care planning, and can influence the quality of patients' lives and care utilisation.<sup>19,20</sup> Although healthcare professionals commonly receive communication skills training, dedicated training interventions regarding identifying and exploring spiritual issues are scarce.<sup>21</sup> In cases where healthcare professionals were trained to discuss these issues, they were found to be more competent to meet their patients' spiritual needs.<sup>22,23</sup> In the past, these courses mostly focused on spiritual assessment, without training practical (communication) skills during live patient contacts.<sup>24</sup> A good alternative to using patients in training courses is to use patient actors; this also has shown promising effects on team processes and patient outcomes.<sup>25,26</sup> In addition, a training intervention that integrated recommendations from a national guideline on existential and spiritual aspects of palliative care gave promising results.<sup>27,28</sup>

However, more comprehensive methods are necessary to evaluate the effects of these interventions; to date their impact has mainly been measured with self-assessment tools.<sup>24</sup> Therefore, the aim of this study was to comprehensively evaluate the effects of an interactive communication training intervention for multidisciplinary palliative care teams, based on a national interdisciplinary guideline. We hypothesised it would increase identification, exploration and proactive integration of patient signals regarding the spiritual dimension, as well as improve carers' spiritual care competences and proactive multidimensional care planning.

## Methods

### Design

A mixed methods pre-post study design was used ; the SQUIRE guideline for reporting.

### Setting

The training intervention took place in a small theatre.

### Population

Three transmurall multidisciplinary palliative care teams working in the south-eastern part of the Netherlands were approached to participate as a team. Transmural care involves close coordination and cooperation across primary and secondary care settings, tailored to a patient's needs.<sup>29</sup> The three teams included physicians and nurses involved in palliative care; each team had a spiritual caregiver. Each team member was asked to participate in both training sessions and to complete the pre and post-tests.

### Recruitment

Of each team, two members were contacted about the proposed training intervention; they in-turn informed their colleagues. Subsequently, all team members received an email in which they were asked to confirm their interest in participating in the two training sessions and completing the pre- and post-test.

### Sample

A team was accepted for the intervention once at least 10 team members, of whom at least two were physicians and one a spiritual caregiver gave consent.

### The intervention

An interactive communication training intervention was developed (Supplemental Appendix I) based on the Dutch guideline 'Existential and Spiritual Aspects of Palliative Care'<sup>27</sup>; the intervention was aimed at increasing participants' skills in identifying and exploring patient signals regarding the spiritual dimension, and to proactively integrate this into healthcare practice. During the intervention, three (non-validated) tools from this guideline were used to explore spiritual issues in non-crisis situations: the Ars Moriendi model (pp. 87– 88),<sup>30</sup> the 'Weiher's Four layers of meaning' model (pp. 22–23)<sup>31</sup> and the Mount Vernon Cancer Network assessment tool<sup>32</sup>; (p. 86) (Figure 1).

The intervention was developed by a professional communication trainer, familiar with training healthcare professionals,<sup>33</sup> incorporating input from YE, ABW and JvM and healthcare professionals. JvM is Researcher and Spiritual Caregiver, ABW is

Postdoc in palliative and meaningful healthcare and YE is Professor in meaningful healthcare.

Patient actors simulated palliative patients during the intervention. Groups were trained in two 3.5-h sessions between February and June 2019 in a small theatre.<sup>33</sup> To enable sufficient interaction with the patient actors, group size was maximised at 15 participants. Each team was trained separately.

The intervention sessions included two lectures: one on proactive palliative care planning<sup>34,35</sup> (Supplemental Appendix II), and the other on communication. The latter focused on verbal (e.g. 'What is the point of suffering like this?' or 'I no longer recognise myself') and non-verbal expressions (symbols of meaning in the patient's immediate environment, clothing or appearance, as well as the patient's use of metaphorical language or imagery, e.g. 'I feel as if I'm jumping from ice floe to ice floe' or 'My mind is just as twisted as the infusion').<sup>36</sup> Participants shared cases from their daily practice. Modelled on these examples, simulated healthcare conversations with the patient actors took place. They gave reflections on these conversations, including thoughts, emotions and actions that they would likely take as a patient based on the healthcare professional's response. The second training session closed with a simulation of transferring the patient's spiritual dimension information to another healthcare professional.

4

### **Data collection and outcome measures**

Following the intervention, participants were asked to indicate their satisfaction with the intervention (0 = not satisfied at all to 10 = extremely satisfied).

Pre- and post-test data a. and b. were collected from the participants four weeks before and four weeks after the training course. The medical record review (c.) regarding the year prior to and the year following the intervention took place retrospectively. (Table 1)

#### *a. Questionnaire (self-assessment)*

The questionnaire consisted of: (1) the 12-item subscale patient- and family centred communication of the End-of-life Professional Caregiver Survey (EPCS),<sup>37</sup> (2) the 8-item Self-Efficacy in End-of-Life Care survey (S-EOLC)<sup>38</sup> and (3) the subscales communication, assessment and implementation of spiritual care and referral of the Spiritual Care Competence Scale (SCCS)<sup>39</sup> (Supplemental Appendix III).

#### *b. Videos with simulated consultations (applied competence)*

As pre- and post-test, the participants observed the same three videos with simulated

patient-healthcare professional consultations, modelled on real cases in palliative care. Before recording and editing, essential elements of the composite real-life cases were commented on by a physician and two nurses from a palliative care team and adjusted if required. To facilitate participants' connection with the cases, only the patient was visible and audible in the final video; the healthcare professional's words were included as text in the video. Both diversity (age, gender and culture) of the simulated patients and different daily workplaces (home situation, outpatient clinic, clinic) of the target group (nurses, physicians, spiritual caregivers) were considered. Each participant was invited to individually watch these three video consultations online, and to subsequently answer the following questions in an online text box:

- (1) *What is this patient most occupied with? How did you notice this?*
- (2) *Was there something the healthcare professional omitted or failed to pay attention to during the consultation? If so, what?*

*c. Electronic medical record review (implementation)*

Two researchers (AS, ABW) retrospectively collected the documentation on the multidimensionality of care in the Electronic Medical Records of participants working in a clinical setting (four sites) of their deceased patients. The records were verified for documentation of non-somatic (psychological, social and spiritual) dimensions and anticipation on these dimensions, on documentation of patient goals and wishes, and on the use of the Mount Vernon Cancer Network, the Ars Moriendi, and the Weiher tools to explore spiritual aspects of palliative care. Any issues with the collection were discussed with three investigators (ABW, JvM, YE).

A cloud-based valid clinical data management platform (Castor Electronic Data Capture (EDC)) was used for quantitative data management and storage. Qualitative data were collected using Wix and stored in Atlas.ti 8.

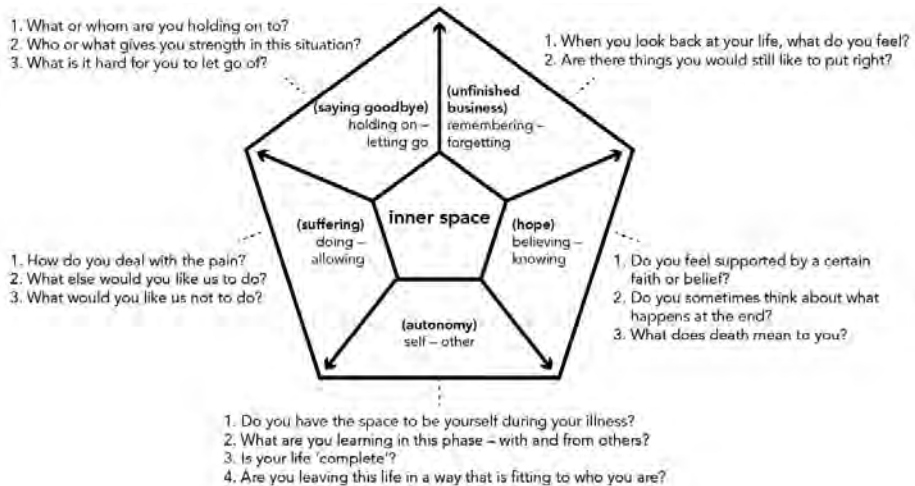
### Three cue questions of the Mount Vernon Cancer Network (MVCN) spirituality assessment tool

32

Developed by MVCN Spiritual support steering group/ Stevenage (UK)

- 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?

### The Ars Moriendi model<sup>30</sup> – developed by Leget C (The Netherlands)



### Four layers of meaning<sup>31</sup> – developed by Weiher E (Germany)

Layers of meaning Statements that patients make rarely mean just one thing; they often contain several layers of meaning. The layer of meaning pertaining to the existential/spiritual dimension often underlies an expression that on the surface appears to be of a physical or psychosocial nature:

- **Factually** : here the meaning is about a factual and objectively verifiable state of affairs
- **Emotionally** : here the meaning is related to thoughts, images, feelings and emotions
- **Biographical** : here the meaning is about a person's social context and says something about their identity
- **Spiritual** : here it is about what moves people most deeply, what inspires them and gives their life meaning; this is often connected with ordinary everyday things in life

**Figure 1.** Three (non-validated) tools to explore spiritual aspects of palliative care. Published in: Dutch Guideline 'Existential and Spiritual Aspects of Palliative Care'.

**Table 1.** Time schedule of enrolment, intervention & data collection

	STUDY PERIOD							
	month -12	month -2	month -1	month 0	month 1	month 2	month 13	
<b>ENROLMENT</b>								
Invitations of teams		X						
Informed consent team members		X						
<b>INTERVENTION</b>								
training session 1				x				
training session 2					x			
<b>DATA COLLECTION</b>								
<b>Self-assessment</b>								
12-item subscale patient- and family centred communication of the End-of-life Professional Caregiver Survey (EPCS)			x			x		
8-item Self-Efficacy in End-of-Life Care survey (S-EOLC)			x			x		
subscales communication, assessment & implementation of spiritual care and referral of the Spiritual Care Competence Scale (SCCS)			x			x		
<b>Applied competence</b>								
Questions regarding <u>videos</u> with simulated patient-healthcare professional consultations			x			x		
<b>Implementation in daily practice</b>								
retrospectively collected <u>electronic medical record review</u> of deceased patients of the participants		x					x	

## Analysis

During analysis, researchers were blinded for pre- or post-test conditions, and were only unblinded after analysis.

*Questionnaires.* Paired-sampled t-tests were conducted to study differences between pre- and post-tests using SPSS version 25. Total scores and scores for questionnaire subscales were analysed, for the whole group as well as for specific healthcare professional groups (nurses and physicians).

*Videos with simulated consultations.* Participants' written answers to the questions on the simulated consultation videos were coded using directed content analysis.<sup>40</sup> Categories and codes were predetermined by elements from the Dutch national guideline Existential and Spiritual aspects of Palliative Care<sup>27</sup> practised during the training intervention and discussed during an expert meeting (trustworthiness).<sup>40</sup> Coding was done independently by two researchers (JvM & ABW). In cases of lack of consensus, a third researcher (YE) was involved (reliability). After unblinding, pre- and post-test results were compared and analysed. Finally, the answers were quantified, using summative content analysis.<sup>40</sup>

*Retrospective electronic medical record review.* Regression analysis was applied to the pre- and post-intervention period, using RStudio Version 1.1.463. A mixed model approach was used, with study centre (hospital) as cluster. Analyses were made on an intention-to treat basis, and on complete case analysis.

## Ethics

The study was performed according to Dutch law and Good Clinical Practice guidelines.<sup>41,42</sup> The Medical Review Ethics Committee region Arnhem-Nijmegen concluded this study was not subject to the Medical Research Involving Human Subjects Act (case number CMO: 20184500). Local ethical committees of the four participating hospitals approved data collection. All data were stored and analysed anonymised.

## Results

### Participants

All three of the transmural palliative care teams approached (24 nurses, 19 physicians, 3 spiritual caregivers in total) gave consent. Non-participation in the intervention was due to personal circumstances, illness and work shifts. The 21 nurses, 14 physicians and 3 spiritual caregivers who participated in both sessions also completed both the pre- and post-measurement (Table 2).

**Table 2.** Characteristics of participants

<b>Profession</b>	
<b>NURSES</b>	
nurse	9
Nurse practitioner	5
Specialised district nurse	4
Nursing consultant	3
<b>PHYSICIANS</b>	
General practitioner	5
Geriatrician	1
Specialist geriatric medicine	4
Internist oncologist	1
Pulmonologist	1
Anaesthesiologist	1
Medical specialist in training	1
Spiritual caregiver	3
Total number	(38)
<b>Gender</b>	
Male	8
Female	30
<b>age in years (min-max)</b>	23 - 63
<b>Self-estimated expertise in palliative care: SCALE</b>	20-80
0-100 (min-max)	
<b>Experience in palliative care in years (min-max)</b>	2-41

### Questionnaires

Participants were very satisfied with the intervention (8.5 on the scale 0-10). Response rates were 90% both in the pre- and post-test. Scores on the subscale *Patient- and family-centred communication* of the EPCS survey increased significantly (+0.37,  $p<0.01$ ); nurses improved more than physicians. Scores on the S-EOLC also increased significantly (+0.54,  $p<0.01$ ). Here again, nurses improved more than physicians; at post-test, the nurses reached the physicians' pre-test values. A significant increase was found (+0.27,  $p<0.01$ ; +0.29,  $p<0.01$ ; +0.32,  $p<0.01$ ) on each of the three subscales of the SCCS. Physicians improved significantly on the sub-scales *Assessment and implementation* and *Referral*, and nurses on all domains. (Table 3)

### Videos with simulated consultations

**Question 1** "What is this patient most occupied with? How did you notice this?"  
After the intervention sessions, when the participants answered what in (simulated)



consultations patients were most occupied with, their focus was less often (21 versus 6 times) (Table 4) on *their personal predefined agenda*. They gave fewer answers like: 'does not want to look and think ahead' or 'does not accept her illness yet'. Moreover, in post-test the participants' focus was more often (26 versus 44 times) on the *aims and needs of the patients*, which emerged in answers such as: 'He wants to make the most of the last part of his life. He still wants to finish his paintings, a triptych' or 'Mrs. is mainly occupied with what she can and wants to do'. Additionally, when commenting on what the patients were most occupied with, participants' focus on *death and dying* decreased (28 versus 14 times) while their focus on *the patient's current life, the here and now* increased (16 versus 20 times). They were also less adamant in interpreting what the patients were most occupied with (47 versus 39 times). Words like 'trivialize', 'avoiding', or "absolutely not" were used less often. Finally, post-test participants more often asked questions on what the patient was most occupied with (1 versus 6 times).

**Table 3.** Differences between pre-test (4 weeks before intervention) and post-test (4 weeks after intervention) on questionnaires

Questionnaire	Group	$\Delta$ (pre- post-test)	95% CI	P-value
<b>EPCS</b>				
<i>Subscale: Patient- and family-centred communication</i>	Total group	0.37	-0.52 – -0.23	0.000
	Nurses	0.46	-0.65 – -0.28	0.000
	Physicians	0.15	-0.37 – 0.07	0.153
<b>S-EOLC</b>				
	Total group	0.54	-0.84 – -0.24	0.001
	Nurses	0.60	-1.04 – -0.16	0.011
	Physicians	0.30	-0.73 – 0.14	0.160
<b>SCCS</b>				
<i>Subscale: Communication</i>	Total group	0.27	-0.45 – -0.09	0.004
	Nurses	0.32	-0.56 – -0.09	0.008
	Physicians	0.18	-0.56 – -0.19	0.301
<i>Subscale: Assessment and implementation</i>	Total group	0.29	-0.42 – -0.16	0.000
	Nurses	0.27	-0.41 – -0.12	0.001
	Physicians	0.41	-0.70 – -0.12	0.011
<i>Subscale: Referral</i>	Total group	0.32	-0.49 – -0.16	0.000
	Nurses	0.27	-0.52 – -0.01	0.042
	Physicians	0.42	-0.63 – -0.22	0.001
<i>Overall</i>	Total group	0.30	-0.42 – -0.18	0.000
	Nurses	0.27	-0.44 – -0.11	0.002
	Physicians	0.37	-0.60 – -0.14	0.005

\*spiritual caregivers are excluded because of their small number (n=3)

*Question 2 “Was there something the healthcare professional omitted, or failed to pay attention to during the consultation? If so, what?”* After the intervention the participants, when specifying what their colleague healthcare professional in the video failed to pay attention to, more often (33 versus 41 times) suggested exploring in a *patient-centred* way. They would ask ‘what is important in life now, what still gives energy and satisfaction; how and when we can best help’. Moreover, participants less often (41 versus 19 times) focussed on *personal predefined (clinical) agenda’s* and less often (18 versus 4 times) on *death and dying*. Participants more often (8 versus 22 times) pointed out that the healthcare professional on the video had neglected an exploration of the patient’s *meaning seeking*: ‘Medication advice given too quickly; ask what thoughts keep her awake, what would she like to discuss with her husband, what is important to her?’ Moreover, participants more often identified (4 versus 13 times) *symbols of significance in the immediate environment, clothing or appearance, or metaphorical language or imagery* used by the patient: ‘Ask about the meaning of the crucifix she is wearing’ or ‘Ask about ‘the two selves’ she mentions; what does she mean?’.

## 4

### **Electronic Medical Record review**

A significant increase of 16% was found in the number of notes regarding anticipation on the non-somatic dimension (OR: 2.2, 95%-CI: 1.2- 4.3,  $p < 0.05$ ) and of 17% regarding identifying and exploring spiritual issues using the Mount Vernon Cancer Network assessment tool (OR: 10.9, 95%-CI: 3.7-39.5,  $p < 0.001$ ). No differences were found on notes regarding the use of the Ars Moriendi and Weiher assessment tools. (Table 5)

## **Discussion**

### **Main findings/results of the study**

The effects of an interactive simulation-based communication training intervention in identifying and exploring patients’ spiritual dimension and in integrating this in proactive care planning were assessed in three transmural, multidisciplinary palliative care teams. Differences between pre-test and post-test measurements demonstrated a clear impact on spiritual care competence (self-assessment), an increased attention to patients’ aims and needs combined with a decreased focus on the clinical agenda (applied competence), and an increased use of the Mount Vernon Cancer Network assessment tool and anticipation on the non-somatic dimensions of care in patient records (implementation). We hypothesise that a combination of integration of a national guideline, training in team context, and the variety of training methods including the use of patient actors were responsible for this.

**Table 4.** Code book of analysis videos

<b>Question 1: What is this patient most occupied with? How did you notice this?</b>				
<b>Category</b>	<b>Code</b>	<b>PRE</b>	<b>POST</b>	<b>Δ (post – pre)</b>
<i>NOTED</i>				
	Metaphors, symbols	3	0	-3
<i>INTERPRETATION</i>				
	adamant	47	39	-8
	questioning	1	6	<b>+5</b>
	seeking meaning	8	10	<b>+2</b>
<i>FOCUS</i>				
	nurse or physicians' personal predefined agenda	21	6	-15
	patients' aims and needs	26	44	<b>+18</b>
	patients' current life, the here and now	16	20	<b>+4</b>
	patients' death & dying	28	14	-14

**Question 2: Was there something the healthcare professional omitted, or failed to pay attention to during the consultation?**

<b>Category</b>	<b>Code</b>	<b>PRE</b>	<b>POST</b>	<b>Δ (post – pre)</b>
<i>NOTED</i>				
	metaphors, symbols	4	13	<b>+9</b>
<i>INTERPRETATION</i>				
	adamant	2	2	<b>0</b>
	questioning	7	4	-3
	seeking meaning	8	22	<b>+14</b>
<i>FOCUS</i>				
	nurse or physicians' personal predefined agenda	41	19	-22
	patients' aims and needs	21	18	-3
	patients' current life, the here and now	7	5	-2
	patients' death & dying	18	4	-14
<i>EXPLORATION</i>				
	close-ended questions	23	21	-2
	patient-centered way	33	41	<b>+8</b>

**Table 5.** Documentation in electronic medical record: differences between the year before and the year after the training

<b>Electronic medical record documentation regarding ..</b>	<b>OR</b>	<b>95%-CI</b>	<b>P-value</b>
.. non-somatic dimension	0.98	0.37 – 2.63	0.976
.. anticipation non-somatic dimension	2.22	1.18 – 4.23	0.015
.. questions Mount Vernon Cancer Network assessment tool	10.93	3.67 – 39.54	0.000
.. referral spiritual caregiver	0.96	0.23 – 3.93	0.958
.. patients' personal goals	1.02	0.49 – 2.12	0.96

### What this study adds

Effects on self-assessed competence differed between nurses and physicians. Nurses showed a significant increase on all SCCS domains (communication; assessment and implementation; referral), physicians only on assessment and implementation and referral. A comparable Dutch study also found an increase on subscales ‘assessment and implementation and referral’, but, in contrast to this study, they found no increase on subscale communication for both groups.<sup>43</sup> The intensive practicing with patient actors in our intervention may be the cause of the significantly increased communication skills. We recommend future multidisciplinary training interventions to incorporate different learning needs and goals of various disciplines, and possible effects at team level. The review of the electronic medical record showed that the Mount Vernon Cancer Network spirituality assessment tool is easy to integrate, and thus fits daily care practice well, especially the first question to find out how patients make sense of what is happening to them, or what occupies them most. This finding is in-line with earlier research, and showed the Mount Vernon Cancer Network assessment tool to be most practical and compatible with the medical model.<sup>28</sup> We recommend that these findings be considered in future education and training interventions, and anticipate that they will also be valuable when training non-expert palliative care providers, plausibly generating even larger effects. Because of their ‘beginners level’, such groups will probably require a more intensive training intervention.

