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Spiritual care by nurses in curative cancer care: Protocol for a national, multicentre, mixed method study

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Abstract

Aim: To gain insight into the quantity and quality of spiritual care provided by nurses in curative cancer care, from the perspectives of both patients and nurses.

Background: Cancer causes patients to suffer from diverse symptoms related to their illness. Nurses play an important role in the care for people with cancer. Next to paying attention to physical and psychosocial needs, caring for spiritual needs of patients also belongs to good nursing. Most of the research concerning spirituality and spiritual care in relation to cancer has focused on palliative care.

Design: A mixed methods design will be used in two sub-phases. First, we will conduct semi-structured interviews with 72–90 patients coming from nine hospitals. Subsequently, approximately the same number of nurses working on oncology wards of these hospitals will be interviewed.

Methods: We meticulously composed both interview guides so that only near the end of the interview explicit terms like spirituality and spiritual care are explicitly mentioned. Until that point, we will use other words to define the concepts. Next to the interviews, demographics, answers to some statements and several questionnaires will be gathered. Content analysis supported by DEDOOSE will be used to answer the research questions.

Discussion: The insight we will gain in this study enables us to compare experiences from the perspective of both patients and nurses. This can also provide us with suggestions for the improvement of nursing care for people with cancer who are treated with curative intent, a topic until now hardly addressed.

KEYWORDS

cancer, mixed method, nurses' experiences, nursing, patient experiences, spiritual care

1 | INTRODUCTION

The number of people experiencing cancer has increased worldwide. Due to, for example, ageing of the population and changes in lifestyle, the amount of new cancer patients in the Netherlands rises

with 3% a year. The number of (new) diagnoses is expected to increase to 123,000 in 2020. Chances of survival depend on cancer type and the stage where the illness is diagnosed. Roughly speaking, half of all people with cancer are still alive 5 years after diagnosis (Siesling, Sonke, De Raaf, & Jansen, 2014).

1.1 | Background

Cancer causes patients to suffer from diverse symptoms related to their illness and people can experience reduced quality of life. Hospital nurses play an important role in the care for people with cancer. In general, they have more frequent contact with patients than do medical doctors. If patients are treated with chemotherapy, either at an outpatient or a clinical department, nurses are the primary professional caregiver in charge of the physical, medical and technical aspects of that treatment as well as for the psychosocial care for the patient. Next to physical and psychosocial symptoms, people might also experience spiritual needs (Moadel et al., 1999). Nurses have to pay attention to and care for their patients' spirituality; a component of care which nurses believe is important (Delgado, 2015; Gallison, Xu, Jurgens, & Boyle, 2013; McSherry & Jamieson, 2011). Patients and their family caregivers also have emphasized the relevance of spirituality and spiritual care for cancer nursing (Highfield, 1992; Taylor & Mamier, 2005). There seems to be a positive correlation between spiritual care perceptions and spiritual care practice (Chan, 2010). Spirituality is regarded as especially relevant for cancer patients' well-being (Visser, Garssen, & Vingerhoets, 2010). Nurses are in the position to safeguard aspects of spirituality like the wholeness and connectedness of their patients and are therefore able to help patients to cope with the illness and its treatment.

To date, research on spiritual care in oncology has mainly focused on patients who were treated with a palliative intent or an undefined mixed population of cancer patients (Chan, 2010; Taylor, Highfield, & Amenta, 1994). To the best of our knowledge, there is a scarcity of research on spiritual nursing care in a specific curative cancer setting and, therefore, it is still unclear if patients who are treated for their cancer with curative intent receive spiritual care from their nurses. We also do not know if, despite the threats that living and coping with a life-threatening disease like cancer and its treatment pose on patients, the patients have a wish for spiritual care or find it appropriate for nurses to pay attention to that dimension.

To address this knowledge gap in the specific Dutch context where the attitude towards religion and spirituality is different from that in the USA, the Dutch Cancer Society/Alpe d'HuZes funded the national research project "Spiritual care by nurses in curative cancer care: experiences and expectations of patients and nurses" (Dutch acronym "SPIR-VONC"). The aim of this mixed methods study is to investigate the quantity and quality of spiritual care in curative cancer care from the view of patients and nurses and, if necessary, to provide suggestions for the improvement of nursing care for cancer patients who are treated with curative intent. The research is done in the specific Dutch context, where the attitude towards religion and spirituality is different from that in the USA (Becker & de Hart, 2006; Heelas, Woodhead, Seel, Szerszynski, & Tusting, 2004).

The objective of this paper is to present the protocol of this patient- and nurse mixed methods study and it includes a detailed

Why is this study needed?

- The topic of spiritual care by nurses in curative cancer care is up to now unexplored.
- Based on the findings of this study, leaders in nursing and nursing education can decide if improvements are needed and if so, what they should look like.

description of the study design and the methodological approach. The methodology described in this paper will also serve as a reference for future publications about the study. Special attention will be given to the way the concepts of spirituality and spiritual care are operationalized.

2 | THE STUDY

2.1 | Aims

This study primarily aimed to gain insight into the quantity and quality of spiritual care provided by nurses in curative cancer care. The following research questions are addressed in this study:

1. (a) How often did curatively treated cancer patients receive spiritual care, and (b) in what way? (c) How many patients wanted more contacts involving spiritual care? (d) Is it the patients' opinion that nurses should provide spiritual care? (e) Do patients think there is room for improvement in spiritual nursing care? (f) If so, how?
2. (a) How much attention is currently being paid to spiritual care by nurses in curative cancer care? (b) In what way did they pay attention to spiritual care for cancer patients? (c) How many nurses see a necessity for improvement and if so, (d) which kind of improvement? (e) Is there room to talk about their own spirituality with colleagues and if yes, to what extent and how?
3. Which patient characteristics are associated with (a) receiving spiritual care by the nurse and (b) with the patient's wish to have received more spiritual care?
4. Which nurse characteristics are associated with (a) nurses' view of spiritual care as being important in curative care and (b) with the frequency with which spiritual care is provided by them?

2.2 | Methodology

2.2.1 | Study design

The study has a mixed methods design and consists of two sub-phases. The first phase will consist of semi-structured interviews with patients coming from nine hospitals in the Netherlands. Subsequently, in phase two, nurses working on the oncology wards of the selected hospitals will also be interviewed. Next to the individual patient- and nurse data, we will gather information about the way oncology care is organized in the nine different hospitals that

participate in the study. This enables us to compare to what extent and how these organizations influence spiritual care and the patients' and nurses' perspectives on spiritual care.

Spirituality and spiritual care are defined in many different ways. It is known that in the Netherlands the attitudes towards religion and spirituality are far more non-theistic and more eclectic, unspecific and diverse (Boeve, 2006; Goud, 2000; Schmeets & van Mensvoort, 2015; Vellenga, 2016) than, for example, in the USA, where much literature concerning this topics comes from. We, therefore, searched for definitions of both concepts that fit in with these attitudes. We used the definition of spirituality that is also used in the Dutch guideline on spiritual care. It states that 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 other and/or the sacred. The spiritual field is multidimensional, it concerns:

1. 'Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
2. Value-based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals and life itself).
3. Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate)' (Agora study group Guideline spiritual care 2010, pg. 3–4).

As there was no unanimously agreed definition of spiritual care beforehand, the project team formulated a working definition. This was based on the literature, discussions in several project team meetings and the definition of spirituality. The definition on spiritual care which we used in the project and in the interviews was: "the attitude, attention and care (of a professional caregiver) that result(s) in the patient's feeling of 'being seen' and where there's attention for life issues and in which (re)finding balance, resilience and inspiration are considered to be important".

2.2.2 | Selection of hospitals

The study will be conducted in nine hospitals in three regions of the Netherlands; the north, middle and south. These regions each represent different majority denominations. For the selection of patients and nurses, it is important to maximize the distribution in religiosity/spirituality, because different levels and perceptions of religiosity and spirituality might influence the amount of spiritual care which is received or provided (Taylor, Highfield, & Amenta, 1999). Next to this variable, we aim to conduct the study in hospitals of different types and sizes. We, therefore, choose three university hospitals, three large regional hospitals and three small regional hospitals; in every region we ultimately will include one

hospital of each type. By means of this inclusion strategy, purposive sampling and 8–10 interviews in each hospital, we expect to reach saturation.