Our findings are relevant for clinical care, as studies have shown that when patients give signals about what occupies them most, these are often left unexplored,<sup>3,8,11,12</sup> and thus not integrated in oral and documented handover and care planning. Discovering how patients make sense of what is happening to them, or what occupies them most, is fundamental for broader, important concepts such as patient-centred care, total pain, advance care planning, and shared decision making. Therefore, in line with Balboni et al.<sup>19</sup> we recommend that identifying, exploring and integrating the spiritual dimension is given more attention in curricular education and training interventions. Simulation-based training, the core element of our intervention, is an excellent way to achieve improvements in team functioning,<sup>26</sup> communication in palliative care,<sup>9</sup> and notably also in the provision of spiritual care.<sup>44</sup> Lastly, our findings are relevant for healthcare professionals, as improving communication skills may play a role in reducing burnout among clinicians.<sup>45–47</sup>

### Strengths and limitations

The comprehensive evaluation of the impact of the training intervention is a clear strength. Apart from the analysis of self-assessed competence scores, we also measured participants’ competence to apply the acquired knowledge and skills and

to implement it in daily care practice. This profound, unprecedented evaluation of effects is in line with recommendations in recent reviews.<sup>19,24</sup> Another strength is that the intervention stayed close to daily practice by using real-world case examples from clinical practice, earlier identified as being a key component of spiritual care training.<sup>24</sup> Moreover, we made innovative use of videos with actual case examples to measure the effects of the training.

A limitation is the absence of a control group. However, as the measured effects all point in the same direction, our findings give a plausible effect of the intervention. There is some sample imbalance: not all disciplines working in palliative care participated. However, the trained teams reflect palliative team composition in the Netherlands, with more nurses than doctors and only one spiritual caregiver. Other healthcare workers such as psychologists or social workers are commonly not part of these teams, but are consulted when required.

The three participating teams all work in the south-eastern part of the Netherlands. However, as they all followed basic and specialised education with national end terms, we do not think this limits generalisability. Moreover, we only measured self-assessed and applied competence effects at one time point, although they are likely to decrease in time, and therefore suggest repeated training interventions. Competence was thereby only measured in the short term (4 weeks before and 4 weeks after the intervention). Moreover, the palliative care professionals' own (attitude towards) spirituality was not part of the intervention, although an own perspective may cause bias.

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## Appendix I. The components of the two training sessions

- **Title of the training:** “Identifying, exploring, proactive; communicating with patients having palliative care needs”
- **Why:** to increase participants’ skills in identifying and exploring patient signals regarding the spiritual dimension, and to proactively integrate this into healthcare practice.
- **How:** face to face group sessions; about 50% plenary, about 50% in subgroups of 4 or 5 participants; with the guidance of actors as simulated patients
- **Where:** in a small theatre.
- **When and how much:** two sessions at an interval of 4 to 5 weeks per team, each lasting 3.5 hours.
- **Materials provided:**

### During the first meeting:

- Updated ‘problems square’, for anticipatory palliative care planning (Appendix II)
- workbook including aspects of the Dutch National guideline: ‘Existential and Spiritual Aspects of Palliative Care’ (1)

### During second meeting:

PowerPoint presentation on possibilities and challenges of applying the spiritual assessment tools of *Weiher* (2), *Ars Moriendi* (3) and the *Mount Vernon Cancer Network* (4), from the Dutch National guideline: ‘Existential and Spiritual Aspects of Palliative Care’ (1)



**Detailed content of the training sessions:**

Training section	Who	Content	Learning objective
<b>Training session 1</b>			
Welcome	Trainer, actors	<ul style="list-style-type: none"> <li>The three actors as simulated patients are already in their role without the participants knowing there are training actors: they welcome participants and serve food and drinks; one of them mainly communicates 'emotions', one of them 'facts' and one of them 'opinions'</li> </ul>	Introduction to trainer and actors and to the method of training with actors
Introduction	trainer	<ul style="list-style-type: none"> <li>Introducing the team</li> <li>Introduction to the programme</li> <li>Joint exchange of ideas about thoughts and views of the "spiritual dimension"</li> <li>Joint exchange of the uniqueness &amp; complementarity of conversations between a patient and the various disciplines present within the palliative team</li> </ul>	Follow-up introduction To be informed
Identifying	Trainer + actors	<ul style="list-style-type: none"> <li>Exercise with the training actors in further exploring the confrontation at the point of entry: What was heard and seen on welcome?</li> <li>Converting what is discussed into an exercise with actors and feedback</li> </ul>	Training in Identifying
Lecture	Associate professor of timely palliative care	<ul style="list-style-type: none"> <li>Practical aspects of proactive palliative care planning with introduction of 'problems square' (5)</li> <li>Introduction to spiritual assessment tools of Weiher (2) and MVCN (4)</li> </ul>	Gathering knowledge of spiritual assessment tools and about proactive palliative care
Identifying (cont.)	trainer + actors	<ul style="list-style-type: none"> <li>Short plenary session with actors as simulated patients and use of assessment tools</li> <li>During the conversation, the 'depth'/'closeness' of a question or the course of a conversation is indicated by physical distance between the simulated patient and the participant</li> <li>At first the simulated patient moves, at second the trainer asks the participant to move in distance</li> </ul>	Experiencing layers in communication (Weiher) and creating closeness in communication

*Continued.*

Training section	Who	Content	Learning objective
Asking questions (introduction)	trainer	<ul style="list-style-type: none"> <li>Jointly explore what types of questions there are</li> <li>Jointly explore identifying and questioning/exploring</li> </ul>	<p>Awareness of the variety of different questions and introduction to types of questions</p> <p>Connecting identifying and exploring</p>
Conversation exercise plenary	actors as simulated patients	<ul style="list-style-type: none"> <li>Bringing together identifying and exploring</li> <li>actors play case as simulated patient and caregiver</li> <li>Directions from audience, turning in</li> </ul>	How to go from identifying and exploration? (plenary)
Conversation exercise subgroups	actors as simulated patients	<ul style="list-style-type: none"> <li>Setting a personal sub-learning goal</li> <li>Split into 2 groups, 1 actor as simulated patient per group</li> <li>3 to 4 participants practise a conversation, others observe and give feedback; preferably use of own cases</li> <li>actor holds feedback round with participants and observers about the experienced</li> </ul>	How to go from identifying to exploring? (individual/subgroups)
Recap and homework	trainer	<ul style="list-style-type: none"> <li>Short evaluation</li> <li>Invitation to apply what has been trained in practice (homework assignment): 'write down an intervention on the spiritual dimension from your daily practice'</li> <li>Sharing a workbook including aspects of the Dutch National guideline: 'Existential and Spiritual Aspects of Palliative Care' (1)</li> </ul>	Evaluation

**Training session 2**Walk-in/  
reception

Introduction	Trainer	<ul style="list-style-type: none"> <li>Explaining the content of programme 2<sup>nd</sup> meeting</li> <li>Recalling associations/experiences with the spiritual dimension: are they changed?</li> <li>Participants write down 1 personal obstacle in entering into conversations on the spiritual dimension in a few minutes; tell about it to a neighbour</li> <li>Reference to interpretation of spiritual dimension; pointing out upcoming lecture II (spiritual caregiver)</li> </ul>	<ul style="list-style-type: none"> <li>reactivation of trained in first meeting</li> <li>Linking the experiences gained in one's own practice with the training course</li> </ul>
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*Continued.*

Training section	Who	Content	Learning objective
	Trainer + actors as simulated patients	<ul style="list-style-type: none"> <li>Collecting experiences with the homework assignment: 'write down an intervention on the spiritual dimension from your daily practice'</li> <li>Plenary session with actors as simulated patients to practice a part of the situation or conversation described Attention to what is 'new' and brought about a different contact with a patient. Focus on what worked and was experienced as positive</li> <li>Feed-back from the other participants and the actors</li> </ul>	<ul style="list-style-type: none"> <li>Linking experiences from one's own practice with the trained</li> </ul>
Lecture	Spiritual caregiver	<ul style="list-style-type: none"> <li>Lecture on theory and practice of exploring the spiritual dimension within healthcare, including possibilities and challenges of applying the spiritual assessment tools of Weiher (2), Ars Moriendi (3) and the Mount Vernon Cancer Network (4)</li> <li>Reference to the Dutch National Guideline 'Existential and Spiritual Aspects of Palliative Care'</li> </ul>	<ul style="list-style-type: none"> <li>Acquiring theoretical knowledge and linking this to one's own practice</li> </ul>
Create inner space in conversations	Trainer + actors as simulated patients + lecturers	<ul style="list-style-type: none"> <li>Participants are given, in pairs, one of the 5 themes of the Ars Moriendi model, including some example questions</li> <li>Assignment to explore in 5 groups what the paradigm evokes in relation to one's own practice</li> <li>Plenary sessions followed with actors on what has been found and thought</li> <li>Further practice in 2 groups</li> </ul>	Awareness and use of inner space (Ars Moriendi) in conversations
The art of asking questions	Trainer	<ul style="list-style-type: none"> <li>Serious side of 'questions', examples</li> <li>In discussion with the group, investigate what types of questions we know</li> <li>Complement with other question types (such as 'Joker questions')</li> <li>Briefly practise with actors as simulated patients</li> </ul>	<ul style="list-style-type: none"> <li>generate (theoretical) knowledge about the different types of questions</li> </ul>

*Continued.*

Training section	Who	Content	Learning objective
Return to practice	Trainer, actors as simulated patients	<ul style="list-style-type: none"> <li>Identifying different roles and discussing which ones overlap: specialist, process facilitator, administrator, coach, neighbour, friend and consider: "What roles do you have as a caregiver?"</li> <li>3 roles/3 participants in a row. actor as simulated patient gives game input, what do you do/say from the role taken?</li> </ul>	<ul style="list-style-type: none"> <li>Role awareness, whether or not to let go of that awareness, being able to switch flexibly between roles, attunement to handover</li> </ul>
Hand over	Trainer, actors as simulated patients	<ul style="list-style-type: none"> <li>Participants are asked to hand over a case in 1 minute to a colleague</li> <li>Zoom in on 'handover strategy</li> <li>Reflection on "transfer strategy"</li> </ul>	Integration of the spiritual domain in care planning (handover & electronic medical record)
Wrapping-up	All	<ul style="list-style-type: none"> <li>Retrieval, short evaluation</li> </ul>	Wrapping up

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2. Weiher E. Mehr als begleiten: ein neues Profil für die Seelsorge im Raum von Medizin und Pflege: Matthias-Grünwald-Verlag; 2001.
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5. Thoonsen B, Groot M, Verhagen S, van Weel C, Vissers K, Engels Y. Timely identification of palliative patients and anticipatory care planning by GPs: practical application of tools and a training programme. BMC palliative care. 2016;15(1):1-9.

Appendix II. Updated problem square

QUADRANTS for anticipatory palliative care planning

patient name:  
patient no:

<b>EXISTENTIAL</b>		<b>SOCIAL</b>	
What is going on?	Care plan	What is going on?	Care plan
Future scenario?	Care plan	Future scenario?	Care plan
<i>How does patient make sense of what is happening? What are sources of strength? Who or what would patient like to have with him/her?</i>			
<b>PSYCHOLOGICAL</b>		<b>PHYSICAL</b>	
What is going on?	Care plan	What is going on?	Care plan
Future scenario?	Care plan	Future scenario?	Care plan

Radboudumc

More information?  
[www.radboudumc.nl/en/research/research-groups/meaningful-healthcare](http://www.radboudumc.nl/en/research/research-groups/meaningful-healthcare)

Appendix III. Questionnaires for intervention participants (pre- and post- measurements)

EPCS: End-of-life Professional Caregiver Survey	
<i>Subscale: Patient- and family-centered communication</i>	<div>1. I am comfortable helping families to accept a poor prognosis</div> <div>2. I am able to set goals for care with patients and families</div> <div>3. I am comfortable talking to patients and families about personal choice and self-determination</div> <div>4. I am comfortable starting and participating in discussions about code status</div> <div>5. I can assist family members and others through the grieving process</div> <div>6. I am able to document the needs and interventions of my patients</div> <div>7. I am comfortable talking with other health care professionals about the care of dying patients</div> <div>8. I am comfortable helping to resolve difficult family conflicts about end-of-life care</div> <div>9. I can recognize impending death (physical changes)</div> <div>10. I know how to use non-drug therapies in management of patients' symptoms</div> <div>11. I am able to address patients' and family members' fears of getting addicted to pain medications</div> <div>12. I encourage patients and families to complete advanced care planning</div>
S-EOLC: Self-Efficacy in End-of-Life Care survey	
	<div>1. Discussing the likely course of a life-limiting illness with the patient.</div> <div>2. Discussing the likely course of a life-limiting illness with the patient's family.</div> <div>3. Discussing general issues related to dying and death.</div> <div>4. Having a discussion with the patient about his/her specific concerns about dying and death.</div> <div>5. Having a discussion with the family about their specific concerns about the patient's dying and death.</div> <div>6. Providing emotional support to the family upon bereavement.</div> <div>7. Responding to the patient's question: "How long have I got to live?"</div> <div>8. Responding to the patient's question: "Will there be much suffering or pain?"</div>
SCCS: Spiritual Care Competence Scale	
<i>Subscale: Communication</i>	<div>1. I can listen actively to a patient's 'life story' in relation to his or her illness/ handicap</div> <div>2. I have an accepting attitude in my dealings with a patient (concerned, sympathetic, inspiring trust and confidence, empathetic, genuine, sensitive, sincere and personal)</div>
<i>Subscale: Assessment and implementation</i>	<div>3. I can report orally and/or in writing on a patient's spiritual needs</div> <div>4. I can tailor care to a patient's spiritual needs/problems in consultation with the patient</div> <div>5. I can tailor care to a patient's spiritual needs/problems through multidisciplinary consultation</div> <div>6. I can record the nursing component of a patient's spiritual care in the nursing plan</div> <div>7. I can report in writing on a patient's spiritual functioning</div> <div>8. I can report orally on a patient's spiritual functioning</div>

*Continued.*

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**SCCS: Spiritual Care Competence Scale**

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- Subscale:* 9. I can effectively assign care for a patient's spiritual needs to another care  
*Referral* 10. provider/care worker/care discipline
11. 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)
12. I know when I should consult a spiritual advisor concerning a patient's spiritual care
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# CHAPTER

# 5

## Effectiveness of meaning-centred coaching on the job of oncology nurses on spiritual care competences: a participatory action research approach

Linda Modderkolk  
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## Abstract

### Background

Nurses' competences in providing spiritual care can increase quality of care for and quality of life of patients with cancer and job satisfaction but are often suboptimal. Training to improve this mostly takes place off-site, although implementation in daily care practice is key.

### Objectives

The aims of this study were to implement a meaning-centered coaching on the job intervention and to measure its effects on oncology nurses' spiritual care competences and job satisfaction, and factors influencing this.

### Methods

A participatory action research approach was adopted. Mixed methods were used to assess intervention effects in which nurses of an oncology ward in a Dutch academic hospital participated. Spiritual care competences and job satisfaction were quantitatively measured and complemented with content analysis of qualitative data.

### Results

Thirty nurses participated. A significant increase in spiritual care competences was found, particularly regarding communication, personal support, and professionalization. More self-reported awareness of personal experiences in caring for patients, and an increase in mutual communication and involvement around meaning-centered care provision as a team were found. Mediating factors were related to nurses' attitudes, support structures, and professional relations. No significant impact was found on job satisfaction.

### Conclusion

Meaning-centered coaching on the job increased oncology nurses' spiritual care competences. Nurses developed a more exploratory attitude in their communication with patients—instead of acting based on their own assumptions about what is of meaning.

### Implications for Practice

Attention to and improving spiritual care competences should be integrated into existing work structures, and terminology used should match existing understandings and sentiments.

## Background

Receiving a cancer diagnosis can have a huge impact on a person's life: both on a practical and a more profound level.<sup>1-4</sup> Although cancer treatment is often highly protocolized, a patient's life context – ranging from the financial situation to the social system, personal values and meaning – often is of such importance that it impacts or should impact treatment preferences and decision-making.<sup>5, 6</sup> Consequently, not integrating it could compromise both quality of life and quality of care.<sup>6</sup> An essential part of personalised, contextual care is the spiritual dimension. It regards “the dynamic dimension of human life that relates to the way persons (individuals and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred”,<sup>7</sup> and has a multidimensional nature – consisting of existential challenges, value-based considerations and attitudes, and religious considerations and foundations.<sup>8</sup> Identifying and exploring aspects related to this dimension can be performed in any encounter between patient and health care provider and should start at the time of diagnosis, and continue through to end-of-life or survivorship.<sup>9</sup> However, specifically in the oncology ward, nurses spend time with hospitalized patients with cancer, giving them a well-placed and important role in providing it.<sup>10</sup>

A prerequisite for spiritual care provision is having the communication skills to identify and explore what is of meaning for a patient. Communication is a central element in daily nursing practice, and several studies showed the effects of enhancing communication between nurses and patients in oncology care. It can not only improve patients' physical and mental well-being, but it also appears to be a vital source of nurses' job satisfaction.<sup>10-12</sup> However, addressing the spiritual dimension during communication appears to be challenging.<sup>10, 13</sup> In practice, this leads to nurses underestimating its importance, a lack of knowledge on the topics addressed by the patient, and limited skills to explore them.<sup>14</sup> Besides, time restrictions, not having the right mindset to explore topics openly, and reluctance to touch upon topics that seem (too) intimate, emotional, or personal, have shown to be serious barriers.<sup>10, 11</sup> Lack of training has shown to be the most important barrier to spiritual care provision.<sup>15-18</sup>

Several studies described training courses to increase nurses' communication competences regarding spiritual care, with varying results.<sup>12, 19</sup> Recurring elements in these interventions are multiday training sessions on communication skills and the use of roleplay or simulation patients to increase relatability and effectiveness. Moreover, integrated training approaches seem to have better results. No studies used workplace learning, also referred to as learning on the job, even though reflecting on real cases from the work setting appeared to be successful in other studies.<sup>20, 21</sup> Until now, there

is very little experience with this type of learning in oncology nursing or spiritual care training. For that reason, we aimed to bridge that gap by exploring the effects of meaning-centred coaching on the job of nurses in an oncology ward on their self-assessed spiritual care competences and job satisfaction, and the factors influencing it.

## Methods

### Design

We used a mixed methods study design to understand whether coaching on the job affected oncology nurses' spiritual care competences and job satisfaction, and the factors influencing it. We employed a participatory action research approach. Participatory action research involves a cyclical process of research, reflection, and action to improve an existing situation, based on input from relevant stakeholders.<sup>22-24</sup> The theoretical framework underpinning the structure of the intervention consists of the work of Tynjälä<sup>25</sup> on workplace learning. The literature and guidance in the Dutch national guideline *Existential and Spiritual Aspects of Palliative care* guided the content of the intervention.<sup>26</sup> Although patients were not necessarily in a palliative phase, facing a life-threatening disease triggers similar existential and spiritual questions and needs.<sup>27</sup> Nolan's definition around spirituality was guiding and perceived 'as being hidden beneath, and often expressed in, the physical, psychological and social dimensions'.<sup>26</sup> To learn to explore the spiritual dimension, often through these other dimensions, the intervention was centered on the assessment tool provided by the Mount Vernon Cancer Institute as described in the data collection.

### Participants

Participants involved an entire oncology nursing team, including the care manager and team leaders. All inpatient oncology ward nurses from an academic hospital in the Netherlands were invited to participate in the intervention. Inclusion criteria were employment on this ward, fluency in Dutch, and having provided informed consent. Using a purposive sampling technique, several of them were also invited by the team leader to participate in one or more of the 3 focus groups—in which 3 to 11 nurses took part—that were held throughout the intervention (see the Focus Groups section). We aimed for a diverse group in terms of age, work experience, gender, and affinity with the subject. Both the care manager and the team leader, with the latter also being one of the nurses, were approached for an individual interview at the start and end of the intervention.

### Data collection

Data were collected through semistructured interviews, an online survey, focus

groups, and team meetings. To answer the research questions, qualitative data (eg, regarding barriers and facilitators) stemming from different data-collection moments (eg, from focus groups and team meetings) were used interchangeably. See Table 1 for an overview.

**Table 1.** Overview of data collection

How?	What?	When?
<b>Semi-structured interviews with care manager and team leader (30-60 min)</b>	<ul style="list-style-type: none"> <li>- Envisioned and observed effects of the intervention</li> <li>- Expected barriers and facilitators</li> </ul>	Before and after intervention
<b>An online survey filled-out by participating nurses (10 min)</b>	Quantitative intervention effects: <ul style="list-style-type: none"> <li>a. Spiritual Care Competence (SCCS)</li> <li>b. Job satisfaction (subscale SWS)</li> </ul>	4 wk before and 4 wk after the intervention
<b>Focus groups with participating nurses (30-60 min)</b>	<ul style="list-style-type: none"> <li>- Suggestions to optimize the intervention</li> <li>- Qualitative intervention effects (reflectively)</li> <li>- Experienced barriers and facilitators (reflectively)</li> </ul>	One before, one during and one after the intervention
<b>Team meetings with participating nurses (30 min)</b>	<ul style="list-style-type: none"> <li>- Qualitative intervention effects (observing)</li> <li>- Experienced barriers and facilitators (observing)</li> </ul>	Once a week during intervention period

#### *a. Semi-structured interviews*

As part of the participatory action research, both the care manager and team leader were interviewed individually before and after the intervention using semistructured interviews to respectively collect their envisioned and observed effects of the intervention. Besides, expected mediating factors (barriers and facilitators) potentially impacting the intervention and spiritual care provision were gathered. Along with the input from the focus groups, the obtained information guided the final design of the intervention. The interviews lasted 30 to 60 minutes and were audiotaped and transcribed verbatim. In addition, field notes were made during the interviews.