2.2.3 | Selection of participants

Patients

People with cancer, who are treated with chemotherapy with a curative intent, will be informed by nurses about the study near the end of the (adjuvant) treatment. This exact moment is chosen, because during the treatment period they have had several interactions with nurses and only afterwards can they say something about the care they received. Patients may be treated at a clinical department (admission) or at an outpatient department (day-care) and need to meet the inclusion criteria listed in Table 1 to be eligible to take part in the study. A nurse will hand the information leaflet to the patient. Together with this leaflet, the patient receives a reply card and a postage paid envelope addressed to the research institute. Patients are asked always to return the reply card, even if they do not want to participate in the study. The reply card offers three possibilities: "No, I don't want to participate", "Yes, I want to participate, please call me" and "I don't know yet, please call me for further information". After the researcher receives a reply card with one of the last two options, she calls the patient to make an appointment for the interview or to further inform the patient so (s)he can make a decision whether or not to participate. Signed informed consent forms will be obtained before study entry.

We aim to achieve a total sample of 72–90 included patients. This means an inclusion of 8–10 patients per hospital. Patients will be selected in such a way that different types of cancer, different age categories and both primary places of treatment (clinical—and outpatient department) will be represented. We have also taken into account that the qualitative data analysis is not postponed to the end of data collection, but will already start after the first interviews, as data analysis in qualitative research is an iterative process.

TABLE 1 Inclusion criteria

Patients
Adults >18 years, no upper age limit
With cancer, defined as those which can be treated with a curative intent
Receiving treatment with chemotherapy
Being in the last or next-to-last chemotherapy episode
Able to adequately speak and understand the Dutch language
Nurses
Adults >18 years, no upper age limit
Having an employment of ≥60%
Having knowledge and experience with chemotherapy treatment on a nursing ward as well as an outpatients' department
Able to adequately speak and understand the Dutch language

Nurses

Nurses who are involved in the patient's care either in the clinical or at the outpatient department will be eligible for participation. We aim to interview approximately as many nurses as we will interview patients. The nurses will be selected by purposive sampling which means that the principal investigator together with the head of the department looks for a mixed sample of possible interviewees. At the end, the sample will consist of both men and women and nurses from different age groups, with different educational levels and dissimilarities in years of experience in nursing or oncology.

2.2.4 | Data collection

Both the patients and the nurses will be interviewed once in a face-to-face contact of approximately 1.5 hr. These interviews will be conducted by trained researchers from the project team, namely MG, HK and AE. The patient interviews will take place after the last chemotherapy treatment, although some people are still in the process of another treatment, like surgery or hormone treatment. Semi-structured interviews will be used to explore views of patients on the meaning of cancer, the impact on life, the way(s) (s)he (re)gained

or maintained strength during the period of illness, the extent to which life questions arose and how the patients handled these, the types and amount of spiritual and psychosocial care nurses delivered and what the patients believed belonged to the spiritual care domain of the nurses (Figure 1).

The nurses will also be asked about the impact of cancer on patients' lives and their resources of strength and resilience, as well as their own resources to rely on in life. They are also questioned about whether or not they delivered spiritual care and if so, how? Furthermore, they will be asked about how they consider the role of nurses in that field, the barriers and facilitators in delivering spiritual care and the way in and extent to which they deliberate their own and patients' spirituality.

At the end of the interview, demographic data and answers to some statements (Table 2) are gathered. These statements are meant to underpin the qualitative material, as they broadly cover the same topics as the interviews (Figure 1).

Next to this semi-structured interview, respondents are asked for demographic data and the completion of several questionnaires. With regard to the vulnerable population of seriously ill patients, questionnaires were selected based on: validation and/or applicability among patients with cancer, time needed for completion to limit burden of

Patients	Nurses
<div></div>	<div></div>
☐ Experiences of disease and treatment	☐ Experiences of patients with disease and treatment
☐ Meaning of cancer and treatment	☐ Meaning of cancer and treatment for patients
☐ Sources of support	☐ Sources of support for the nurse
☐ Delivered care by nurses (specifically with regard to meaning, resilience, sources of support)	☐ Sources of support for patients
☐ Nurse's responsibilities in spiritual and psychosocial care	☐ Delivered care (specifically with regard to meaning, resilience, sources of support)
☐ Possible improvement(s) in the care by nurses	☐ Responsibilities in spiritual and psychosocial care
☐ Meaning of the concept of spirituality	☐ Education
	☐ Department's culture and atmosphere
	☐ Barriers & facilitators
	☐ Possible improvement(s) in the care
	☐ Meaning of the concept of spirituality
	☐ Non-western immigrants