#### *b. Survey*

To measure the effects of the intervention, participants filled out an online survey 4 weeks before and 4 weeks after the intervention (see Appendix I, available at <http://links.lww.com/CN/A124>). It is composed of the Spiritual Care Competence Scale (SCCS) and the job satisfaction subscale of the Spiritual Well-Being Scale.<sup>28, 29</sup> The SCCS assesses nurses' competences by measuring abilities on subscale assessment and implementation, professionalization and quality improvement, personal support and patient counseling, referral, attitude, and communication. It consists of 35

questions on a 5-point Likert scale ranging from “strongly disagree” to “strongly agree.” The Spiritual Well-Being Scale job satisfaction subscale contains 10 questions on a 10-point Likert scale ranging from “totally not” to “very much.”

*c. Focus groups*

In total, 3 focus groups were held: 1 before, 1 during, and 1 after the intervention in which nurses had the opportunity to reflect on the experienced effects of the intervention, on barriers and facilitators, and on the intervention process itself. Suggestions made to optimize the intervention were integrated where possible. The focus groups lasted 30 to 60 minutes and were audiotaped and transcribed verbatim.

*d. Intervention (during nursing staff team meetings)*

The intervention consisted of weekly coaching on the job during the daily 30-minute nursing staff team meetings in which patients are discussed and took place from June to November 2021. In total, the coaching intervention took place in 18 of the 21 planned team meetings; 3 were canceled because of acute circumstances on the ward. Coaching focused on uncovering barriers and facilitators in providing spiritual care for both patients and themselves. The intervention was alternately conducted by 2 researchers with a background as counselor (L.M., J.v.M.). It centered around the following content: (1) in daily practice applying a modified version of the first Mount Vernon Cancer Network question (“What are you most occupied with at the moment?”) to explore what is meaningful to a patient,<sup>30</sup> (2) learning to explore topics with patients instead of making own assumptions, (3) distinguishing between a patient’s values and own values, and (4) becoming aware of own experiences in taking care of patients. As suggested by nurses, at the beginning of the intervention, the Mount Vernon Cancer Network question was integrated into the electronic patient file. After the second focus group halfway through the intervention, a few changes were made to the coaching intervention. The most important adjustment, again suggested by nurses, concerned a recurring focus on positive aspects of caregiving as a counterbalance to the (perceived) difficulties. The team meetings were audiotaped, and parts of relevance for data analysis (regarding experiences’ effects, and barriers and facilitators) were transcribed verbatim. As nurses within a secular European setting like the Netherlands are primarily concerned with secular existential orientations such as meaning, value of life, and personal values that are not centered in religious ideological personal beliefs,<sup>31</sup> the intervention had a meaning-centred approach. During the intervention, the word ‘spirituality’ was replaced by ‘meaning’ (‘zingeving’ in Dutch) when it concerned this dimension.

## **Data analysis**

Quantitative data were analyzed using paired-sample *t* tests in SPSS version 25. For

the SCCS and Spiritual Well-Being Scale job satisfaction subscales, general means were compared. For the SCCS, means on the 6 subscales were also compared. Qualitative data were analyzed using a conventional content approach.<sup>32</sup> The transcripts of the first 3 team meetings were read and coded line-by-line by 2 researchers (L.M., A.W.) using Atlas.ti version 9. The codes were discussed until consensus about the codebook was achieved. The remaining team meetings and focus groups were analyzed by 1 researcher (L.M.) using the developed codebook. The first interviews were also coded line-by-line by 2 researchers (L.M., A.W.), and after consensus, they were finished by 1 researcher (L.M.). Two peer group sessions (L.M., A.W., Y.E., J.v.M.) took place to cluster codes and define categories and themes.

Finally, quantitative and qualitative findings were integrated and compared to better understand the effects of coaching on the job on nurses' competence and job satisfaction, and the barriers and facilitators influencing it.

### **Ethical considerations**

Because participants were not subject to treatment or required to behave in a certain way, the Medical Research Ethics Committee Oost-Nederland concluded this study was not subject to the Medical Research Involving Human Subjects Act (2021-8158). Written (quantitative) or verbal (qualitative) informed consent was obtained from all participants. The anonymity of the participants and discussed patients was guaranteed by removing information from the transcripts that could lead to identification.

## **Results**

In the description of the results, we distinguish between the effects of the intervention (quantitatively and qualitatively) and mediating factors facilitating or hindering providing spiritual care (qualitatively).

Of the 35 nurses invited, three left for a new job and two were on maternity leave during the intervention period. Consequently, 30 nurses were included at the start of the intervention. The unit-based design of the intervention meant that nurses participated in the intervention if it took place on their working day, regardless of whether they participated in the research through the survey and/or focus groups. An overview of the 28 participants who provided characteristics can be found in Table 2.

**Table 2.** Characteristics of Participants of the Intervention

<i>Gender</i>	<i>Year of birth</i>	<i>Highest education</i>	<i>Function</i>	<i>Years experience</i>
Male	1994	Secondary vocational education	Nurse	4
Female	1970	Higher vocational training	Nurse	31
Female	1989	Academic education	Case manager	10
Female	1991	Higher vocational training	Nurse	4,5
Female	1994	Higher vocational training	Nurse	3
Female	1959	Higher vocational training	Nurse	40
Female	2001	Secondary vocational education	Case manager	0
Female	1972	Higher vocational training	Nurse	20
Female	1992	Higher vocational training	Nurse	5
Female	1964	Higher vocational training	Case manager	37
Female	2000	Secondary vocational education	Nurse	1
Female	1990	Secondary vocational education	Nurse	8
Female	1961	Higher vocational training	Case manager	42
Female	1978	Higher vocational training	Nurse	15
Female	1995	Higher vocational training	Nurse	2
Female	1995	Higher vocational training	Nurse	3
Female	1997	Higher vocational training	Nurse	3
Female	1968	Higher vocational training	Nurse	7
Female	1994	Higher vocational training	Nurse	3
Female	1977	Higher vocational training	Nurse	20
Female	1996	Academic education	Nurse	3
Female	1996	Higher vocational training	Nurse	2
Female	1989	Higher vocational training	Nurse	12
Female	1964	Higher vocational training	Nurse	37
Female	1967	Higher vocational training	Nurse	40
Female	1991	Higher vocational training	Nurse	9
Female	1980	Higher vocational training	Nurse	5
Female	1988	Higher vocational training	Nurse	10

## **The effects of coaching on the job**

### ***Envisioned effects***

In the interviews preceding the intervention, the manager and team leader articulated their expected increase in nurses' job satisfaction and well-being when they would be facilitated in sharing and reflecting on spiritual care provision. These increased shared reflections were expected to be translated in better care for patients, contributing to high-quality person-centered patient care. This was understood as "tailored to a patient's life and values, without judgment—and communicated to the physician if needed." According to interviewees, this required an open attitude and proficient communication skills in spiritual care from nurses.



## Achieved effects

### Quantitative

The online survey response rate was 57% (N=17). Self-assessed competence on the SCCS increased significantly (+0.29,  $p < .001$ ), especially on subscales *communication* (+0.32,  $p < .01$ ), *professionalization* (+0.46,  $p < .01$ ) and *personal support* (+0.29,  $p < .05$ ). No significant effects were found on job satisfaction (-0.01,  $p = .91$ ). See Table 3.

**Table 3.** Differences in competence (SCCS) and job satisfaction (SWS)

	Pretest	Posttest	Significance (p)
SCCS (mean)	3.77	4.06	.00
- Attitude	4.37	4.49	.48
- Communication	4.29	4.62	.01
- Assessment and implementation	3.95	4.11	.15
- Referral	4.02	4.20	.12
- Personal support and patient counselling	3.70	3.99	.02
- Professionalization and quality improvement	3.16	3.61	.00
Job satisfaction scale WBS	8.04	8.03	.91

Abbreviations: SCCS, Spiritual Care Competence Scale; SWS, Spiritual Well-Being Scale.

### Qualitative

The interviews, focus groups and team meetings revealed three main categories of intervention effects which are set out hereinafter.<sup>1</sup>

*Becoming more aware of own care experiences.* The first category is about nurses becoming more aware of how they experience caring for patients. Jointly sharing own experiences during the team meetings – including accompanying questions and reflections – increased mutual connection and attention to spiritual care provision. Normalizing the topic lowered the threshold to discuss concerns or doubts in caregiving with fellow nurses, or to address others on it.

*I also notice during the team meetings, on Wednesdays but also on other days, that the nurse who brings in a case is asked how it is going or how it is for that person. I do notice a difference and I like that. But I found that with us anyway, there was often attention for that (i.e. before the intervention); only then it was perhaps just asked if someone indicated it themselves or if you really noticed it in someone, and now it*

1 As the interviews and focus group had a more reflective nature, and the team meetings a more observing nature, most illustrative quotes derived from the first.

*is perhaps asked a little earlier.’ (Nurse, focus group 2)*

The intervention normalized not only the mutual conversation about spiritual care, but also the perspective on how to work, as described by the team leader:

*Nowadays, when someone stays with a patient longer, I don’t think ‘she’s cutting corners,’ but rather: how good that she is taking the time.*  
(Team leader, interview R2)

*Exploring without judging* The increased focus on spiritual care helped in making nurses more aware of distinguishing their own values in life of those of patients. They began to realize that in interactions with patients, they sometimes tend to unconsciously assume the patient has the same values as they themselves have. The coaching helped in seeing that, as nurses, their job is to explore the patient’s values in life and subsequent care wishes, without letting their own values and preferences guide them.

*It’s more about being aware, that what I think about it is not of the utmost importance, that if it’s good for her [the patient], then it’s good.*  
(Nurse, focus group 2)

5

In line with this, nurses described filling in less. To be more careful with assumptions about patients’ feelings. It was mentioned that they therefore now more often explored them, which they assumed leads to patients feeling more seen and heard.

*So you have to keep that question [the Mount Vernon question: (‘What are you most occupied with at the moment?’)] in the back of your mind, I think it’s a very good one and patients like that too, because it gets them seen and heard, but not structured at a time.* (Nurse, focus group 1)

*Shifting Focus: What Goes Well?* Finally, the intervention led to an increased conscious focus on things going well in providing spiritual care. Nurses mentioned that the implementation of structural attention to this aspect in the second part of the intervention led to an increased perceived job satisfaction.

*We never say positive things to each other, never is a big word, but few. And I think with positive energy you can also do quite a lot with your mindset and with your day. Of course, you shouldn’t give ten compliments every day, because then you get uncomfortable, but if someone gets a compliment once a week like ‘you worked so well today,*

*you did so well for the patient', then I think yes, that's right, and then I'm proud of that and then you feel much better about yourself.* (Nurse, focus group 2)

The care manager and team leader noticed an increased mutual connection between the nursing staff. More attention was being paid to their own wellbeing, as well as the wellbeing of their colleagues.

*I notice that the team leaders come to me more often to say that we need to pay close attention to someone, that there is more care towards each other.'* (Care manager, interview R1)

### Facilitators and barriers in providing spiritual care

The interviews, focus groups and team meetings also revealed barriers and facilitators mediating intervention effects in providing spiritual care. An overview of the barriers and facilitators identified were compiled in the 3 categories *nurses' attitudes*, *support structures* and *professional relations*. (see Table 4).

**Table 4.** Facilitators and barriers in providing spiritual care

	Facilitators	Barriers
<b>1. Nurses' attitudes</b>	a. Sensitivity and responsiveness to patient needs	e. Busyness and practical incline
	b. Having time to explore	f. Nurses' unawareness of own values
	c. Diverse approaches in the team	g. Making assumptions about what patients think and feel
	d. Care vision and word use	
<b>2. Support structures</b>	a. Continuation of coaching	d. Terminology (e.g. negative associations with term <i>spirituality</i> )
	b. Regular coaching	e. Imposing intervention
	c. Integration of attention to spiritual care in work structure	f. Lack of integration spiritual care in history taking and transfer
<b>3. Professional relations</b>	a. Supporting team leaders	e. Hierarchical relation with physicians
	b. Supporting colleagues	f. Large group
	c. External coaching	
	d. Open attitude patient	

## Nurses' attitudes

Nurses' attitudes include nurses' attitudes and habits that were mentioned as aspects promoting or hindering their spiritual care provision.

### *Facilitators*

Effectively identifying and exploring what is meaningful to patients showed to be dependent on the nurses' attitude; (1a) *being sensitive and responsive to patients' needs* regarding what is of meaning to them. Some nurses expressed the necessity to distinguish between the patients' need to talk about meaning-related themes and their own need to address them. Providing spiritual care should match a patient's wish and be explored at an appropriate time.

*I also think that sometimes the person doesn't always know what to do with the question [the Mount Vernon question: 'what are you most occupied with at the moment?']. So I don't ask the question, because I don't know what to do next. And of course, some nurses ask this question all the time, and sometimes patients literally say: well, this nurse doesn't need to ask this question today. It is also a degree of appropriateness, this is very much putting it in boxes, of whether something is appropriate or not. But it has to do with feeling, being sensitive. (Nurse, focus group 2)*

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Having the opportunity to collect pieces of the puzzle during a patient's hospital stay – (1b) *having time to explore* – instead of in one conversation, was considered helpful. Moreover, it was a positive to be able to explore meaning-related topics in a way and at a time convenient to him- or herself. Reluctance to discuss these topics decreased when nurses were given the autonomy to make it their own – without having to conform to a certain protocol.

Most nurses appreciated the (1c) *diverse ways of approaching meaning-related topics in their team*. They perceived such different approaches as complementary, together enhancing the quality of patient care:

*But I think that is also the beauty of it, that you can complement each other. Suppose N4 is on day shift and just had a nice deep conversation and N1 is on evening shift and she brings in some lightness, then there is a balance. You can't just have tough conversations all day long. (Nurse, focus group 2)*

The nurses' (1d) *care vision* influenced their attention to spiritual care. However, sometimes the terminology or *word use* related to spiritual care created challenges

in communication between nurses because it evokes (negative) stereotypical associations. Moreover, even though some nurses don't explicitly discuss meaning-related issues, they were praised for their holistic approach and are known to (unconsciously) focus on providing spiritual care.

*They think these questions are too spiritual, too 'woo woo'. Yes, but we do talk about it and it does come up and then it needs to have a name again. I think that some nurses really do talk about it and they don't feel it is spiritual care, they just see it as part of their work without it having a name. (Team leader [nurse], interview R1)*

### Barriers

One of the most frequently mentioned challenges when it comes to the nurses' attitude, was their *(1e) busyness and practical incline*. Solving problems instead of taking the time to explore the actual question often was the default mode.

*I think that as nurses we are very practical-oriented and trained. [...] So I would say that that's what you go on about, what you can solve and what you can do at that moment. I also notice this in rounds, when we bring in a new patient and he has questions about school, we are the first ones to say 'oh we can ask social work and we can do this and do that', ok solved. While sometimes we could also dwell a bit more on oh gosh, he has questions about school, but what is it that keeps him busy about school? Is he afraid that he cannot go to school? That he cannot finish his education? There's also an underlayer under the fact that this boy would like to ask something or is worried about school. And I think sometimes we can be a little more aware of that. But that's just what happens because that's just what you can tick off at that time. (Nurse, focus group 2)*

In line with this: the expected time investment necessary to explore meaning-related topics prohibited nurses to engage in conversations regarding this dimension with patients, often unconsciously. At times they also shied away from such conversations, as they were perceived as uncomfortable or intense:

*I'm not really the best example I think. I do like humour and a certain lightness, and I think that is also partly self-protection, because every time such a deep conversation takes place, that also affects me. For me, it shouldn't become too intense. (Nurse, focus group 1)*

While their busyness and practical incline were familiar to them and often referred to, the limiting attitude that comes from (1f) *being unaware of their own values* was surprising to the nurses. Nurses sometimes, wrongly, assumed patients value the same things in life as they do.

This realization made nurses aware that they (1g) *make assumptions about what patients think and feel*, without exploring them. This regularly led to guesswork in the team meetings about a patient's behaviour or wishes. The coaching then centred around becoming aware of the limiting effect of this way of working, and solving it by going back to the patient to explore the topics that came up:

*When it came to what quality of life was for the patient, I noticed that, not that you fill in the blanks yourself, but maybe you subconsciously think of your own things as important. I didn't ask it specifically while it was actually running through the patient's whole day. You [the coaches] can just ask the right questions so that you are triggered to think a bit more about it with the patient. (Nurse 1)*

*You give your own opinion about it, but for someone else quality can be something completely different, but then it's hard to let go of yourself a bit because sometimes you think: "is that quality for you?" It's hard for me to imagine so to speak and you're going to give your own quality the upper hand over what the patient would want. I don't want that, but it does happen. (Nurse 2)*

*And then it's nice that someone else asks you at a certain point, because then you notice, oh, I don't really know [what the patient values]. (Nurse, focus group 2)*

### Support structures

Support structures are structures or processes in a department to streamline care delivery, like team meetings or reporting systems. These support structures can either increase or prevent attention to spiritual care provision.

#### Facilitators

(1) *Continuation of the coaching* was mentioned as one of the most important facilitating factors. This goes for the actual intervention period but was also mentioned as one of the essential components for creating sustainable future attention for this part of patient care.

*Yes, because you do something structured and more often, there is structure again and otherwise it is a bit strange to suddenly ask a blank question which is normally never done. And now it's more normal and yes, I do like it. (Nurse, focus group 2)*

*At least when I look at when one of the coaches was around, we also looked at ourselves a bit more. What does it do with you as a team and what happens to you when you're there? And I had the feeling when spiritual care wasn't around, that it was becoming a bit diluted. (Nurse, focus group 2)*

(2) *Regular coaching* – at least weekly – of the nurses was appreciated as a way to pay attention to the nurses themselves as well as help them increase their ability to provide spiritual care. Looking at the future, a wish was expressed for increasing the coaching to two times a week to reach more nurses who often work on different days, because the presence of a coach makes a difference.

Moreover, (3) *integration of attention to spiritual care into the existing work structure* proved to be one of the crucial elements for successful implementation. Not only did it work smoothly, it also provided several reminders throughout the day to pay attention to this dimension. Integration into the existing work structure consisted of a reminder at the start of the day by the nurse in charge to ask the Mount Vernon question, including feedback on that exploration during the doctor's visit halfway through the morning, discussing it with colleagues after lunch and at the end of the day reporting it in the electronic medical record where the Mount Vernon question was inserted in the format instead of the term 'spiritual dimension'. This last practical adjustment proved to be especially helpful:

*I think it does add value, especially that question in the electronic medical record. And naming it, especially if you come on a fixed day and it's in the index card every day, so you also mention under the heading 'spiritual care' or something like that you come and if you then see that specific question every time, I think that's a good reminder that, oh yes, I have to pay attention to it. (Nurse, focus group 1)*

### *Barriers*

When it comes to barriers, (4) *terminology – and particularly negative associations with the term spirituality* – was mentioned.

*Yes, for me that does provide clarity [using the Mount Vernon question],*

*because then you just have a question and you know more or less what to ask, not literally, but which way you can go, and you can also answer it more easily, 'the patient is most concerned with..'. Because 'spirituality' – I personally find it a very heavy word with which I have certain associations. (Nurse, focus group 1)*

Getting nurses on board to increase their attention to spiritual care is (5) *expected to fail when imposed on them*. Cultivating intrinsic motivation and giving it time to grow on them is proposed as the preferred strategy as this quote shows:

*And you have to dress it up a bit nicely that it's part of the care and not because you find it interesting yourself. Because in the standard electronic patient file, there is a heading for spirituality that was used a while ago: 'We need to pay more attention to spirituality', but nobody fills in the heading because it is imposed, you know? There must be an intrinsic motivation so that you are fascinated and touched instead of doing this now because it is said to be a quality improvement. Every week someone comes to the hospital with a new plan, but yes, you have to be really triggered. (Nurse, focus group 1)*

(6) *Not integrating attention to what is meaningful to a patient in history taking or transfer to other health care providers is perceived as a barrier as well:*

*No, we don't have an electronic medical record-focused format or a SMART text on how to transfer to home care or anything like that. (Team leader, interview R1)*

### **Professional relations**

Professional relations includes all interactions between healthcare providers in the nursing department related to patient care. These relationships can promote or hinder attention to spiritual care in various ways.

#### *Facilitators*

Facilitating factors were mentioned related to the team, the coach and the relationship with the patient. When it comes to the team, it was expressed that (1) *support by the team leaders* to address spiritual care was helpful. (2) *Supporting colleagues* - helping each other out by taking over care tasks for a colleague to give him or her more time to invest in meaning-centred conversations or care proved to be supportive and appreciated:



*At the time of the patient's passing, I was there for her loved ones. I was not really called away, because there were two of us, so I could say to N2 'you finish room 28, and I will stay here with the family'. So I was able to help them all along, we were able to wash her together, we were able to take our time, we all went to the mortuary together, that's nice, that that's possible. And N3 took my pager for a while, I've had my phone off for a while, that that's possible, that for me makes that I had the time to be able to give the care that I wanted to give. (Nurse, team meeting 16)*

Moreover, (3) *having an external coach specialized in spiritual care* was felt to help address meaningful topics. The coach's attitude was specified as respecting the nurses' profession, supporting the conversation instead of taking over and making a heartfelt connection:

*You focused on "what does that do to you?". You (i.e. the coach) don't take over, you connect to where we are. What you do is sit back and listen. In our work, the emphasis is on clinical reasoning, you don't do that. The attitude of sitting back is opposite to that and thus complements it. It is a different way of communicating and making contact. It's about connecting, also with the perception of the nurse. Real contact, paying attention to each other. (Care manager, final interview R2)*

Finally, (4) *an open attitude of the patient* was perceived as helpful (or hindering when framed negatively) in having a meaning-centred conversation as this nurse shares:

*Of course, some patients are easier and more open than others and with some you have a nicer connection to sit down with than others. If you have someone who very much resists you, then it is of course much more difficult, but if you have someone with whom you can chat all day, then asking such a question is much easier. That all plays into it as well. (Nurse, focus group 2)*

### *Barriers*

The (5) *hierarchical relationship with the physicians* by some nurses was perceived as challenging in addressing spiritual care. Sometimes the perceived responsibilities of a physician by a nurse led to unhelpful assumptions:

*I think sometimes we should listen better to our patients, and not just*

*the nurse but certainly the doctors should. They, of course, have taken an oath to treat, up to, well, and we may have earlier that we think: should we do this? And that we then have to enter into a conversation with the patient to ask 'where are you now?', 'is this really what you want, otherwise you have to discuss this with the doctor.' And then you're also dealing with a bit of a hierarchy. (Team leader, interview R2)*

Some nurses felt uncomfortable sharing their challenges in (6) *a larger group of nurses*. Especially when a significant part of the group consisted of nurses in training, some nurses refrained from sharing their experiences, as this example shows:

*For example, today there were twelve of us in the coffee room with ten students, so I don't show the back of my tongue about what this has done to me, I am very honest about that. But I also remember that the mother of a patient really raged against me and that I walked up to the team leader and thought 'what is happening to me now?' And then the team leader can very well ask the questions and then it comes out, but if I am sitting with ten of those people then I would also just keep my mouth shut. So that is a tricky thing, what is a good time for that? (Nurse, focus group 2)*

## 5

## Discussion

This study explored the effects of coaching on the job of oncology nurses. A significant overall increase in their spiritual care competences was found, but no impact on job satisfaction. Specifically, competences in *communication*, *personal support*, and *professionalization* increased. Nurses described an increased awareness of their own experience of taking care of patients and a developed ability to distinguish their own values from those of the patient. The intervention led to normalizing discussions between nurses on what matters most for patients as well as a conscious focus on the actual care provided to patients. Several mediating factors were identified influencing spiritual care provision, which could be categorized in the nurses' attitudes, support structures, and professional relations.

### Comparison with previous literature

One of our key findings is that nurses had difficulty recognizing their own values and differentiating them from the patients'. This confirms a study showing that addressing healthcare providers' personal values and meaning is the strongest factor to improve spiritual care provision.<sup>33</sup> Training should therefore not be limited to providing

patient-centred care, but also include attention to the providers' experience. One of the biggest challenges we found was related to work attitude, and that it is needed to move from a place of 'busyness' to working attentively and reflecting on the care provided, an aspect also described in other studies.<sup>13, 34, 35</sup> The 'culture of busyness' is an attitude most nurses learn from the start of their working career and emphasizes task-orientation, which resembles the traditional working culture in healthcare. Learning to pause and reflect requires a supportive work culture, optimal physical and work structures, the support of management and good personal relations.<sup>36</sup>

Moreover, this study shows the unease nurses felt with the term *spirituality*. The word does not appeal to them, and although often used in the medical field, it is associated with 'heavy' and 'woo-woo' topics. This was also found in adjacent articles.<sup>37-40</sup> Not surprising, given the fact that medical dictionary definitions for example are: "*An awareness of the metaphysical, the religious, or the sublime*",<sup>41</sup> and "*something that in ecclesiastical law belongs to the church or to a cleric as such*" or "*sensitivity or attachment to religious values*".<sup>42</sup> Therefore, the coaching on the job of this study was meaning-centred, and the word *spirituality* was not used during the intervention.

No quantitatively measured changes in job satisfaction were found; however, with an 8/10 this was already quite high at baseline. This is not to say it was not affected. One of the biggest changes made based on nurses' requests after the midway evaluation was an increased focus on the positive side of their work and performance. This need for approval and support from peers and team leaders is in line with research on job satisfaction among millennial nurses, which made up a large part of the nursing team in our study.<sup>43</sup>

Study results are in line with insights on effective workplace learning. Essential characteristics used are collaboration, the use of various tools as opposed to solely cognitive reasoning, applying concrete case studies and learning tailored to the situation.<sup>25-44-45</sup> By using the existing work structures for workplace coaching on the job, necessary infrastructure was put in place to support learning. Doing this ensures learning is embedded in the organization, especially relevant given the large turnover of nurses.<sup>46</sup> In this study, integration of the Mount Vernon question (*What are you most occupied with at the moment?*) into the electronic patient record proved to be an important catalyst.

### Strengths and limitations

This study yields clinically relevant findings to move the field forward. Moreover, the participatory action research study was performed with the involvement of an

entire oncology nursing team, including the care manager and team leaders. This co-creative approach proved valuable amidst a demanding COVID-19 pandemic. However, our study also has limitations. First, the main researcher combined performing the coaching process and the interviews, which might have caused bias. We minimized this risk by working with another coach throughout the study and by analyzing data with 2 independent researchers. Second, this study was executed during a COVID-19 wave. Many nurses were working overtime and on COVID-19 wards to collectively bear the burden of the pandemic. As a result, questionnaire response rates were relatively low. Finally, we implemented the intervention at the team level but measured effects at the individual level. All nurses were exposed to the intervention, but not all of them completed the survey. Although we also expect effects on nonresponders given the unit-based design of the intervention, we are not able to confirm this hypothesis.

### **Implications for practice and future research**

Attention to and improving spiritual care competences should be integrated into existing work structures, and the terminology used should match common understandings and sentiments. Coaching nurses on the job can increase self-assessed spiritual care competences—assessing whether this also translates into improved quality of care and communication could be the next step.

## **5**

## **Conclusion**

Coaching oncology nurses on the job increased spiritual care competences. No effects on job satisfaction were found. Mediating factors could be categorized in nurses' attitudes, support structures, and professional relations. Workplace learning proved to be an effective learning strategy, because of the involvement of nurses in the development of the training program and favorable conditions such as workplace culture, integration in existing work structures, management support, and good personal relations.

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## Appendix 1. Questionnaire

### Case mix

- 1| Gender
- 2| Year of birth
- 3| Highest level of education
- 4| Current position
- 5| Number of years of work experience
- 6| How often were you present during the coaching on the job meetings?

### SCCS

- 1| I am open to a patient's beliefs, even if they differ from my own – *attitude*
- 2| I do not try to impose my own beliefs and world view on a patient – *attitude*
- 3| I am aware of my personal limitations when dealing with a patient's beliefs – *attitude*
  
- 4| I can listen actively to a patient's 'life story' in relation to his or her disease – *communication*
- 5| I have an accepting attitude in my dealings with a patient (involved and open) – *communication*
  
- 6| I can tailor care to a patient's meaning-related needs/problems in consultation with the patient – *assessment and implementation*
- 7| I can report in writing on a patient's meaning-related needs/problems – *assessment and implementation*
- 8| I can report orally on a patient's meaning-related needs/problems – *assessment and implementation*
- 9| I can tailor care to a patient's meaning-related needs/problems through multidisciplinary consultation – *assessment and implementation*
- 10| I can record the patient's meaning-related care in the medical record/nursing plan – *assessment and implementation*
  
- 11| I can effectively assign care for a patient's meaning-related care needs to another care provider/care worker/care discipline – *referral*
- 12| At the request of a patient with meaning-related needs, I can in a timely and effective manner refer him or her to another care worker or own confidant (e.g. a therapist/coach, imam, pastor) – *referral*
- 13| I know when I should consult a spiritual advisor concerning a patient's meaning-related care – *referral*
  
- 14| I can provide a patient with meaning-related care – *personal support and patient counselling*
- 15| I can evaluate the meaning-related care I have provided in consultation with the patient and in the disciplinary/multi-disciplinary team – *personal support and patient counselling*



- 16| I can give a patient information about meaning-related facilities within the hospital (e.g. spiritual care, Blue Zone, silence center) – *personal support and patient counselling*
- 17| I can help a patient continue his or her daily meaning-related practices (e.g. reading, listening to music, writing, meditating, praying) – *personal support and patient counselling*
- 18| I can attend to a patient's meaning during the daily care (e.g. physical care)
- 19| I can refer members of a patient's family to a relevant expert if they ask me and/or if they express meaning-related needs (e.g. to another health care provider, spiritual carer, own confidant, or a center for life questions like ZinPlus) – *personal support and patient counselling*
  
- 20| Within the department, I can contribute to quality assurance in the area of meaning-related care – *professionalization and quality improvement*
- 21| Within the department, I can contribute to professional development in the area of meaning-related care – *professionalization and quality improvement*
- 22| Within the department, I can identify problems relating to meaning-related care in peer discussion sessions – *professionalization and quality improvement*
- 23| I can coach other care workers in the area of meaning-related care delivery to patients – *professionalization and quality improvement*
- 24| I can make policy recommendations on aspects of meaning-related care to the management of the nursing ward – *professionalization and quality improvement*
- 25| I can implement a meaning-related care improvement project in the nursing ward – *professionalization and quality improvement*

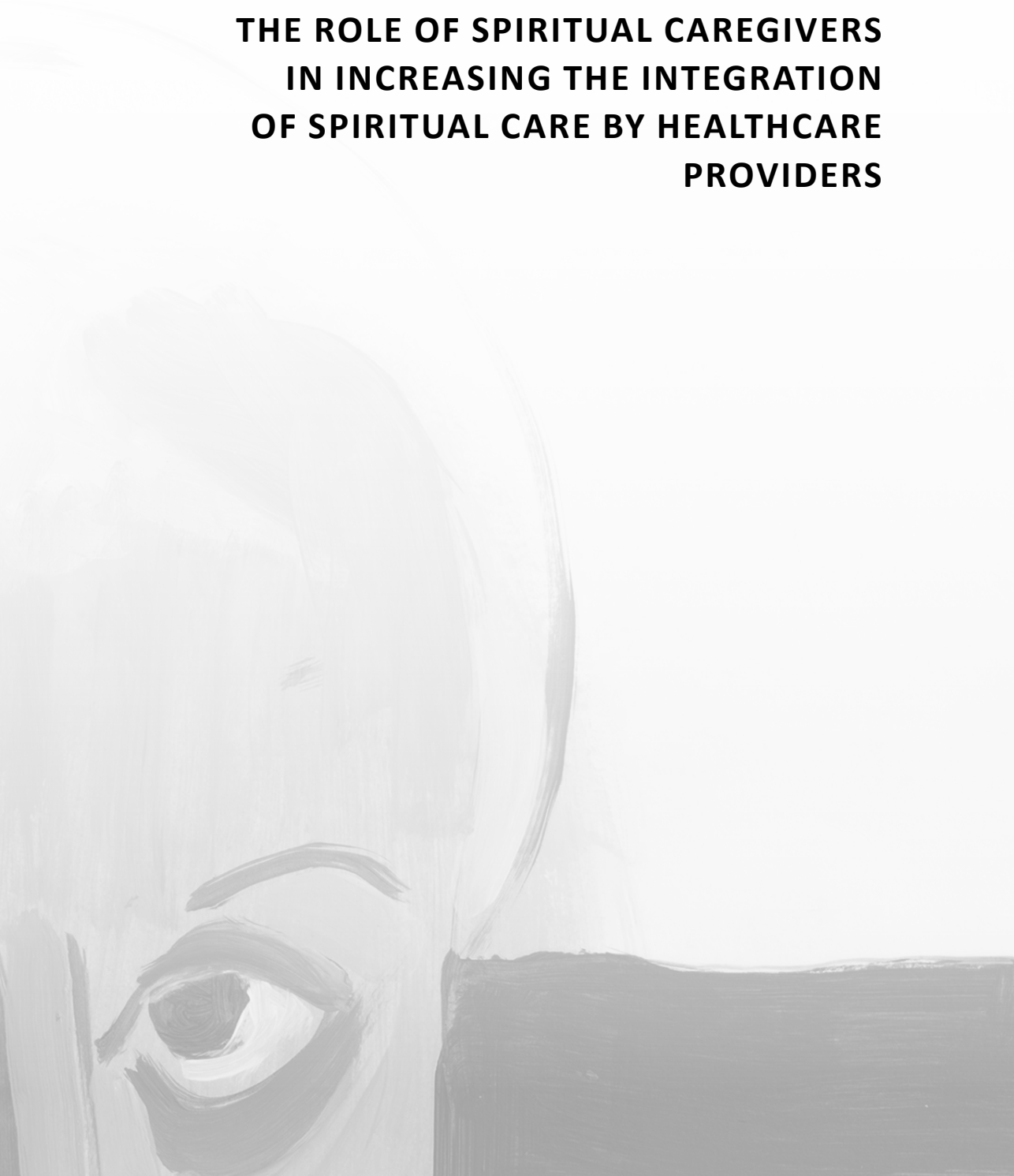
### **Job satisfaction (scale WBS)**

- 26| I experience quality of life/am satisfied with my life
- 27| I feel involved with the patient
- 28| I feel involved with the family of the patient
- 29| I feel involved with myself/know what is of importance to me
- 30| I experience anxiety about the dying process
- 31| I experience anxiety about death
- 32| I feel satisfied about my work
- 33| I feel my work is meaningful
- 34| I have a good connection with my colleagues
- 35| I experience work-related stress



# **PART III**

## **THE ROLE OF SPIRITUAL CAREGIVERS IN INCREASING THE INTEGRATION OF SPIRITUAL CARE BY HEALTHCARE PROVIDERS**





# CHAPTER

# 6

## Role-perceptions of Dutch spiritual caregivers in implementing multidisciplinary spiritual care: A national survey

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## Abstract

### Background

During the course of their disease, patients are, apart from suffering physical discomfort, also confronted with psychological, social, and spiritual challenges. However, healthcare professionals often lack the knowledge and skills to address the spiritual dimension and are in need of support for taking this responsibility. Spiritual caregivers are experts in spiritual care, but their contribution to the integration of this care by other healthcare professionals is largely unknown.

### Objective

The aim of this study was to investigate how Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals in the Netherlands, and how they address this role.

### Methods

An online survey was conducted from May until June 2021 among spiritual caregivers working in Dutch healthcare. Data were analysed using descriptive statistics.

### Results

The majority of the 174 respondents answered that they already fulfil a role in the integration of spiritual care by, for example, providing education, coaching on the job, or participating in multidisciplinary consultation. However, the majority of respondents experienced barriers to their contribution, such as confusion of terminology and use of language while collaborating with other healthcare professionals and reluctance to share information.

### Conclusions

While spiritual caregivers realise having the potential to make important contributions to the further process of integration of spiritual care into the daily practice of other healthcare professionals, some practices and perceptions, especially from within their own discipline, may hamper this.

# 1. Introduction

For over 40 years, the biopsychosocial model of Engel (1977) has been used as a multidimensional framework in healthcare, education and research [1]. Moreover, about two decades ago, the WHO reported an increasing awareness of the importance of faith, hope and compassion among both patients and physicians as part of the healing process and relationship [2]. In 2002 the WHO published a definition of palliative care that includes the spiritual dimension as an important dimension of full care [3]. However, in the literature, spirituality is still a highly contested term, often framed within religion and even referred to as a ‘weasel word’ [4,5]. At the same time, while recognising the vagueness of the term, the number of publications on this dimension increases, highlighting the importance of further developing it in health care [5–8]. In 2011, the European Association for Palliative Care (EAPC) defined a European consensus definition of spiritual care: ‘Spirituality is the dynamic dimension of human life that relates to the way persons (individuals 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’ [9]. This definition takes into account the secularisation in Northern Europe and underlines the multidimensionality of the dimension by stressing the fact it consists of existential challenges (e.g., questions concerning identity, meaning and responsibility), value-based considerations and attitudes (what is most important for each person) and religious considerations and foundations (faith, beliefs and practices) [10]. Although the practice is stubborn and the discussion regarding the suitability of the term is still ongoing, this consensus definition offers room within healthcare for spirituality not to be narrowed down to its religious aspects and the work of clergymen [9]. Since then, increasing attention to spiritual care can be found within statement documents of medical societies [11,12].

However, adequate implementation of addressing the spiritual dimension, even within the daily practice of palliative care programs, is still limited and needs more attention [13–16]. Healthcare professionals often lack the knowledge and skills to address the spiritual dimension at the right moment due to only minimal attention to this dimension in their training and education [10,15–18]. Spiritual caregivers are experts in spiritual care, while other healthcare professionals, especially when it comes to seriously ill patients, ideally provide a generalist approach to such care [19,20]. A recent literature review concluded that spiritual caregivers are actually “key personnel” when it comes to increasing the provision of spiritual care by other healthcare professionals [21]. Yet this is not today’s reality [21–23]. Moreover, the integration of spiritual and medical care is generally absent in many healthcare institutions [24]. Spiritual caregivers are mostly consulted when a patient is facing

an existential crisis or has a pronounced concern with finding meaning when health is challenged. Their services are often considered as only ancillary [20,21]. Relatively little outcome-oriented research has been performed on their contributions to healthcare, which is also detrimental to a more integrated approach to spiritual care [16,25].

In the Netherlands, the national multidisciplinary guideline ‘Existential and Spiritual Aspects of Palliative Care’ [26] and the palliative care quality framework [27] both state that any professional who cares for palliative patients should also pay attention to their spiritual concerns. A shared decision-making model for the elderly also explicitly recommends including what is of value to the patient [28]. In the last decade, the positive health model of Machteld Huber has become very popular to also pay attention to the patient’s contextual issues, including the spiritual dimension [29]. However, because of the earlier mentioned reasons, healthcare professionals are in need of support for taking this responsibility: in identifying what is meaningful to the patient, in addressing this in their daily care provision and in integrating such findings into decision-making, care planning and after care. Consensus on the responsibilities of spiritual caregivers in the further integration of spiritual care into healthcare is crucial [30,31]. Therefore, the aim of this study was to investigate how Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals in the Netherlands and how they address this role.

## 2. Materials and Methods

### 2.1. Design

We performed a survey study. The survey was based on literature, including the Dutch

national guideline Existential and Spiritual Aspects of Palliative care [26], and discussions with a team of experts, all working in an academic hospital: a professor in meaningful healthcare (YE), a postdoctoral researcher in contextual and meaningful healthcare (ABW), a medical student (RB), an associate professor ‘Innovation in Spiritual Care’ (WS), and a spiritual care provider experienced in training and educating healthcare professionals (JvM). The Checklist for Reporting of Survey Studies (CROSS) was used for reporting. See Appendix A for the survey. The survey started with demographic questions (e.g., age, gender, years of work experience, worldview, having a mandate or endorsement by a religious or other worldview institution to undertake the work [yes/no], and if yes, which institution). Next, (see Appendix A) 26 questions followed about the participants’ view on the role of other



healthcare professionals in providing care on the spiritual dimension, the role of the spiritual caregiver in increasing the integration of spiritual care by other healthcare professionals in their daily healthcare practice, their current role in coaching, training and guiding other healthcare professionals, and the role of the spiritual caregiver in teamwork. We also explored how, according to the respondents, the various dimensions of care (somatic, psychological, social and spiritual) have a place within the daily provision of care by the various disciplines. A distinction was made between multidisciplinary and interdisciplinary collaboration. Multidisciplinary was defined as: different disciplines work together in a team but remain within their own discipline; interdisciplinary as: different disciplines work together in a team, and each team member also identifies and explores problems outside one's own discipline. In particular, interdisciplinary collaboration requires both spiritual caregivers and other care disciplines to move into the dimension that is the primary dimension for the other. Some questions related to the 'duty of confidentiality' that has its origins in the confessional secrecy of clergy to explore the possible differences and overlaps with confidentiality inherent to all healthcare professions.

Respondents were invited to comment on the answers or to formulate in one's own words alternatives to the possible answers.

The questions mostly used 5-point Likert-scale answering options (e.g., agree, somewhat agree, neutral, somewhat disagree, disagree). Besides, several binary (e.g., "Do you work in a team?" yes or no), open-ended, and multiple-choice questions were asked to provide more insights and nuances on certain subjects. Some questions were conditional; they were only asked if the participants had given a specific answer to a previous question. For example, questions regarding teamwork were only asked if the participant worked in a team. The survey took 10–15 min to complete.

## 2.2. Participants

The Dutch national Professional Association for Spiritual caregivers ("Vereniging van Geestelijk Verzorger", VGVZ) agreed to send the survey by e-mail to all members working in healthcare settings (hospitals, nursing and care homes, revalidation, psychiatry, care for the disabled, youth care and home care). The survey was conducted in May and June 2021. Since the VGVZ never sends email reminders about research to their members, a message on the LinkedIn of the VGVZ and through our own network was used as a reminder. All participants were a regular or prospective member of the VGVZ and working in healthcare, meaning: a hospital, nursing or care home, rehabilitation, psychiatry, youth care, with people with disabilities or in primary care.

### 2.3. Analysis

Q-survey, an online tool to anonymously send and store electronic surveys for research purposes, was used for data collection. Data were exported from Q-survey to Microsoft Office Excel 2016 and then imported to IBM SPSS Statistics 25. Participants were given a unique record-ID. All results were analysed using descriptive statistics.

### 2.4. Ethics

The ethics committee MREC Oost-Nederland declared this study was not subject to the Medical Research Involving Human Subjects Act (WMO), file number 2021-8292. The information for participants was made with the guidance of the Integrated Quality System scientific research of the Radboudumc. Questions were filled out anonymously. Data will be saved for 15 years; only the study team and research management team of the department have access to it.

## 3. Results

The survey was emailed to 908 spiritual caregivers, of which 414 survey emails were successfully received and opened. Two participants were excluded; one because of failure to provide informed consent and the other because the inclusion criteria were not met. A total of 174 surveys out of 414 (42%) were completed. Characteristics of study participants can be found in Table 1.