FIGURE 1 Interview topics

TABLE 2 Statements used in the interviews with patients and nurses

Statement	Number and content of answer options
<i>Interview with patients</i>	
In my opinion, spiritual care belongs to the nurses' domain	5 (very much agree—absolutely disagree)
It's my experience that nurses' (attention for) spiritual care to people with cancer is.	3 ([very] insufficient) – ([very] good)
Spirituality plays a part in dealing with the disease and treatment	4 (not at all—very much)
I've discussed spiritual issues with nurses	5 (very often—never)
Are you satisfied with that?	2 (yes—no)
I consider myself as religious	4 (not at all—very much)
I consider myself as spiritual	4 (not at all—very much)
<i>Interview with nurses</i>	
It's my experience that the (attention for) spiritual care to people with cancer on my ward is.	3 ([very] insufficient)—([very] good)
Spiritual care in cancer care is.	5 (absolutely unimportant—very important)
I provide spiritual care to my patients.	5 (very often—never)
I discuss my own spirituality with my colleagues.	2 (yes—no)
I discuss my patients' spirituality within my team.	5 (very often—never)

assessment and available translations into the Dutch language. Patients are requested to complete the Spiritual Attitude and Involvement List (SAIL) (de Jager Meezenbroek et al., 2012) and the European Organization for the Research and Treatment of Cancer Quality-of-Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993). These questionnaires will provide us with descriptive data on various spiritual aspects and the experienced quality of life. Nurses will also be asked to complete the SAIL and the Spiritual Care Competence Scale (SCCS) (van Leeuwen, Tiesinga, Middel, Post, & Jochemsen, 2009). The SCCS, a valid and reliable instrument for measuring spiritual care competencies, will be used to describe the self-assessed competencies in providing spiritual care from the nurses in our study.

The interview guide is framed in such a way that only near the end of the interview terms like spirituality and spiritual care are explicitly mentioned. Until that point in time, we will use other words to define the concepts. Next to these words that are introduced by the researcher to distinguish the psychosocial and spiritual aspects or domains—like resilience, life issues, meaning, life/world view—we try to connect to words used by the respondents themselves. This strategy is used to open up and connect to the way respondents think about spirituality and spiritual care and to smoothly introduce our own broad views on these concepts. In this way, we will try to avoid

all kinds of vague connotations with the concepts. Just after introducing both terms, we will give an explanation about what we think are spirituality and spiritual care. Just after and with these explanations in mind, we will ask the respondents to react to the statements. The data collection period will last for an extended period of time; in the course of 2016 we expect to finish all interviews with patients and nurses.

2.2.5 | Data management and analysis

Anonymous participant data will be stored in a protected XLS database. Interviews will be tape recorded and transcribed verbatim. Transcriptions will be analysed using two types of content analysis techniques (Hsieh & Shannon, 2005) supported by the qualitative analysis package DEDOOSE. We have deliberately chosen two different types of content analysis, because this allows us to handle the volume as well as the complexity of the data (e.g. not mentioning spirituality/spiritual care until the end of the interview) and to remain research-question-driven. The transcripts will first be analysed by dividing the text in main themes the researchers agreed on by discussion (Figure 1). These main themes are based on the research questions. The next step will be to perform line-by-line coding in these main themes; very detailed codes, so-called “baby codes”, will be created. To avoid interpretation, we will stay as close as possible to the data. In this way, the informants' meanings and experiences are mostly caught. After this step, these baby codes will be clustered into subthemes. One of the measures that will be taken to prevent this process from being (over)interpretative will be that two researchers are working on this together. Analysis will be iterative during the fieldwork phase to allow emergent (sub)themes to be incorporated into the data collection.

The questionnaires will be statistically analysed by using SPSS Statistics 23. We will use descriptive statistics such as frequencies, crosstabs, means and standard deviation to describe and synthesize the characteristics of the participant population and to answer the quantitative research questions. Furthermore, during this analytical phase we will integrate the quantitative variables and qualitative findings to draw a more complete picture on spiritual care by nurses in oncology.

2.3 | Ethical considerations

As in all ethically conducted research, informed consent will be obtained to guarantee voluntary participation and participants may withdraw at any time should they wish to do so. We believe that the potential for risk in this study is minimal and that it may even benefit participating patients and nurses because previous psychosocial end-of-life research showed that participants were unlikely to experience significant burden from participation and, in fact, experienced benefits (Pessin et al., 2008). Qualitative research interviews in palliative care were considered helpful by the patients themselves as they experience sharing problems as therapeutic and being able to contribute to research as empowering (Gysels, Shipman, & Higginson, 2008). To minimize the burden of data collection on patients, questionnaires have a short completion time and the total duration of interviews will be limited to a maximum of 90 min. Interviews will

be conducted by researchers who are experienced and well trained in research with vulnerable patients.

For professional caregivers, participating in the study may be beneficial because during the interviews they will have the opportunity to reflect on their experiences of the provision of spiritual care. This reflection could be a prompt to improve their collaboration with other caregivers and may provide an impetus to improve daily practice. The study does not fall in the remit of the Dutch Act on Human Research and for this reason did not have to go through the Dutch ethical review committee.

2.4 | Reliability and validity

In our study, special attention is given to the construct validity. This is fostered by repeated and extensive discussion about the best way to find an answer to the research questions without mentioning "spirituality" and "spiritual care" in a too early phase of the interview. We also held some pilot interviews from which we acquired additional useful information, based on which we made some adaptations before starting with the other interviews.

Furthermore, we have chosen well-known and psychometrically sound questionnaires for measuring the various spiritual aspects that are especially important for the respondents (SAIL), the experienced quality of life (EORTC QLQ-C30, only patients) and the self-assessed competencies in providing spiritual care (SCCS, only nurses). Next to this, we have taken other measures to promote the validity and reliability of the qualitative part of this study. The researchers are reflexive and participate in regular meetings where data collection, data management and data analysis will be discussed. Pilot interviews with patients and nurses are held and other project team members independently listen to a couple of interviews to improve interview techniques and to align the interviewers as much as possible. The audio files will be transcribed verbatim and in the beginning of the analysis the two researchers will analyse the same transcript and compare and discuss their results until consensus is reached. After this initial period, regular checking of each other's coding will be done. Furthermore, feedback to and discussion with the most close project team member (BG) will be carried out. Integrating the statement results with the qualitative data also contributes to scientific rigor.

3 | DISCUSSION

3.1 | Strengths

This mixed methods study allows us to gain insight in the quantity and quality of spiritual care provided by nurses in curative cancer care. It includes the patients' as well as the nurses' perspective and has a broad national perspective. This has the advantage that we can compare experiences of respondents working in and being cared for in a variety of different hospitals where curative oncology care is organized differently. The information we gain in this study can provide suggestions for the improvement of nursing care for people with cancer who are treated with curative intent, a topic until now hardly addressed.

3.2 | Challenges

One of the challenges in undertaking this study is a practical one; how to gather a large amount of data in a timely manner among patients who are in a very vulnerable period in their lives and among nurses who are under a continuous professional time pressure. The distribution over nine hospitals, resulting in a hopefully acceptable amount of respondents per hospital, will help us in this process. We know that there are far more patients treated with curative intent per hospital than we need for this study. Next to this, we planned for a protracted data collection period. Based on this, we expect that we will be able to reach our expected numbers of respondents.

Another challenge for this study is the method and the moment in the interviews that we have chosen for talking about spirituality and spiritual care. We deliberately chose our method to avoid all kinds of vague connotations with both concepts which might result in very narrow-minded interviews, e.g. only about religion or only about transcendence. On the other hand, the usage of the words we have chosen (resilience, meaning, support, life issues) might lead to a conflation of psychosocial and spiritual issues during parts of the interviews. The rigorous data analysis method we will use will prove its worth in dealing with these borderline situations.

4 | CONCLUSION

This study will provide valuable data about patients' and nurses' experiences with spiritual care in curative cancer care in a variety of hospitals in the Netherlands. Using a mixed methods approach, we will be able to explore the complex phenomenon of spiritual care in curative cancer care in more detail. By combining quantitative and qualitative data from patients' as well as nurses' interviews, we will be able to provide important insights into what constitutes patient-centred spiritual care. This knowledge will add to the scientific evidence and might provide clues for improvements of the quality of care for patients with a severe illness.

COMPETING INTEREST

There is no conflict of interest.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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