**Table 1.** Characteristics of respondents

	N (%)
Number of respondents	172
<b>Gender</b>	
Male	53 (31)
Female	117 (68)
Other (e.g., non-binary)	2 (1)
<b>Age</b>	
21-30	10 (6)
31-40	18 (10)
41-50	30 (17)
51-60	67 (39)
61-70	43 (25)
71-80	2 (1)
Missing	2 (1)

**Table 1.** Continued.

	N (%)
<b>Years of work experience</b>	
0-10	98 (57)
11-20	41 (24)
21-30	24 (14)
31-40	8 (5)
Missing	1 (1)
<b>Worldview:</b>	
Atheism	0
Buddhism	0
Catholicism	41 (24)
Hinduism	0
Humanism	14 (8)
Islam	2 (1)
Judaism	0
Protestantism	67 (39)
A combination of beliefs	39 (23)
None	1 (1)
Other	8 (5)
<b>Endorsement or mandate</b>	
by a religious or worldview institution	90 (52)
from the Council Non-Denominational Spiritual Caregivers (RING-GV) <sup>1</sup>	57 (33)
Neither	25 (15)

<sup>1</sup> This council screens the competence of all spiritual caregivers who do not have a mission from a church or worldview institution.

### 3.1. Joint Task

Almost all respondents (167; 97%) agreed or somewhat agreed that not only spiritual caregivers but also other healthcare professionals should pay attention to spiritual care in their daily care provision. (Q13) Likewise, almost all respondents agreed or somewhat agreed (166; 97%) that identifying and exploring spiritual issues is a joint task of both the spiritual caregivers and other healthcare professionals. (Q14) One of the respondents phrased it as follows: “The person seeking care is a complete human being, who cannot and does not need to be divided into different parts depending on which healthcare professional she/he is seeing. It is up to the caregivers to identify what is going on, what they can address themselves and where they need to collaborate with or refer to colleagues from other disciplines”. If other healthcare professionals also pay attention to the spiritual dimension, this may contribute to more referrals to the spiritual counsellor. In the words of a respondent working in care for the elderly: “Since, as a spiritual caregiver, you are frequently called in by

other disciplines, it is important that other disciplines also identify and explore what is going on with residents in terms of meaning". One in four respondents (43; 26%) agreed or somewhat agreed that other healthcare professionals already sufficiently identify spiritual issues, however, two-thirds of the respondents (119; 69%) agreed or somewhat agreed that the subsequent exploration by other healthcare professionals of these issues lags behind. (Q15 & Q16) In addition, the majority of respondents (160; 93%) agreed or somewhat agreed that it is one of their tasks to contribute to the increased identification and exploration of spiritual issues by other healthcare professionals. (Q25)

### 3.2. Current Contribution

A majority of the respondents (105; 78%) agreed or somewhat agreed that they already contribute to a more integrated identification and exploration of spiritual issues by other healthcare professionals, mainly by educating their colleague healthcare professionals (105; 78%). In the words of a respondent: "In collaboration with the psychologist or social workers, they too can discuss the end of life, guilt or grief. Because I train them, I empower them. ( . . . ) I am the only spiritual caregiver and I cannot be present everywhere". Often mentioned was the role of giving feedback to other healthcare professionals when the spiritual caregiver observed that they were missing a spiritual issue (74; 55%), participating in a multidisciplinary consultation or a consultation on a patient's treatment plan (107; 80%) and involvement in moral case deliberations (91; 68%). (Q17) Only a minority contributes to teaching at training institutes for healthcare professionals or to coaching other healthcare professionals in the course of their work (27; 20%). Few respondents (15; 11%) coach other healthcare professionals on the job. (Q18) One respondent shared the following experience on this: "Healthcare professionals can be somewhat wary when it comes to spiritual issues, even though they often already do a lot well in this respect; that's what I notice when I discuss something that has happened in the care they provided. It helps then to point out their instincts, intuition and gut feelings and 'to soften their heads'. And I combine that with more information about loss, grief, life stories, hope and sources of strength. They are often open to that".

### 3.3. Appreciation of Spiritual Caregivers/SCPs' Contribution

Most respondents usually or always experience positive reactions when they share their expertise with other healthcare professionals (146; 84%): (Q19) "Mostly, there is recognition of the importance of spiritual care and the insight that this can be found in small things. Enthusiasm is contagious. The ability to identify what is causing friction in a given situation is also considered valuable". But negative reactions are also sometimes (28; 16%;) or always (2; 1%) experienced: "Sometimes there is resistance, often beforehand, to spiritual care in general because of people's own image of it,

and then you can hardly get through that". (Q21). About one in four respondents (47; 27%) sometimes experience resistance from other healthcare professionals when they want to share their expertise: "Other healthcare professionals (such as nurses and therapists) are often busy with the primary process and experience a question about meaning as "troublesome "or "complicated". However, most respondents (123; 72%) never or usually do not experience such resistance. "Usually other disciplines are happy with the added value I bring regarding meaning". (Q23).

Several respondents also commented in their own words on the overlap of their work with that of psychologists or social workers. According to some of them, this can be positive but, according to others, it can also have a negative influence when sharing their expertise. For example: "What is missing here in the hospital is a team spirit among the psychosocial disciplines. There is a lot of resistance and fear that the work will be "taken away". I would like to see more of a team feeling; everyone has their own expertise, but there will also be some overlap. In my opinion, good communication and complementarity can only benefit healthcare". But also: "Together with psychology and social work, we have developed a referral scheme for other healthcare professionals, so that they know where to go with what question. This is considered helpful".

### 3.4. Modes of Collaboration

The majority of respondents (142; 83%) indicated that they work in collaboration with other healthcare professionals or form a team with them. (Q26) Of those respondents who collaborate, about half (91; 53%) said it is mainly multidisciplinary, while about a third (50; 29%) said it is interdisciplinary. Asking their opinion about the best mode of team collaboration, almost half (77; 44%) found interdisciplinary or somewhat interdisciplinary collaboration the best, while about a fourth (39; 23%) hold the view that multidisciplinary or somewhat multidisciplinary collaboration is best. One respondent argued: "Only working in a multidisciplinary way chops it up too much, recognising too little connection. Only interdisciplinary undermines the expertise too much and then the client loses the overview in care providers". Another respondent noted: "Everyone is a specialist in their own discipline; that argues for multidisciplinary. Then there is overlap; that argues for interdisciplinary".

### 3.5. Barriers in Collaboration

Language and terminology confusion regarding spiritual care was reported by two-thirds of the respondents (69; 62%) as being sometimes or usually a barrier to collaboration. (Q35) Some respondents described their own share in this: "Spiritual caregivers usually do not succeed in explaining their work in understandable language to others. They use too much of their own vocabulary". It has also been

argued that it is due to the language of the discipline, or as one respondent puts it: “Language, related to issues of meaning, is often not everyday language. Terms such as existential, spirituality, meaningfulness and ethics are wide-ranging and “vague”, and are (usually) not part of the “normal” language used by other healthcare professionals. This can widen the gap between healthcare professionals and spiritual caregivers, creating a situation where they speak to each other less often”. Not being conversant with the profession of spiritual caregivers was also mentioned: “So if people no longer think that you only come for religious matters, they think that you are half a psychologist. And then you’d better get a psychologist right away”. Only a few (5; 4%) never experienced vocabulary confusion with colleagues from other disciplines. (Q35). That their work is interpreted as that of a cleric or mainly related to religion came up several times in the open text fields. As one respondent put it: “There are referrers who think we are pastoral workers who come for spiritual (read: church) guidance and to talk about faith issues”.

For quite some respondents, the ‘duty of confidentiality’, specific to the profession of a spiritual caregiver, hinders sometimes (33; 32%) or usually (3; 3%) the collaboration with other healthcare professionals, while this is not the case for half of them (usually not 53; 52%) (Q33). As one respondent put it: “Maybe it is because I have only been working as a spiritual caregiver for a short time, but I am still searching. How do I do justice to the duty of confidentiality and how can I contribute to the entire healthcare delivery process? It sometimes feels like a balancing act, where confidentiality is paramount and therefore I share little with other healthcare professionals or only in general terms”. Only a small minority (8; 13%) never experienced this as an obstacle in the collaboration with other healthcare professionals.

6

Accordingly, responses showed reluctance to share information about a patient with other healthcare professionals, even when this information is relevant to the medical team, and the patient has given permission to share it within the team. As one respondent put it: “I want to emphasise that I often find it a difficult balancing act. Sometimes I share with the doctor what is relevant, for example if there is a risk that a choice is made that is undesirable for the patient”. In a patient file, one in five respondents (30; 21%) never or usually does not share information about a patient with other healthcare professionals, one in five does it sometimes (30; 21%), and more than half (82; 58%) does it usually or always. (Q 31a) One of the respondents noted: “In the hospital, a short note is made in the file. In the rehabilitation centre, no information has been shared so far, but soon the spiritual caregiver will be part of an outpatient team and the outcome of the meaning assessment will be shared with the team, after the patient’s approval, via the patient file”. Verbally sixteen per cent (22; 16%) of the respondents never or usually do not share information

about a patient with other healthcare professionals, and over half (85; 60%) do it sometimes, and one out of four (35; 25%) does it usually or always. (Q31b) During a multidisciplinary meeting or a meeting about the patient's treatment plan, one in five (31; 21%) never or usually does not share relevant information about a patient, forty-one per cent (58; 41%) does this sometimes, and around the same percentage (53; 37%) does it usually or always. (Q31c) When they do share such information, it is often with a nurse (173; 74%) or physician (103; 73%) and half of the cases with a healthcare assistant (68; 48%).

## 4. Discussion

Of the total 172 Dutch spiritual caregivers who completed the survey, three-quarters said they already contribute to enhancing the integration of spiritual care provided by other healthcare professionals: by teaching and coaching them on the job, by participating in multidisciplinary consultations, consultation on the patient's treatment plan, or through participation in moral deliberation. However, it remained unknown whether these contributions are incidental or structurally embedded in their daily practice. And despite this relatively favourable picture, respondents pointed to several barriers that stand in the way of a solid profiling of their profession. These barriers were recently also identified as a research priority among Dutch spiritual caregivers [32]. Language confusion regarding spiritual care emerged as one such barrier among almost all respondents. Handzo et al. argued that such confusion occurs as spiritual caregivers use 'their own idiosyncratic language' [33]. It is about communication that is often cumbersome, full of jargon and gets in the way of a good exchange of information between the spiritual caregiver and other care professionals [33,34] (p. 199–204). Until a few years ago, all spiritual caregivers in healthcare had a mission from an ideological, often religious, denomination which may also have reinforced (adherence to) jargon [6]. Incidentally, Bracken et al. emphasise that all disciplines have their own use of language, so intelligibility is a key factor in interdisciplinary cooperation anyway: "Common understanding derived from shared languages, in turn, plays a vital role in enhancing the relations of trust that are necessary for effective interdisciplinary working" [35]. Adding to this, other healthcare professionals may frame the contribution of a spiritual caregiver in terminology with which the spiritual caregivers, in turn, can only partly identify [36,37]. This poses a particular challenge for spiritual caregivers, as they often see themselves as the much-needed translators of the patient's lived experience in the world of healthcare provision [38]. Therefore, curricula for spiritual caregivers should also focus on communication with other healthcare providers. More specifically: on communication in multidisciplinary consultations and team meetings and on reporting in patient files [37]. This education should be up to date with current affairs and insights,

including the ability to understand and use the practices and language of both patients and colleagues from diverse backgrounds and disciplines (e.g., nurses and physicians). This, among others, can be reached by employing language and practices that build upon commonalities rather than differences [39]. This approach can, in turn, contribute to arriving at a common, multidisciplinary language for, teamwise, identifying and responding to spiritual struggles [40]. The ‘duty of confidentiality’ appeared to be a barrier for about one in three respondents in sharing any information from the patient orally or via the electronic medical record, and thus in optimal collaboration with other healthcare professionals. This finding is remarkable, as in the Dutch context, there are actually no impediments for spiritual caregivers to be communicative in a team setting, given each healthcare professional is strongly bound by medical confidentiality outside a patient’s care team. According to the Dutch Professional Standard on Spiritual care, the spiritual caregiver is allowed to share information with other healthcare professionals if the information is relevant to and shared in the context of a joint care assignment and provided the patient has given consent [41]. This is also in agreement with the 2014 Dutch national guide ‘The Professional confidentiality in collaborations’, which was approved by eight associations of healthcare professionals [42]. Nevertheless, some spiritual caregivers experience the duty of confidentiality in daily healthcare provision as a balancing act [34] (p. 66–87). This can be attributed to the strict confidentiality of pastors, pastoral workers and clergy who visit patients from faith communities. Sending agencies have never adapted this for today’s spiritual caregivers operating in healthcare and within teams. However, not sharing relevant patient information, also regarding the spiritual dimension may result in inappropriate care [34] (p. 66–87). Moreover, in communicating information obtained from a patient within the team caring for this patient, spiritual caregivers make themselves known as reliable colleagues and thus also have the opportunity to educate other healthcare professionals on the integration of spiritual care in daily practice [37]. The reported reluctance of responding spiritual caregivers to share information is incidentally in line with that of their European colleagues [37].

### **Strengths and Limitations**

This is the first study that examined whether guideline recommendations on interdisciplinary spiritual care are applied in practice. Another strength of this study is that it connects perfectly with a recent survey on research priorities among Dutch spiritual caregivers, a study that highlights the importance of research into developing a stronger profile of their profession [32]. However, this study also has limitations. Part of the invitations to participate did not reach potential participants. Moreover, spiritual caregivers who are already involved in this subject matter, or have a strong opinion on it, might have been more inclined to fill in the survey and consequently have caused bias. This strengthens our findings, as we expect that non-responders



will experience even more barriers. Furthermore, it remained unknown whether the reported contributions were incidental or structurally embedded in daily practice. Therefore, we suggest future qualitative and quantitative, preferably international research, to get a clearer picture on this.

## 5. Conclusions

Spiritual caregivers in our survey realise that they have the potential to make important contributions to the further process of integration of spiritual care into the daily practice of other healthcare professionals. However, spiritual caregivers' use of language or jargon and their reluctance to share information within the treatment team hamper this. We recommend further research into this, both within and outside the Netherlands. Moreover, if spiritual caregivers in the Netherlands want to avoid being regarded as an 'allied healthcare profession', we also recommend the Dutch professional association of spiritual caregivers and the sending agencies to clearly define the overlap and difference of confidentiality inherent to all health care professions, and 'clergy confidentiality' in their policy and guidelines.

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## Appendix A. Survey

Part I : demographic questions (not shown)

Part II : role of spiritual caregiver/questions 13 – 36 (below)

role of spiritual caregiver

### Used definitions:

#### ***Spirituality***

We adopt the **consensus definition of the European Association for Palliative Care (EAPC)**: *‘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.’*

#### ***Other healthcare professionals***

In the questions, we often talk about **other healthcare professionals**, by this we mean all healthcare professionals (mainly physicians and nurses) **except** spiritual caregivers.

#### ***Care recipient***

The term **care recipient** was chosen because, depending on the setting one works in, the person one cares for is called differently (patient, client, resident, etc.).

13. Other healthcare providers should also pay attention to spiritual care of care recipients in daily care provision
  - a. Disagree
  - b. Somewhat disagree
  - c. Neutral
  - d. Somewhat agree
  - e. Agree
  
14. Identifying and exploring spiritual issues of care recipients is a joint task of spiritual caregivers and other healthcare providers
  - a. Disagree
  - b. Somewhat disagree
  - c. Neutral
  - d. Somewhat agree
  - e. Agree

15. Identifying spiritual issues: other healthcare providers already do this sufficiently
- Disagree
  - Somewhat disagree
  - Neutral
  - Somewhat agree
  - Agree
  - I don't know
16. Exploring spiritual issues: other healthcare providers already do this sufficiently
- Disagree
  - Somewhat disagree
  - Neutral
  - Somewhat agree
  - Agree
  - I don't know
17. Within my current work, I contribute to more integration - of identifying and exploring spiritual issues of care recipients - by other healthcare providers in their daily healthcare practice
- Disagree
  - Somewhat disagree
  - Neutral
  - Somewhat agree
  - Agree

**Your current role in coaching & training other healthcare providers**

18. (only applicable if for question 17 'Somewhat agree' or 'Agree' was answered) How do you contribute to increasing the integration of spiritual care by other healthcare professionals in their daily healthcare practice? *multiple answers possible*
- Teaching other healthcare providers
  - Giving lessons in educational institutes of future healthcare providers
  - Feeding back to other healthcare providers when I observe them missing/ignoring a spiritual issue
  - Coaching other healthcare providers on the job
  - Joining in multidisciplinary meetings and/or meetings about patients' treatment plans
  - Systematically integrating the spiritual dimension during a multidisciplinary meeting and/or a meeting about patient's treatment plan
  - Joining 'PatZ'-groups\*
  - Involvement in moral deliberation
  - Participation in a scientific study about the integration of spiritual care by other

- healthcare providers in their daily work (other than this survey)
- j. Other, namely: ...  
\*PaTz stands for palliative care at home ('Palliatieve zorg Thuis') and concerns collaboration between GPs, (district) nurses and palliative care experts.
19. I experience positive reactions when I share my expertise of spiritual care with other healthcare providers
- Never
  - Usually not
  - Sometimes
  - Usually
  - Always
  - Does not apply
20. If 'Usually' or 'Always' -> Would you explain? (open question)
21. I experience negative reactions when I share my expertise of spiritual care with other healthcare providers
- Never
  - Usually not
  - Sometimes
  - Usually
  - Always
  - Does not apply
- 22 If 'Usually' or 'Always' -> Would you please explain? (open question)
23. I experience resistance from other healthcare providers when I share my expertise of spiritual care
- Never
  - Usually not
  - Sometimes
  - Usually
  - Always
  - Does not apply
24. If 'Usually' or 'Always' -> Would you please explain? (Answer will be typed in)

25. It is the task of the spiritual caregiver to contribute to more identification and exploration of spiritual issues of care recipients by other healthcare providers in their daily healthcare practice
- Disagree
  - Somewhat disagree
  - Neutral
  - Somewhat agree
  - Agree
26. I am part of a team/work together with other healthcare providers
- Yes
  - No
27. If so; the work is mainly
- Multidisciplinary
  - Interdisciplinary
  - Not filled in, since it was a conditional question

28. It is best if a team; n (%)

*Multidisciplinary: different disciplines work together in a team, but stick to their own discipline. One remains with one's own profession.*

*Interdisciplinary: different disciplines work together in a team in which there is overlap between disciplines, one also identifies and explores issues or problems outside one's own discipline.*

- Works multidisciplinary
- Works somewhat multidisciplinary
- Does a bit of both
- Works somewhat interdisciplinary
- Works interdisciplinary

29. Please explain (open question)

30. Spiritual caregivers should also have attention for the somatic, psychological, and social dimension
- Disagree
  - Somewhat disagree
  - Neutral
  - Somewhat agree
  - Agree



31. a (Only if 26 answered with 'Yes') After consultation with a patient I share, via the patient file, what has been discussed with other healthcare providers; if the patient gives permission and it is relevant
  - a. Never
  - b. Usually not
  - c. Sometimes
  - d. Usually
  - e. Always
31. b (Only If 26 answered with 'Yes') After a consultation with a patient I share verbally, if the patient gives permission and it is relevant, what has been discussed verbally with other healthcare providers
  - a. Never
  - b. Usually not
  - c. Sometimes
  - d. Usually
  - e. Always
31. c (Only if 26 answered with 'Yes') After consultation with a patient I share with other healthcare providers what has been discussed during a multidisciplinary meeting or a meeting about patient's treatment plan, if the patient gives permission and it is relevant
  - a. Never
  - b. Usually not
  - c. Sometimes
  - d. Usually
  - e. Always
32. If at 26 Yes -> If the patient gives permission and it is relevant, I share what I have discussed with the patient with (multiple answers possible)
  - a. The healthcare assistant
  - b. The nurse
  - c. The doctor
  - d. I never share what is discussed with other healthcare providers
33. If at 26 Yes -> I experience confidentiality obligation towards other healthcare providers within the treatment team
  - a. Disagree
  - b. Somewhat disagree
  - c. Neutral
  - d. Somewhat agree
  - e. Agree

34. Only if 33 is answered with 'Agree' or 'Somewhat agree' -> This duty of confidentiality hinders the collaboration with Other healthcare providers within the treatment team
- Never
  - Usually not
  - Sometimes
  - Usually
  - Always
35. If at 26 Yes -> Language confusion around spiritual issues hinders the collaboration with other healthcare providers within the treatment team, n (%)
- Never
  - Usually not
  - Sometimes
  - Usually
  - Always
  - Does not apply
36. If 35 is answered with 'Usually' or 'Always' -> Would you please explain? (Answer will be typed in)

Thank you and closing page

This is the end of this survey.

Thank you for your participation.





# CHAPTER

General Conclusions &  
Discussion

7

In 2002 the WHO published a definition of palliative care that includes the spiritual dimension as an important dimension of care. [1] In the Netherlands, the national multidisciplinary guideline ‘Existential and Spiritual Aspects of Palliative Care’, [2] and the palliative care quality framework, [3] both state that any professional who cares for seriously ill or palliative patients, should also be attentive to their spiritual concerns, to how they make sense of what is happening to them. A shared decision making model for elderly also explicitly recommends to include such an exploration. [4] Additionally, in the Netherlands the positive health model of Machteld Huber has become very popular to also pay attention to the patient’s contextual issues, including the spiritual dimension.[5]

Globally, there is growing interest among physicians and nurses in spiritual care, especially within the care of critically ill and palliative patients. However, when I started the research as described in this thesis, it was insufficiently known whether and to what extent this care is actually provided in day-to-day care. *Therefore, the aim of this thesis was to find out if and how physicians and nurses identify and explore spiritual needs of their patients in daily care giving and to investigate the effects of two interventions to increase their awareness and skills on exploring this dimension. Moreover, we studied how Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals.*

All studies in this thesis were conducted in the Netherlands.

## Main findings and conclusions

### PART I: Observing daily practice of health care professionals

#### ***Nurses on an oncology ward do identify possible spiritual issues of their patients but don’t explore them (chapter 2)***

In our first study, we wanted to gain insights in the way and extent to which nurses during daily caregiving observe and explore spiritual issues of hospitalized patients with cancer. We performed an ethnographic study with participant observation. Observed was if and how nurses addressed spiritual issues of their patients and whether the Mount Vernon Cancer Network tool, as represented in de Dutch Spiritual Care Guideline, was used.

Although the patients did send many implicit and explicit messages concerning spiritual issues, the nurses did not explore them. If noticed, three barriers for

exploring spiritual issues were mentioned by the nurses: lack of time, conflict with their mindset, and being reluctant to talk about these issues.

We concluded that hospitalized patients provide many opportunities to nurses to explore the spiritual dimension, but nurses don't explore them. To close this gap, nurses should be coached or trained to allow them to naturally, and in a way commensurate with their work, explore the spiritual dimension of patients and to identify the need for specialist counselling and crisis intervention.

***Medical oncologists can encourage patients to share what matters most to them when raising a lived illness experience, but often they do not (chapter 3)***

We conducted an observational study to gain insights into whether and how medical oncologists working at an outpatient clinic identify and explore lived illness experiences raised by patients with advanced cancer, and how this influences patients' responses. In most of the observed consultations, patients did raise lived illness experiences. In line with our first study within nurses' daily care providing, it was found that patients directly or indirectly initiated talking about what concerns them most.

We concluded that when a patient with advanced cancer introduces a lived illness experience, it helps when the medical oncologist identifies and explores it by producing a continuer or by trying to capture this experience in their own words. Patients did not elaborate on their experiences in cases where oncologists responded with optimistic talk or presented more medical evidence.

Our findings give clear directions to improve person-centred communication. Training or support is needed to help medical oncologists to become more alert to raised lived illness experiences of patients, to actively listen to patients who spontaneously introduce such issues and to adequately react. Although our study did not examine the reasons for exploration or not, previous studies showed that oncologists often find it challenging to talk to patients about the impact of illness, their life and death. [6] [7] To acquire dedicated competences in the exploration of raised lived illness experiences we recommend interactive training or coaching on the job. [8] Moreover, we recommend that what has been trained should then be frequently highlighted, for example during patient handovers or case discussions. [9]

These first two studies revealed that *patients themselves provided the observed nurses and oncologists many opportunities to respectively explore spiritual issues or lived illness experiences*. Two previous studies, a survey and an interview study, also indicated that communication on spiritual issues is often initiated by patients themselves. [10] [11]

Because of experienced barriers, the nurses in our study did not engage in exploration of the observed signals. Among the medical oncologists, reasons for exploration or not were not investigated. *When the oncologists did pay attention to the lived illness experience, consultations did not last longer than those where this was not addressed*, which is consistent with previous findings. [12] Interestingly, in those conversations where the patient elaborated most on the lived illness experience, *the computer screen and keyboard were put aside*. Earlier research showed that physicians' simultaneous use of a computer and speech compromises communication skills [13], and that the computer is often a distracting source of information [14]. And although it was not part of our study, after one observation I did talk about this with one of the oncologists. He then shared a personal experience about his own GP not touching the keyboard during a consultation with him: "This impressed me; I found it reassuring. If it is not really necessary, I no longer use the computer during a consultation."

Due to the choice of Conversation Analysis as a method to analyse the patient - oncologists conversations in chapter 3, we operationalised 'spiritual issues' to 'lived illness experiences'. To what extent a (further) exploration of the raised lived illness experiences would also reveal spiritual concerns was beyond the scope of this study. However, when I escorted the patients to an adjacent room after the consultation, a small conversation often unfolded in which they told me what concerned them most. One patient stressed throughout the consultation that he wanted to receive all possible curative oncological treatments even if they had considerable side effects or just a small chance to have positive results. After the consultation, he shared about a disabled and sick daughter for whom every day of his life is of great meaning and whom he wants to care for as long as possible.

Patients and their proxies confronted with a life-threatening disease highly value attention from their health care providers to what concerns them most. [5] [15] Moreover, Weiner et al. denote 'listening to what matters' as efficient healthcare provision 'because it uncovers the actual underlying issues that account for the presenting problem'. [9] Overlooking the patient's life context may even result in inappropriate and costly care. [12] Exploring how patients make sense of what is happening to them, or what occupies them most, is fundamental for broader, important concepts such as patient centred care, multidimensional pain treatment, advance care planning, and shared decision making. Quite possibly there is even overlap with research on the intuitive identification by nurses of patients' deterioration. After all, this too involves a 'concern' about an individual patient that requires exploration so that patient-centred care can be realised. [16] I believe our findings provide clear guidance for improving the quality of such communication, not at least because they were drawn from daily practice of nurses and doctors.



## PART II: Training and coaching health care professionals

### *An interactive training intervention increased multidisciplinary palliative care professionals' competences in identifying and exploring patients' spiritual dimension and its integration in care planning (chapter 4)*

From the previous two studies we concluded that during patient - health care professional contacts, patients provide many opportunities to explore their search for meaning and their spiritual concerns. Previous studies revealed that addressing these concerns is important for proactive care planning and can influence the quality of patients' lives and care utilisation. [17] [18] Moreover, as their content and meaning can only be identified by multidimensional exploration, [19] these concerns often remain unrecognised, and thus remain unexplored. [20] [21] [22] [12] A dedicated training intervention for health care providers that integrated recommendations from a national guideline on existential and spiritual aspects of palliative care gave promising results. [2] [23]

We therefore conducted a mixed methods pre-post study to evaluate the effects of an interactive communication training intervention for transmural palliative care teams in identifying and exploring patients' spiritual dimension and its integration in proactive care planning. Its content was based on the Dutch national guideline 'Existential and Spiritual Aspects of Palliative Care'. During the intervention, three (non-validated) tools from this guideline were used to explore spiritual issues in non-crisis situations: the Ars Moriendi tool, 'Weiher's Four layers of meaning' tool and the Mount Vernon Cancer Network assessment tool. We studied the effects of the training by comparing the answers on self-assessment questionnaires, comments on videos of simulated consultations and a medical record review before and after the intervention. The analyses showed a significant increase of participants' competences in identifying and exploring patients' spiritual needs, and its integration in multidimensional proactive palliative care plans.

Training with training actors allowed for optimal approximation of situations in daily care practice. Our results align with previous studies that demonstrate promising effects of simulation based learning on team processes and patient outcomes. [24] [25] As a next step, research by Randomized Controlled Trials (RCTs) such as those by Tilburgs et al, is needed to confirm our findings. [26]

Differences between pre-test and post-test measurements demonstrated a clear impact on spiritual care competences (self-assessment), increased attention to patients' aims and needs combined with a decreased focus on the clinical agenda (applied competence), and an increased use of the Mount Vernon Cancer Network

(MVCN) assessment tool and anticipation on the non-somatic dimensions of care in patient records (implementation). We assume that the combination of a communication training using the basic concepts of the national guideline, training in team context, and the variety of training methods including the use of patient actors were responsible for the positive outcomes. We recommend that our findings be considered in future education and training interventions.

### ***Meaning-centred coaching on the job of oncology nurses increases their spiritual care competences (chapter 5)***

As shown in chapter 2, specifically in the oncology ward, nurses spend time with hospitalized patients with cancer. Giving them a well-placed and important role in providing spiritual care can increase quality of care for and quality of life of patients with cancer as well as job satisfaction of nurses, all of which is now often suboptimal. For that reason we implemented a meaning-centred ‘coaching on the job’ intervention, and measured its effects on oncology nurses’ spiritual care competences and job satisfaction, and factors influencing this. A participatory action research approach was adopted. Thirty nurses participated. A significant increase in spiritual care competences was found, particularly regarding communication, personal support and professionalization. More self-reported awareness of personal experiences in caring for patients, and an increase in mutual communication and involvement around meaning-centred care provision as a team were found. Mediating factors were related to nurses’ attitudes, support structures and professional relations. No significant impact was found on job satisfaction, which was already quite high before the intervention.

A significant overall increase in their spiritual care competences was found. Specifically, competences in *communication*, *personal support* and *professionalization* increased. Nurses described an increased awareness of their own experience of taking care of patients and a developed ability to distinguish their own values from those of the patient. The intervention led to normalizing discussions between nurses on what matters most for patients, and a conscious focus on the actual care provided to patients. Several mediating factors were identified influencing spiritual care provision, which could be categorized in the nurses’ attitudes, support structures and professional relations.

*One of our key findings was that nurses had difficulty recognizing their own values and differentiating them from the patients’.* This confirms a study showing that addressing healthcare providers’ personal values and meaning is the strongest factor to improve spiritual care provision.<sup>30</sup> Training should therefore not just focus on providing patient-centred care, but also include attention to the providers’ experience. This

includes, which is a challenge in a 'culture of busyness', learning to pause and reflect, which requires a supportive work culture, optimal physical and work structures, the support of management and good personal relations.<sup>33</sup>

Study results are in line with insights on effective workplace learning.<sup>41-43</sup> By using the existing work structures for workplace coaching on the job, necessary infrastructure was put in place to support learning. Doing this ensures learning is embedded in the organization, especially relevant given the large turnover of nurses.<sup>44</sup>

Like in the training intervention as described in chapter 4, integration of the Mount Vernon question (*What are you most occupied with at the moment?*) into the electronic patient record proved to be an important catalyst.

### **PART III: The role of spiritual caregivers in the process of integration of spiritual care into daily practice of other healthcare professionals**

***Dutch spiritual caregivers do realise they have an important role in the process of integration of spiritual care into daily practice of other healthcare professionals, but confusion caused by their vocabulary and reluctance to share information appeared to be barriers (chapter 6)***

Drawing from prior studies [27] including chapters 4 and 5 of this thesis, we hypothesised that spiritual caregivers may have a significant role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals.

We conducted an online survey among Dutch spiritual caregivers working in Dutch healthcare and all members of the professional association for spiritual caregivers. Data were analysed using descriptive statistics.

The majority of the responding spiritual caregivers answered that they already have a role in the integration of spiritual care in daily clinical practice by, for example, providing education, coaching on the job, or participating in multidisciplinary consultation. However, it remained unknown whether these contributions are incidental or structurally embedded in their daily practice.

Despite the relatively favourable picture they painted of their role, respondents also indicated several barriers to improve the impact of their profession. Language confusion regarding spiritual care emerged as one such barrier among almost all respondents. Also the 'duty of confidentiality' appeared for about one in three respondents a barrier in sharing any information from the patient and thus in optimal

collaboration with other healthcare professionals.

We concluded that while spiritual caregivers recognize that they can make an important contribution to the continuing process of integrating spiritual care into the daily practice of other health professionals, specific practices and guidelines for communication and collaboration within the professional network around the patient should be developed to further improve the impact of their profession.

However, reflecting on the training intervention we described in chapter 4, *we did not observe any reluctance of or language confusion within the participating teams with regard to the participating spiritual caregivers*. Although it only involved one spiritual caregiver per team, I think this is still a remarkable observation. I assume that, because of the interdisciplinary character of these palliative care teams, spiritual care is strongly embedded in the daily practise of these teams and therefore also influences how the spiritual caregiver works and speaks within such a team.

To increase collaboration on the spiritual dimension with other healthcare providers within a palliative care team, at the hospital where I work (Radboudumc), medio 2010 the position of spiritual care consultant was created in the transmural supportive and palliative care team. The position is explicitly embedded in interdisciplinary collaboration of the palliative care consultation team. [28] (p. 66 - 87) From a juridical perspective, such a position gives spiritual caregiver all the scope and opportunities to optimally communicate about the spiritual needs of a patient in a palliative trajectory without the limitations of specific religious regulations, like the 'duty of confidentiality'. (p. 66 – 87) Although we stated that there are actually no impediments in the Dutch context for spiritual caregivers to be communicative in an interdisciplinary team setting, (chapter 6) the creation of a clear consultancy position within such a team facilitates the implementation of the national guideline on spiritual care and offers the best possible multidimensional care for patients and their caregivers without limiting their specific professional standards as a chaplain or religious professional.

## Methodological considerations

### Strengths

The sequencing of the different research methods used, is certainly a strength of this thesis. First, we studied daily clinical practice of nurses and doctors in an academic hospital, through observation and conversation analysis. Follow-up studies (a training intervention; a coaching on the job intervention (workplace learning) and

a survey) emerged from this research, making this thesis not only methodologically interesting. It also provides guidance for the improvement of identifying and exploring spiritual issues of critically ill and palliative patients by healthcare providers. That the researcher had worked at the oncology department as a spiritual care provider may have influenced the observations in the first two studies. However, it also made the nurses and oncologists feel at ease in the presence of the researcher, which made the situation more natural.

The multidisciplinary approach to the analysis of the patient-oncologists communication as described in chapter 3 resulted in a wide range of relevant viewpoints. Conversation Analysis (CA) proved a valuable method in capturing the real time interaction of the outpatient consultations.

A major strength of the study described in chapter 4 was the comprehensive evaluation of the impact of the training intervention. Apart from the analysis of self-assessed competence scores, we also measured participants' competence to apply the acquired knowledge and skills to simulated situations but also its implementation it in their own daily care practice. This profound, unprecedented evaluation of effects is in line with recommendations in recent reviews. [17] [29] Additionally, this study approached daily practice as close as possible by making use of training actors and real-world case examples from clinical practice, earlier identified as a key component of spiritual care training. [29] Moreover, we made innovative use of videos with actual case examples to measure the effects of the training. Our intervention has been chosen by ZonMw for further implementation in other teams that provide palliative care. Moreover, in a new ZonMw funded project we will adapt the training intervention for teams who care for and treat patients with life-limiting diseases, but who are not labelled yet as 'palliative patients'. And currently, the training is also the basis for a training for medical specialists in order to increase their communication skills with vitally endangered patients.

A strength of the coaching on the job intervention, as described in chapter 5, was including the attention to the nurses own (spiritual) experience. Also the choice for workplace learning might have contributed to the results.

A major strength of chapter 6, the survey study among spiritual caregivers, is being the first to examine whether guideline recommendations on interdisciplinary spiritual care are applied in practice. Another strength of this study is that it is perfectly in line with a recent survey on research priorities among Dutch spiritual caregivers; a study that highlights the importance of research into developing a stronger profile of their profession. [30]

## Limitations

In contrast to the strengths of our research methodologies, several limitations of our studies also need to be addressed.

A limitation of the two observational studies is that they were conducted in only one department of only one academic hospital in the Netherlands. In addition, only a limited number of nurses and oncologists were observed. And even though in the study in which consultations of medical oncologists with patients with advanced cancer were observed nearly 40 extracts were analysed, these originated from just 11 of the 16 consultations, conducted by just 9 oncologists. Possible influences of oncologists' gender, age and professional experience were not studied. Although earlier research did not find any significant influence of those variables on communication outcomes [8], we do recommend including such characteristics in future studies. Furthermore, for each patient, we only recorded one consultation, not knowing what had already been discussed at other consultations, which limits its generalisability. Moreover, our analyses did not capture how conversations created conditions to actually express lived illness experiences. Another limitation of this thesis is that due to the focus on the patient-provider relationship, the influence of patients' relatives was not included or only indirectly. Lastly, although video recordings would have made it possible to also fully include non-verbal communication in the analyses, audio recordings were chosen in order to prevent patients from feeling uncomfortable.

A limitation of the training intervention study described in chapter 4, is the absence of a control group. Moreover, there is some sample imbalance: not all disciplines working in palliative care participated in the training intervention. Besides, the three participating teams all work in the south-eastern part of the Netherlands. As a result, cultural specificity varied little in this thesis.

A limitation of this study is that we only measured self-assessed and applied competence effects at one time point, although they are likely to decrease in time, and therefore suggest a need for repeated training interventions. Competence was thereby only measured in the short term (4 weeks before and 4 weeks after the intervention). Moreover, the palliative care professionals' own (attitude towards) spirituality was not part of this intervention, although an own perspective may cause bias. Yet, medical record review concerned a total year before and after the intervention.

A limitation of the coaching on the job intervention study as described in chapter 5 is that the main researcher performed the coaching process as well as the interviews, which might have caused bias. We minimized this risk by working with another coach throughout the study, and by analysing data with two independent

researchers. Secondly, this study was executed during a COVID-19 wave. Many nurses were working overtime and on COVID-wards to collectively bear the burden of the pandemic. As a result, questionnaire response rates were relatively low.

Chapter 6, the survey study, also has methodological limitations. Part of the invitations to participate did not reach potential participants. Moreover, spiritual caregivers who were already involved in this subject matter, or had a strong opinion on it, might have been more inclined to fill in the survey, and consequently have caused bias. However, we expect that non-responders will experience even more barriers, making our findings even more relevant.

In this thesis, we used spiritual issues, spiritual concerns, and spiritual dimension to refer to the same or similar phenomena. We also used ‘meaningful’ and ‘making sense’ and, guided by the method of research, even ‘raised lived illness experience’. This variety of terms used represents the discussions, uncertainties and discomforts around such terminology in society, health care and our research team. Also in the coaching on the job study, nurses shared unease with the term *spirituality*. The word did not appeal to them, and although often used in the medical field, they associated it with ‘heavy’ or even ‘woo-woo’ topics. This was also found in adjacent papers.<sup>34-</sup>  
<sup>37</sup> Not surprising, given the fact that medical dictionary definitions for example are: “An awareness of the metaphysical, the religious, or the sublime”,<sup>38</sup> and “something that in ecclesiastical law belongs to the church or to a cleric as such” or “sensitivity or attachment to religious values”.<sup>39</sup>

Terminological clarity contributes to good research. In 2023, in collaboration with the professional association for spiritual caregivers (VGvZ) and the national support network for palliative care (Agora), we will start a project to contribute to increase terminology clarity and creating consensus.

## Recommendations

According to CanMEDS, the most widely accepted and applied physician competency framework in the world, being a ‘communicator’ is one of the eight core skills of physicians [37]. We believe our findings make a valuable contribution to bridging the gap between healthcare professionals like nurses and physicians and their patients when discussing illness, life and death. Moreover, discovering how patients make sense of what is happening to them, or what occupies them most, is fundamental for broader, important concepts such as patient-centred care, total pain, advance care planning, and shared decision making.

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**Recommendations for clinical practice**

- Nurses and physicians should be trained or coached in identifying and exploring patients' spiritual issues, its integration in multidimensional proactive palliative care plans, and in including it in oral handover and written documentation. Such training or coaching should
  - o consider the different learning styles and learning needs of doctors and nurses.
  - o include exploration of their own spirituality (including their view on dying and death)
  - o be respectively based on realistic cases or workplace learning
- Spiritual caregivers should:
  - o collaborate in an integrated way within the interdisciplinary team
  - o consider to become a core team member as spiritual care consultant
  - o participate in patient transfers and multi-disciplinary consultations
  - o offer coaching on the job to health care professionals
  - o Document and handover their patient findings

I hypothesize that this is possible within the actual workload of spiritual caregivers, as it may reduce the need for 1-to-1 spiritual caregiver-patient consultations.

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**Recommendations for education**

- The identification, exploration and integration of the spiritual dimension in daily health care provision should be integrated in basic nursing and medical education curricula.
  - Such education should focus not only on providing patient-centred care on this dimension, but also address the providers' experience while providing it
  - Optimal deployment of 'duty of confidentiality' as well as language use (like jargon) should be included in the basic curriculum to become spiritual caregivers
  - The basic curriculum to become spiritual caregivers should include teaching and coaching skills
  - The basic curriculum of spiritual caregivers should include practising in a multidisciplinary clinical team
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**Recommendations for research**

- The findings of our observational studies should be further explored by reflections on the observations by patients, family caregivers and health care professionals
  - The findings of our intervention studies should be confirmed in randomized controlled trials including:
    - o impact on health care costs
    - o impact on work satisfaction
    - o impact on other health care professionals
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**Recommendations for policy makers**

- The professional association for spiritual carers (VGVZ) and the sending agencies should jointly decide on an unambiguous interpretation of the "duty of confidentiality" that is compatible with healthcare practice
  - Standardisation of the interdisciplinary work of spiritual caregivers within healthcare. Registering spiritual caregiver as a registered professional title (BIG registration in the Netherlands) can be helpful here
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**Recommendations for scientific organisations**

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- Our findings should be integrated into clinical guidelines, including the Dutch national guideline Existential and Spiritual Aspects of Palliative Care
  - A blueprint, derived from the Dutch national guideline Existential and Spiritual Aspects of Palliative Care, should be developed to broaden attention for the spiritual dimension to other fields of health care
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# CHAPTER

# 8

Summary

Nederlandse Samenvatting

Data management

Dankwoord

Curriculum vitae

Publication list

PhD Portfolio

## Summary

More and more, the spiritual or existential dimension is considered as one of the domains that needs to be addressed in patients with life-shortening, advanced diseases. An advanced cancer patient's life is often disturbed by fear of cancer recurrence, cancer progress, approaching suffering, and fear of dying.

In **chapter 1** we describe that the role of nurses and physicians taking care for such patients is not only to provide best quality anti-cancer treatment, but also to address the impact of the disease and treatment on a patient's life. Consequently, nurses and physicians should be able to identify and explore spiritual issues, and integrate this in patient centered care provision. However, these needs often remain unexplored as healthcare professionals lack the skills to identify and explore them and then integrate this into care plans.

Spiritual caregivers, who are experts in this field, might have a role in increasing nurses' and physicians' awareness, knowledge and skills on this topic.

Therefore the aim of this thesis was to explore to what extent physicians and nurses currently identify and explore patients' spiritual concerns and whether a training intervention or coaching on the job increases this practice. Finally, we studied how spiritual caregivers view their role in increasing this competence of healthcare professionals.

### **Part I. Current practice of nurses and physicians in identifying and exploring the spiritual dimension of patients with advanced cancer**

#### ***Chapter 2***

Particularly nurses caring for patients with advanced cancer might have opportunities to give attention to the spiritual dimension of their patients. For that reason, the aim of this study was to gain insight in the way and extent to which nurses during daily caregiving observe and explore spiritual issues of hospitalized patients with cancer.

We performed an ethnographic study with participant observation. Data were collected in 2015 during four shifts at the medical oncology department of a university hospital. The researcher, a spiritual care provider (chaplain) wearing the same kind of uniform as the nurses, observed the nurses, participated in their actions, and interviewed them after the shift.

We found that, although the patients did send many implicit and explicit messages

concerning spiritual issues, the nurses did not explore them. If noticed, three barriers for exploring spiritual issues were mentioned by the nurses: lack of time, conflict with their mindset, and being reserved to talk about such issues.

We concluded that, during their daily caregiving to patients with a life-threatening illness, nurses have many opportunities to explore spiritual issues, but they do not often recognize them. If they do, they tend not to explore the spiritual issues. Communication training for nurses is necessary to develop skills for exploring the spiritual dimension in patients with cancer. In such training, attention to the misconception that such a conversation requires a lot of time and for recognizing signals from patients inviting an exploration of their concerns is necessary.

### ***Chapter 3***

We aimed to gain insights into whether and how medical oncologists working at an outpatient clinic identify and explore lived illness experiences raised by patients with advanced cancer, and how this influences patients' responses. We observed, audio-recorded, verbatim transcribed 16 consultations between medical oncologists and patients with advanced cancer, and analysed them with conversation analysis.

We identified 37 fragments in 11 of the 16 consultations in which patients expressed a lived illness experience. We found differing responses from different oncologists. Patients continued talking about their lived experiences if the listener produced a continuer such as humming or tried to capture the experience in their own words. In contrast, a response with optimistic talking or the presentation of medical evidence prevented patients from further unfolding the experience. In consultations in which the lived illness experience was most extensively unfolded, medical oncologists and patients could constantly see each other's facial expressions.

We concluded that, when a patient with advanced cancer spontaneously introduces a lived illness experience, it helps to identify and explore it when the medical oncologist produces a continuer or tries to capture this experience in their own words. Our findings can be implemented in training sessions, followed by frequent reinforcement in daily care.

## **Part II. Increasing the competence of nurses and physicians in identifying and exploring the spiritual dimension of patients with advanced illness**

### ***Chapter 4***

To evaluate the effects of an interactive communication training intervention for palliative care teams to identify and explore the spiritual dimension and integrate

it in patients' care plans, we performed a pre-post study. We used mixed methods, including self-assessment questionnaires, evaluation of videos with simulated consultations (applied competence) and medical record review (implementation). Three palliative care teams including nurses ( $N = 21$ ), physicians ( $N = 14$ ) and spiritual caregivers ( $N = 3$ ) participated in this training.

The questionnaires showed an improvement on 'Patient and family-centred communication' of the End-of-life professional caregiver survey ( $+0.37$ ,  $p < 0.01$ ; the 8-item S-EOLC ( $+0.54$ ,  $p < 0.01$ ) and regarding the Spiritual Care Competence Scale, on the three subscales used ( $+0.27$ ,  $p < 0.01$ ,  $+0.29$ ,  $p < 0.01$  and  $+0.32$ ,  $p < 0.01$ ). Video evaluations showed increased attention being paid to patient's aims and needs. The medical record review showed an increase in anticipation on the non-somatic dimension (OR: 2.2, 95% CI: 1.2-4.3,  $p < 0.05$ ) and, using the Mount Vernon Cancer Network assessment tool, addressing spiritual issues (OR: 10.9, 95% CI: 3.7-39.5,  $p < 0.001$ ).

Our training intervention resulted in increased palliative care professionals' competence in identifying and exploring patients' spiritual issues, and their integration in multidimensional proactive palliative care plans. The intervention directly addresses patients' spiritual concerns and adds value to their palliative care plans.

## Chapter 5

The aims of this study were to implement a meaning-centered coaching on the job intervention and to measure its effects on oncology nurses' spiritual care competences and job satisfaction, factors influencing this. A participatory action research approach was adopted. Mixed methods were used to assess intervention effects in which nurses of an oncology ward in a Dutch academic hospital participated. Spiritual care competences and job satisfaction were quantitatively measured and complemented with content analysis of qualitative data.

In total, 30 nurses participated. A significant increase in spiritual care competences was found, particularly regarding communication, personal support and professionalization. More self-reported awareness of personal experiences in caring for patients, and an increase in mutual communication and involvement around meaningful care provision as a team were found. Mediating factors were related to nurses' attitudes, support structures and professional relations. No significant impact was found on job satisfaction.

Nurses developed a more exploratory attitude in their communication with patients – instead of acting based on their own assumptions of what is meaningful



to a patient. Attention to and improving meaningful care competences should be integrated in existing work structures, and terminology used should match common understandings and sentiments.

### **Part III. The role of spiritual caregivers in increasing the integration of spiritual care by healthcare providers**

#### ***Chapter 6***

Spiritual caregivers are experts in spiritual care, but their contribution to the integration of this care by other healthcare professionals is largely unknown. Therefore, the aim of this study was to investigate how Dutch spiritual caregivers view their role in increasing the integration of spiritual care in daily healthcare practice as provided by other healthcare professionals in the Netherlands, and how they address this role. We conducted an online survey in 2021 among spiritual caregivers working in Dutch healthcare. Data were analysed using descriptive statistics.

The majority of the 174 respondents answered that they already fulfil a role in the integration of spiritual care by, for example, providing education, coaching on the job, or participating in multidisciplinary consultation. However, the majority of respondents experienced barriers to their contribution such as confusion of terminology and use of language while collaborating with other healthcare professionals, and reluctance to share information.

While spiritual caregivers realise having the potential to make important contributions to the further process of integration of spiritual care into daily practice of other healthcare professionals, some practices and perceptions especially from within their own discipline, may hamper this.

#### ***Chapter 7***

In this general discussion, I give an answer on the research question, discuss the studies in this thesis and their strengths and limitations, and give recommendations for practice, education and research.

## Nederlandse samenvatting

### ***Hoofdstuk 1***

In dit inleidende hoofdstuk leg ik uit hoe de spirituele of zingeingsdimensie meer en meer gezien wordt als een van de domeinen waar aandacht aan besteed moet worden bij mensen met een levensverkortende, progressieve aandoening zoals gevorderde kanker. Wanneer iemand ongeneeslijke kanker heeft maar nog levensverlengende behandeling krijgt, bestaat er vaak vrees dat de kanker terugkeert, angst voor mogelijk toekomstig lijden, alsmede angst voor de dood.

Het is niet alleen aan verpleegkundigen en artsen om deze patiënten optimale tumorgerichte behandeling te geven maar ook om aandacht te hebben voor de impact die de ziekte en behandeling heeft op het leven van de patiënt, aan wat voor hem of haar van betekenis is. Verpleegkundigen en artsen zouden daarom in staat moeten zijn om zingeingsvragen te signaleren en verkennen, en deze te integreren in patiëntgerichte zorgplanning. Echter, zingeingsvragen worden vaak niet verkend. Zorgprofessionals geven aan niet of onvoldoende over vaardigheden hiertoe te beschikken.

Geestelijk verzorgers, experts op dit gebied, zouden een rol kunnen spelen hierbij. In deze thesis exploreren we bovenstaande aan de hand van vijf onderzoeksvragen.

### **Deel I. Signaleren en verkennen van zingeingsvragen in de huidige praktijk van artsen en verpleegkundigen**

### ***Hoofdstuk 2***

Verpleegkundigen die werken op een verpleegafdeling oncologie hebben tijdens hun dagelijkse zorgverlening wellicht de gelegenheid om aandacht te besteden aan de zingeingsdimensie van de patiënten voor wie ze zorgen. Daarom was het doel van dit onderzoek om inzicht te krijgen in de wijze en mate waarin verpleegkundigen tijdens hun dagelijkse zorgverlening de zingeingsissues van opgenomen patiënten met kanker signaleren en verkennen.

We voerden een etnografische studie uit waarbij de verpleegkundigen geobserveerd werden. Data werden verzameld in 2015 gedurende vier diensten op de verpleegafdeling oncologie van een academisch ziekenhuis. De onderzoeker, zelf geestelijk verzorger, droeg dezelfde witte kleding als de verpleegkundigen, observeerde de verpleegkundigen, assisteerde soms in kleine niet medische handelingen, en interviewde ieder van hen na afloop van de dienst.

Hoewel de patiënten veel impliciete en expliciete signalen gaven die konden verwijzen naar zingevingssissues, werden deze nooit door de verpleegkundigen verkend. Tijdens afgenomen interviews werden hiervoor drie redenen genoemd: tijdgebrek, conflicterend met hun mindset, en terughoudendheid om over dergelijke issues te praten.

We concludeerden dat verpleegkundigen tijdens hun dagelijkse zorgverlening aan patiënten met kanker weliswaar genoeg mogelijkheden krijgen aangereikt om zingevingssissues te verkennen maar deze vaak niet herkennen. Ook wanneer ze mogelijkheden wel herkennen laten ze een verkenning ervan doorgaans achterwege. Communicatietraining is nodig om vaardigheden hiertoe te ontwikkelen. In een dergelijke training moet er aandacht zijn voor het ontkrachten van de veronderstelling dat dergelijke gesprekken veel tijd kosten, alsmede voor het leren herkennen van uitingen van patiënten die mogelijk naar zingevingssissues verwijzen.

### **Hoofdstuk 3**

In deze studie wilden we nagaan of en hoe medisch oncologen tijdens poliklinische consulten geleefde ziekte-ervaringen (*lived illness experiences*) van patiënten met gevorderde kanker signaleren en verkennen, en hoe dit de reacties van patiënten beïnvloedt. Zestien consulten werden geobserveerd waarvan geluidsopnames werden gemaakt die vervolgens woordelijk werden uitgetypt. Deze data werden geanalyseerd middels conversatieanalyse.

In 11 van de 16 consulten werden 37 fragmenten gevonden waarin patiënten een dergelijke *lived illness experience* uitten. We zagen een aantal manieren waarop oncologen hier op reageerden en de daaropvolgende reactie van de patiënt. Patiënten vervolgden in het delen van een *lived illness experience* wanneer de oncoloog de patiënt reageerde met 'hummen' of datgene wat hij meende te horen of observeren te vangen in eigen bewoordingen. Echter, wanneer de oncoloog de uiting van de patiënt omzette in positieve bewoordingen, of aanvullende medische informatie deelde, dan staakte de patiënt het delen van zijn of haar verhaal. In consulten waarin *lived illness experiences* van de patiënt de meeste ruimte kregen, was de computer terzijde geschoven en konden oncoloog en patiënt voortdurend elkaars ogen en gezichtsuitdrukkingen zien.

We concludeerden dat wanneer patiënten met gevorderde kanker spontaan een *lived illness experience* introduceren, zij zich uitgenodigd voelen om hier meer over te delen wanneer een oncoloog uitnodigende uitingen hiertoe produceert of in eigen bewoordingen teruggeeft aan de patiënt wat hij/zij heeft gezegd. Onze bevindingen geven handvatten om te gebruiken in trainingen in combinatie met regelmatige bekrachtiging in de praktijk.

## **Deel II. Het trainen en coachen van zorgprofessionals in het signaleren en verkennen en in de zorgplanning integreren van zingeingsvragen van oncologische of palliatieve patiënten**

### ***Hoofdstuk 4***

We ontwikkelden een interactieve training met trainingsacteurs voor palliatieve zorgteams om zingeingsvragen van hun patiënten te signaleren, verkennen en te integreren in zorgplanning en overdracht. Om het effect van deze training te evalueren vergeleken we voorafgaand aan de training en erna zowel eigen ingeschatte competentie, eigen toegepaste competentie als ook implementatie in de praktijk. Drie transmurale expert teams palliatieve zorg werden getraind, bestaande uit verpleegkundigen ( $N = 21$ ), artsen ( $N = 14$ ) en geestelijk verzorgers ( $N = 3$ ).

‘Patient- en familiegerichte communicatie’, zoals gemeten met de end-of-life professional caregiver survey (+0.37,  $p < 0.01$ ; the 8-item S-EOLC (+0.54,  $p < 0.01$ ) verbeterde significant, alsmede drie subschalen van de Spiritual Care Competence Scale (+0.27,  $p < 0.01$ , +0.29,  $p < 0.01$  en +0.32,  $p < 0.01$ ). Evaluatie van video’s met gesimuleerde gesprekken met patiënten toonde dat na de training meer aandacht werd besteed aan de doelen en behoeften van de patiënt. Medische dossieranalyse toonde een toename van het anticiperen op de niet-somatische dimensies van zorg (OR: 2.2, 95% CI: 1.2-4.3,  $p < 0.05$ ), het gebruik van de Mount Vernon Cancer Network assessment tool, en het aandacht hebben voor zingeving (OR: 10.9, 95% CI: 3.7-39.5,  $p < 0.001$ ). De traininginterventie resulteerde bij de deelnemers in toegenomen competentie in het signaleren en verkennen van zingeingsissues, en de integratie ervan in proactieve zorgplanning.

### ***Hoofdstuk 5***

Om de competenties van verpleegkundigen op een verpleegafdeling medische oncologie van een academisch ziekenhuis in het signaleren en verkennen van zingeingsissues van hun patiënten te verbeteren, met specifieke aandacht voor ook hun eigen betekenisgeving, maakten we gebruik van ‘coaching on the job’. Als onderzoeksdesign kozen we participierend actieonderzoek. Competenties in zingeingszorg alsmede werktevredenheid werden kwantitatief gemeten met vragenlijsten. Daarnaast werden kwalitatieve data met behulp van content analyse geanalyseerd.

In totaal namen 30 verpleegkundigen deel. We vonden een significante verbetering van zingeingszorgcompetenties, met name betreffende communicatie, persoonlijke ondersteuning en professionaliteit. Ook vonden we meer zelfgerapporteerd bewustzijn van persoonlijke ervaringen in het zorgen voor patiënten en een toename

van wederzijdse communicatie en betrokkenheid binnen het team in betekenisvolle zorgverlening. Mediërende factoren waren de attitude van de verpleegkundigen, ondersteuningsstructuren en professionele relaties. We vonden geen impact op werktevredenheid (die bij de voormeting al hoog was).

Verpleegkundigen ontwikkelden tijdens het coachingstraject een meer verkennende houding in hun communicatie met patiënten in plaats van te handelen op basis van hun eigen veronderstellingen wat betekenisvol is voor een patiënt. Aandacht voor en het verbeteren van competenties in zingevingszorg zouden geïntegreerd moeten worden in bestaande werkstructuren, en terminologie rondom zingeving moet overeenkomen met gebruikelijke begrippen en gevoelens.

### **Deel III: de rol van geestelijk verzorgers bij het integreren van zingevingszorg door zorgprofessionals**

#### ***Hoofdstuk 6***

Geestelijk verzorgers zijn experts in zingevingszorg. Het is echter grotendeels onbekend in hoeverre zij een bijdrage leveren aan het integreren van zingevingszorg in de dagelijkse zorgverlening die verleend wordt door andere zorgprofessionals. Daarom was het doel van deze studie om na te gaan hoe geestelijk verzorgers in Nederland hun rol zien in het integreren van zingevingszorg in de dagelijkse zorgpraktijk zoals die wordt geboden door andere zorgprofessionals, en hoe zij die rol invullen. Daartoe voerden we in 2021 een online vragenlijstonderzoek uit onder geestelijk verzorgers werkend in de Nederlandse gezondheidszorg. Data werden geanalyseerd met behulp van beschrijvende statistiek.

De meerderheid van de 174 respondenten gaven aan dat ze al een rol vervullen in het integreren van zingevingszorg door bijvoorbeeld het geven van onderwijs, ‘coaching on the job’, of deel te nemen aan een multidisciplinair overleg (MDO). Echter, de meerderheid van de respondenten ervoer belemmeringen bij het uitvoeren van dergelijke activiteiten zoals verwarring over terminologie en taalgebruik wanneer zij samenwerken met andere zorgprofessionals alsmede hun eigen weerstand om patiënteninformatie te delen.

Hoewel geestelijk verzorgers beseffen dat ze een belangrijke bijdrage kunnen leveren aan het verdere proces van integratie van zingevingszorg in de dagelijkse praktijk van andere zorgverleners, kunnen sommige praktijken en percepties, vooral vanuit hun eigen discipline, dit belemmeren.

### ***Hoofdstuk 7***

In de algemene discussie beantwoord ik de onderzoeksvragen, bediscussieer ik de deelstudies met hun sterke aspecten en beperkingen, en geef ik aanbevelingen voor praktijk, onderwijs en scholing en onderzoek.

## Data management plan

This thesis is based on the results of human studies, which were conducted in accordance with the principles of the Declaration of Helsinki. The medical ethics Committee on Research Involving Human Subjects the Netherlands East considered each study as not subject to the Medical Research Involving Human Subjects Act and gave approval to start the studies.

The study described in chapters 2, 3 and 6 were performed without external funding. The study described in chapter 4 was performed with funding from ZonMw Palliantie. The study described in chapter 5 was performed with funding from KWF.

For the study described in chapters 3 and 5, audio-taped data were used. Audio recordings were transcribed. These studies, as well as qualitative data of studies described in chapters 4 and 6, were stored in and analysed with ATLAS-ti, licensed under Radboudumc.

Quantitative data of chapters 4, 5 and 6 were entered in Castor and after closing the data set uploaded in SPSS. All data are stored at the h-disc of the department of anaesthesiology, pain and palliative medicine:

chapter 2: Nurses-15 ENG

chapter 3: Zing-19 ENG

chapter 4: SVP-18 YE

chapter 5: ZIN-COM-21 LM

chapter 6: GV-ROL 21 AW

The survey as described in chapter 6 was send to spiritual caregivers by e-mail by the Dutch Association of Spiritual Caregivers, and after completion emailed to the researchers at Radboudumc.

Paper data were stored at Anes\_research\_archief, under the same names as the studies have at the h-disc. Hard copies of the studies are archived at UTS VERKROOST Nijmegen BV ; Bijsterhuizen 11-31 6546 AR Nijmegen. Privacy of the participants in all studies is warranted by use of encrypted and individual subject codes. To keep confidentiality, all data were stored anonymously. All data are only accessible by project members and the research management of the department of anaesthesiology, and will be saved for 15 years after closure of the study.

Datasets analysed during the studies are available from the corresponding author on reasonable request. Requests can be made via [Onderzoek.anes@radboudumc.nl](mailto:Onderzoek.anes@radboudumc.nl).

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Het feitelijke onderzoek maar ook de aanloop naar dit proefschrift kent een aanloop van jaren van samenwerken met vele zorgverleners in de kliniek en daarbuiten. Dank aan allen waarmee ik heb gezocht, gediscussieerd, gevonden en nog mee op weg ben. Volgt nog een persoonlijk dankwoord aan collega's, aan reisgenoten in werk en leven.

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**Kris**, jij was het die besloot tot het creëren van de functie van consulent spirituele zorg binnen het Team Ondersteunende en Palliatieve geneeskunde van het Radboudumc, met een prachtige start met mijn voorganger Ries van de Sande. Het is precies vanuit deze functie, en jouw blijvende nieuwsgierigheid naar de dagelijkse praktijk en naar nationale en internationale ontwikkelingen, dat voorliggend onderzoek er is gekomen. Ik zie jou als iemand die altijd bezig is en onderweg maar ook als iemand met wie ik, vaak onverwacht, in alle rust, ineens een prachtig beschouwend gesprek kan hebben. Ik ben je enorm dankbaar dat je mijn promotor wilde zijn en kijk uit naar verdere samenwerking en ontmoeting.

**Yvonne**, toen eind 2018 er onverwachts een deur openzwaaide naar een promotietraject, wist jij mij te overtuigen dat dit een kans was om betekenisvol onderzoek te gaan doen. Jij twijfelde geen moment, zag kansen, zag ook mijn potentie. Je lichtte het anker en ik dacht: we zien wel waar het schip strandt. Pas enige tijd nadat het proefschrift al was goedgekeurd door de manuscriptcommissie besepte ik pas ten volle wat een wonder de afgelopen jaren zijn geweest en waar het leven mij (en ook jou!) heeft gebracht. Jij verstaat bij uitstek de kunst om momenten van werk en vriendschap zowel te scheiden als in elkaar over te laten lopen; het was hard werken maar wat hebben we ook veel gedeeld, gelachen, gezongen. Ik heb geen enkele twijfel: zonder jou was dit proefschrift er niet gekomen.

**Anne**, je bent mijn steun en toeverlaat geweest op vele momenten tijdens dit traject. Een betere copromotor had ik mij niet kunnen wensen. Anne, ik ben je zo dankbaar voor al het meedenken, het delen van je kennis en ook de technische en morele ondersteuning met name toen COVID-19 de kop opstak en we alleen nog maar vanuit thuis konden werken. Je bent van onschatbare waarde geweest de afgelopen jaren.



De koffiebekers die ik kreeg van jou en Yvonne zijn een blijvende herinnering aan de vele gedeelde momenten met jullie vanuit thuis en, later gelukkig weer, in het Radboudumc.

**Joep**, al heel lang noem ik jou ‘mijn maatje’ op weg door geestelijk verzorger-land in de setting van het ziekenhuis. Jouw pionieren als geestelijk verzorger, trainer en wetenschapper heeft mij steeds weer geïnspireerd. Wat een geluk dat jouw prachtige thesis er lag en we voort konden bouwen op jouw onderzoek. En wat een geluk dat jij mijn copromotor wilde zijn! Wij zijn nog lang niet uitgepraat!

**Carlo**, samen met Marieke van den Brand publiceerden we al in 2014 in *Oncologica* een artikel over ‘spirituele vragen verkennen’ dat, achteraf, de opmaat was voor verder onderzoek. Over pionieren gesproken. Toen eind 2018 de deur naar promotieonderzoek openzwaaide was je direct bereid om, samen met Joep, promotor te zijn en konden we verder bouwen. Later in het traject gunde je Anne het copromotorschap en stond jij jouw rol als promotor af. Ik wil je bedanken voor al jouw input, jouw reflecties tijdens promotieoverleg, jouw medeauteurschap maar ook jouw collegialiteit en vriendschap door de jaren heen.

Vele verpleegkundigen en artsen, menig paramedicus en heel veel patiënten zijn mijn reisgenoten geweest binnen de klinische praktijk en in onderzoek. Zonder hen was dit proefschrift er überhaupt niet geweest. Twee afdelingen wil ik er met name uitlichten. Allereerst de **afdeling Anesthesiologie, Pijn en Palliatieve geneeskunde** waar het voor mij door de jaren heen steeds weer een beetje thuiskomen is. Toen ik niet meer wist hoe en zelfs of ik verder zou kunnen werken in het Radboudumc, zwaaide de deur van deze afdeling nog verder open. Dank jullie allemaal: verpleegkundigen, artsen/anesthesiologen, voormalig hoofd Prof. dr. **Gert Jan Scheffer**, bedrijfsleider **Ester Cardinaal** en de medewerkers van het secretariaat: **Miranda, Daniëlle, Nicole, Lotte, Natasja, Monique** en natuurlijk al die jaren ook **Rina**. Met name noem ik de collega’s van het **Team Ondersteunende en Palliatieve zorg**; (in willekeurige volgorde): **Henny** (altijd welkom bij jou!), **Marieke** en **Carel** (jullie aandacht, vriendschap en trouw op mooie maar ook moeilijke momenten; zonder jullie was ik vast niet zo ver gekomen..), **Hans** (kan nog meer van jou leren), **Evelien** (delen van ervaring, kennis en interesses), **Floor** (jouw evenwichtigheid en rust – en nu ook ‘buurvrouw!’), **Simone** (denk nog kleine diamantjes met jou te gaan delven), **Heinrich** (uit samenwerken komt nog iets moois...), **Bart Jorrit** (waardevolle, kleine gesprekjes).

Dank jullie wel alle (ex) collega-onderzoekers/PhD kandidaten/buitenpromovendi en andere medewerkers onderzoek van de afdeling Anesthesiologie, Pijn en Palliatieve geneeskunde voor het sparren, koffie en pauzemomenten, het delen van lief en leed. Toch een paar namen: **Marianne, Hans, Anne, Daisy, Agnes, Ria, Maaike, Tanja**, en natuurlijk onderzoek medewerkers **Jackie en Ilona**.

**Leon**; steeds weer een zoeken met de agenda van Kris; dank voor je vriendschappelijke

collegialiteit. En hier noem ik dan ook jou, **Jeroen Fokke**. Jij opende mij de ogen zoals beschreven in de proloog; nog vele momenten van wijsheid volgden. Zo mooi dat we nog steeds contact hebben.

Zeer veel dank ook aan de verpleegkundigen, oncologen, verpleegassistenten en overig personeel van de **afdeling Medische Oncologie** van het Radboudumc. Dank voor alle medewerking aan onderzoek in het kader van dit proefschrift maar ook voor jullie blijvende openheid om zingeving verder op de kaart te zetten. En hier is ook de plek om jouw naam te noemen **Jacco**. Steeds opnieuw communiceerde jij, ziekenhuisbreed, het belang van zingeving in de zorg; de verrijking hiervan voor de patiëntenzorg maar juist ook voor de zorgverlener, de verpleegkundige. Wat hebben we, ook samen met Linda, **Veronique** en anderen, belangrijke stappen binnen onderzoek gezet. Wie weet waar we elkaar weer treffen!

**Baziel** van Engelen, dank voor je toezegging om mijn mentor te zijn gedurende dit promotietraject. Het verplichtte mij om eens per half jaar met jou te spreken maar ik zag het als een kans om jou te ontmoeten, jou te spreken over een blijvend zoeken naar de menselijke maat in zorginstellingen, in het Radboudumc. Dank je wel. Tot gauw.

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**Linda en Marieke**, al zo lang deel ik met jullie gedachten over en ervaringen met spiritualiteit en zingeving in werk en privé. En meer. Dat jullie er zijn als mijn paranimfen voelt zo goed! Laten we van 11 januari een mooie dag maken!

Lieve vrienden, vriendinnen en (schoon)familie; ook op vrije uren en dagen zat ik regelmatig achter de pc. Ik denk er komt nu meer ruimte om elkaar te ontmoeten. **Isa, Noa, Evi, Seb en Robin**: gauw weer wat leuks plannen! **Lieve zussen**: Atlanta? Amsterdam? Here I come!

**Riet:** uren van tekenen en schilderen hebben mij, zeker in de stille periode gedurende COVID, geholpen om, naast het werken aan al het onderzoek, geestelijk gezond te blijven. Jij was mijn maatje hierin. Dank je wel. En **Chris** bedankt voor het fotograferen van acryl schets op de voorkant van het boekje.

**Mama;** wat heb je steeds opnieuw moeite gedaan om te begrijpen waar ik mee bezig was; je vindt het prachtig! We zullen papa missen juist ook op 11 januari; ik weet dat hij dit heel mooi had gevonden.

Lieve, lieve **Julie** en **Rémy**. Wat zijn jullie een geweldige kinderen. Wat zijn jullie mooi op weg door het leven, en altijd ook belangstellend naar waar ik mee bezig ben, hoe het ook met mij gaat. Wat een rijkdom om jullie moeder te zijn! Meer ruimte in mijn tijd en in mijn hoofd komt allereerst vrij voor jullie.

Lieve **Matthijs**. Het is zo prachtig om steeds weer met jou te kunnen delen wat onze aandacht heeft, wat ons beweegt en waarin we zoekend en anders zijn. Als geen ander begrijp jij mijn doorgaand zoeken naar spiritualiteit en zingeving in het leven, in de zorg. Jij hebt de afgelopen jaren ook thuis veel op je genomen, mij ruimte gegund om dit promotietraject in te gaan en af te ronden. Dank je wel hiervoor en voor jouw liefde, vriendschap, geduld en wijsheid. *“Just a perfect day; I’m glad I spend it with you.”*

## Curriculum Vitae (NL)

### **Jacqueline van Meurs**

Jacqueline is in 1965 geboren in Den Haag en groeide op in Noord Brabant. Na haar middelbare school studeerde ze aan de Academie voor Journalistiek in Tilburg waarna ze twee jaar werkte en reisde in Zwitserland, Australië, Indonesië, Thailand en Maleisië; ze verdiepte zich in culturen en religieuze tradities van deze landen en de geloofsbeleving of spiritualiteit van de mensen die ze ontmoette. Ze was te gast in onder andere een hindoeïstische tempel, een boeddhistisch klooster en studeerde ze Tai Chi in George Town, Penang (Maleisië). Terug in Nederland wilde ze opgedane ervaringen verder bestuderen en behaalde ze in 1998 de Master Religiestudies aan de Radboud Universiteit Nijmegen. Na haar studie verrichte ze van 1999 – 2001 veldonderzoek vanuit het Nijmeegs Instituut voor Missiologie naar de integratie van woonwagengedwongen, en met name Sint, in parochiekerken van het Heuvelland, Zuid-Limburg. Vervolgens werkte ze vijf jaar bij de Nederlandse r. k. instelling voor migrantenpastoraat en interreligieuze dialoog, Cura Migratorum in 's Hertogenbosch en Utrecht.

Groeiende interesse in spiritualiteit en zingeving rondom ziekte, geboorte en sterven leidde naar het beroep van geestelijk verzorger. Ze volgde in 2005 de Klinisch Pastorale Vorming (KPV) in Nijmegen, en werkte als geestelijk verzorger i.o. op verschillende afdelingen van het Radboudumc Nijmegen. In 2007 behaalde ze de Master Pastorale studies aan de Radboud Universiteit Nijmegen en werkte ze aansluitend anderhalf jaar in het Radboudumc en twee jaar in het Jeroen Bosch ziekenhuis te Den Bosch. In 2010 kreeg ze een aanstelling in het Radboudumc alwaar ze zich specialiseerde als geestelijk verzorger binnen de oncologische zorg en palliatieve geneeskunde. Gedetacheerd vanuit de Dienst Geestelijke Verzorging en Pastoraat had ze eveneens een aanstelling als consulent spirituele zorg van het Team Ondersteunende en Palliatieve Zorg, afdeling Anesthesiologie, Pijn en Palliatieve geneeskunde (PIPA). Binnen deze laatste functie ontwikkelde ze visie op het interdisciplinair werken aan zingeving in de zorg wat in 2019 er toe leidde dat ze als PhD kandidaat, gedetacheerd bij de afdeling PIPA, aanving met haar promotieonderzoek.

Vanaf begin 2023 werkt ze vanuit de Afdeling Zingeving & Spiritualiteit van het Radboudumc weer als geestelijk verzorger in de kliniek en is ze als consulent spirituele zorg aangesloten bij het Team Ondersteunende en Palliatieve Zorg. Ze geeft onderwijs zowel binnen het Radboudumc (o.a. Health Academie, Klinische Minor Palliatieve zorg, en tot 2018 aan de Vervolgopleiding tot specialist ouderengeneeskunde) als daarbuiten (Hogeschool Arnhem Nijmegen/HAN).

Jacqueline heeft zich middels deelname aan commissies en andere overlegorganen ook ingezet om aandacht voor zingeving in de zorg te bevorderen, onder andere als lid van de Programmaraad Netwerk Palliatieve Zorg Zuid Gelderland (NPZZG), als bestuurslid van Geestelijke Verzorging binnen Palliatieve Zorg thuis (GVPZ) Nijmegen (nu opgenomen in ZinPlus), binnen de commissie Oncologische en Palliatieve Zorg, van de Vereniging van Geestelijk Verzorger (VGVZ) en binnen het Landelijk Adviesteam Palliatieve Zorg (APZ), een expertteam dat geconsulteerd kan worden bij complexe casuïstiek.

Tijdens het PhD traject heeft Jacqueline ook lessen gevolgd aan de (deeltijd) kunstacademie Nieuwe Academie Utrecht (NAU). De afbeelding op de omslag van haar proefschrift is eigen werk. Jacqueline is moeder van Julie (1998) en Rémy (2001) en woont met haar man Matthijs Glastra in Malden, nabij Nijmegen.

## Curriculum Vitae (EN)

### **Jacqueline van Meurs**

Jacqueline was born in The Hague in 1965 but grew up in Noord Brabant, south of the Netherlands. After secondary school, she studied at the Academy of Journalism in Tilburg, after which she worked and travelled for two years in Switzerland, Australia, Indonesia, Thailand and Malaysia, immersing herself in cultures and religious traditions of these countries and the beliefs or spirituality of the people she met. She was guest in, among others, a Hindu temple, a Buddhist monastery and she studied Tai Chi in George Town, Penang (Malaysia). Back in the Netherlands, she wanted to further study the experiences she had acquired and obtained a Master's degree in Religious Studies from Radboud University Nijmegen in 1998. After her studies, she carried out field research from 1999 - 2001 from the Nijmegen Institute of Missiology (NIM) on the integration of Travellers, and particularly Sinti, in parish churches of the Heuvelland, Zuid Limburg and then worked for five years at the Dutch Roman Catholic institution for migrant chaplaincy and interfaith dialogue, Cura Migratorum in 's Hertogenbosch and Utrecht.

A growing interest in spirituality and meaning around illness, birth and dying led to the profession of spiritual caregiver. She took the Clinical Pastoral Training (KPV) in Nijmegen in 2005, and worked as a spiritual caregiver in formation at several departments of Radboudumc Nijmegen. In 2007, she obtained a Master's degree in Pastoral Studies from Radboud University Nijmegen, and subsequently worked for one and a half years at Radboudumc and two years at Jeroen Bosch Hospital in Den Bosch.

In 2010, she got an appointment at the Radboudumc where she specialised as a spiritual caregiver within oncological care and palliative medicine. Seconded from the Department of Spiritual and Pastoral Care, she also had a position as consultant in spiritual care of the palliative care team, Department of Anaesthesiology, Pain and Palliative Medicine (PIPA). Within the latter position, she developed vision for interdisciplinary work on spirituality in healthcare which led her to start her PhD research in 2019, seconded to the PIPA department.

From the beginning of 2023, she works from the Department of Meaning & Spirituality of the Radboudumc as a spiritual caregiver in the clinic again. She teaches both within the Radboudumc (e.g. Health Academy, Clinical Minor Palliative Care, from 2013-2018 also at the Continuing Education for Specialist in Geriatrics) and outside (University of Applied Sciences, Arnhem/Nijmegen).

Also through participation in committees and other consultative bodies, Jacqueline has worked to increase awareness for spirituality in healthcare, including as a member of the Programme Council Network Palliative Care South Gelderland (NPZZG), as a board member of Spiritual Care within Palliative Care at home (GVPZ) Nijmegen (now included in ZinPlus), within the Oncological and Palliative Care Committee, of the Dutch national Professional Association for Spiritual caregivers (Vereniging van Geestelijk Verzorgers: VGVZ) and within the Landelijk Adviesteam Palliatieve Zorg (APZ), an expert team that can be consulted in complex case histories.

During the PhD trajectory, Jacqueline took classes at the (part-time) art academy Nieuwe Academie Utrecht (NAU). The image on the cover of her thesis is one of her paintings. Jacqueline is mother of Julie (1998) and Rémy (2001) and lives with her husband Matthijs Glastra in Malden, near the city of Nijmegen.

## Publication list

### Publications, PubMed indexed

1. L. Modderkolk, **J. van Meurs**, V. de Klein, Y. Engels and A. B. Wichmann. *Effectiveness of Meaning-Centered Coaching on the Job of Oncology Nurses on Spiritual Care Competences: A Participatory Action Research Approach*. Cancer Nursing 2023 Pages 10.1097
2. **J. Van Meurs**, R. Breedveld, J. v. d. Geer, C. Leget, W. Smeets, R. Koorneef. *Role-Perceptions of Dutch Spiritual Caregivers in Implementing Multidisciplinary Spiritual Care: A National Survey*. International Journal of Environmental Research and Public Health 2023 Vol. 20 Issue 3, Pages 2154
3. **J. van Meurs**, A. B. Wichmann, P. van Mierlo, R. van Dongen, J. van de Geer, K. Vissers. *Identifying, exploring and integrating the spiritual dimension in proactive care planning: A mixed methods evaluation of a communication training intervention for multidisciplinary palliative care teams*. Palliative medicine 36(10): 1493-1503.
4. **J. van Meurs**, W. Stommel, C. Leget, J. van de Geer, E. Kuip, K. Vissers, Y. Engels, A. Wichmann. *Oncologist responses to advanced cancer patients' lived illness experiences and effects: an applied conversation analysis study*. BMC palliative care 2022; 21(1): 1-9.
5. **J. van Meurs**, W. Smeets, K. C. Vissers, M. Groot and Y. Engels. *Nurses exploring the spirituality of their patients with cancer: participant observation on a medical oncology ward*. Cancer nursing 2018 41(4): E39.

### Other Publications (not PubMed indexed)

1. N. Hijweege, H. Lammers, **J. van Meurs**, W. Smeets, K. Vissers. *Handboek spiritualiteit in de palliatieve zorg: terminale zorg, onderwijs, onderzoek en samenwerking samenhangend in beeld*, 2016 Parthenon Almere.
2. **Van Meurs, J.** *De zorg om het verhaal. Spreken over de dood in het algemene ziekenhuis*. Handelingen. Tijdschrift voor Praktische Theologie 2014 41(2), 29 – 38.
3. **Van Meurs J.** *Wachten met de wachtenden. Geestelijke begeleiding in een zorginstelling*. Handelingen. Tijdschrift voor Praktische Theologie 2011 38(3), 48-53.
4. Hijweege N, Pieper J, Smeets W, Hamers H, **Van Meurs J.** Rituals in general spiritual care. In: *Yearbook for Ritual and Liturgical Studies* 2011, 27: 29-48.
5. **Van Meurs J.** *Werken met rituelen in de geestelijke verzorging*. Tijdschrift Geestelijke Verzorging 2009 52 (12), 34-39
6. **Van Meurs J.** *Wij moeten nu iets doen. Woonwagengewoners in Kerk en Samenleving*. Een casestudy in het Heuvelland, Zuid Limburg. Nijmeegs Instituut



voor Missiologie 2002 Occasional Papers 4.

7. **Van Meurs J.** *'Mamele en Maidel, de communie van twee Sinti-meisjes'*, documentaire Nijmeegs Instituut voor Missiologie (NIM) & Pastoraat Woonwagenbewoners Nederland, PWN 2002; (camera en montage, M. Ploum en J. Bouwens).

## PhD portfolio

Department: **Anesthesiology, Pain and Palliative Medicine**

PhD period: **01/01/2019 – 11/01/2024**

PhD Supervisor(s): **Prof. dr. K.C.P. Vissers, Prof. dr. Y.M.P. Engels**

PhD Co-supervisor(s): **Dr J. van der Geer, Dr. A.B. Wichmann**

<b>Training activities</b>	<b>Hours</b>
<b>Courses</b>	
- PubMed I workshop (2019) UB	2.00
- RU - Qualitative Research Methods and Analysis (2019)	84.00
- RU - Project management for PhD candidates (2019)	56.00
- Conversation Analysis (CA) Beginners' Workshop (2020) Loughborough University, UK	8.00
- Conversation Analysis and Healthcare Interactions (2020) Loughborough University, UK	16.00
- RIHS - Introduction course for PhD candidates (2020)	15.00
- RU - Writing Scientific Articles (2020)	84.00
- Radboudumc - Scientific integrity (2020)	20.00
- Meet the Expert; How to Write a Rebuttal. (2021) RIMLS	1.00
- Radboudumc - eBROK course (for Radboudumc researchers working with human subjects) (2021)	42.00
- Compassion in Healthcare (Compassie in de Zorg) (2022) ZINacademie Vugt (NL) & Radboudumc Nijmegen (NL)	16.00
<b>Seminars</b>	
- Science Café Anesthesiology Radboudumc (2019) – oral presentation	11.00
- Symposium: A day worth having! (2019) ZZG zorggroep Nijmegen (NL) – oral presentation	11.50
- In search of stories (2022) Amsterdam UMC, Radboud Universiteit Nijmegen & HKU University of the Arts Utrecht	4.00
- Science Café Anaesthesiology Radboudumc (2023) Department of Anaesthesiology, Pain and Palliative Medicine Radboudumc (NL) – oral presentation (nomination best abstract)	3.00
<b>Conferences</b>	
- Evidence Based Supportive Oncology: revisited (2019) NVMO. Nederlandse Vereniging voor Medische Oncologie – oral presentation	15.00
- Dutch-Flemish Science Days Palliative Care (2019)	15.00
- Dutch-Flemish Science Days Palliative Care (2023) – oral presentation	15.00
- Symposium Education Palliative Care: become part of the solution (2021) O2PZ VUmc	4.00
- Digital expertise exchange Palliative care (2021) Palliative Care Consortium Limburg & Zuidoost Brabant (NL)	2.00
- Dutch National Congress Palliative Care (2022) – oral presentation	14.00
<b>Other</b>	
- Zazen & silence meditation retreat (2019) Abbey Maria Toevlucht Zundert (NL)	16.00
- Focus group support for complex ethical dilemmas in healthcare practice (2020) Think Tank Ethical Dilemmas in Health Care	2.50
- Zazen & silence meditation retreat (2022) Abbey Maria Toevlucht Zundert (NL)	16.00
- PhD retreat (2022) RIHS	16.00
- Career coaching & Talent management (2022) Bron-X (Wijchen NL)	28.00
- Zazen & Silence meditation retreat (2023) Abbey Maria Toevlucht Zundert (NL)	16.00

<b>Teaching activities</b>	
<b>Lecturing</b>	
- Meaningful aspects and quality of life (2019) Radboud University; Faculty of Medical Sciences; Medicine	1.00
- Spiritual care and ethics in palliative care (2019) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- Spiritual care and mourning (2020) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- Spiritual care and ethics in palliative care (2021) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- Spiritual care and ethics in palliative care (2021) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- Spiritual care and mourning (2022) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- Spiritual care in Palliative care for experienced nurses (2022) University of Applied Sciences Arnhem Nijmegen HAN (NL)	6.00
- How do I relate to death? (2023) Radboud University; Faculty of Medical Sciences; Medicine;	1.00
- Mourning and bereavement (2023) Radboud University; Faculty of Medical Sciences; Medicine;	1.00
- Spiritual care and mourning (2023) University of Applied Sciences Arnhem Nijmegen HAN (NL)	3.00
<b>Supervision of internships / other</b>	96.00
- Coach for Medical Students (1 <sup>st</sup> year students) (2022)	
<b>Total</b>	<b>643.50</b>

