Aspects of spirituality concerning illness

René van Leeuwen1 RN, MScN (Lecturer and Researcher), Lucas J. Tiesinga2 PhD (Senior Researcher), Henk Jochemasen3 PhD (Lecturer), Doeke Post4 PhD (Professor)

1Health Department Ed. Christian University Ede, Netherlands, 2University of Groningen, University Medical Centre Groningen, The Netherlands, 3Ethics of Care, Ede Christian University, Ede The Netherlands and holder of Lindeboonchair of Medical Ethics, VU-Medical center, Free University Amsterdam, Netherlands, 4Institute of Social Medicine, University of Groningen, Netherlands

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The spiritual dimension of illness, health and care may be seen as a unique aspect in addition to the physical, mental and social dimension. This contribution describes experiences of patients, nurses and hospital chaplains in relation to the spiritual aspects of being ill. Qualitative research was performed with the design of a focus group study, consisting of 13 focus groups with a total of 67 participants. A purposive sample was used comprising patients, nurses and hospital chaplains working in oncology, cardiology and neurology in different institutions and regions in the Netherlands. The qualitative analysis consisted of open coding and the determining of topics, followed by the subsequent attachment of substantial dimensions and characteristic fragments. Data were analysed by using the computer program KWALITAN. Spirituality play various roles in patients lives during their illness. There is a wide range of topics that may have an individual effect on patients. Despite differences in emphasis, the topics play a role in different patient categories. Although the spiritual topics seem to manifest themselves more clearly in long-term care relationships, they may also play a role during brief admittance periods (such as treatment decisions). The spiritual topics that arise from this study offer caregivers a framework for signalling the spiritual needs of patients. The question is not whether spirituality is a relevant focus area in care, but how and to what degree it plays a role with individual patients. Follow up research should aim at further exploration of spiritual aspects in care, the relationship between spirituality and health and at effective training of caregivers.

Keywords: focus groups, cardiology, neurology, oncology, caring, spirituality.

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Introduction

The spiritual dimension of illness, health and care may be seen as a unique aspect in addition to the physical, mental and social dimensions (1–3). The relation between spirituality and healthcare is part of medical scientific research (4, 5) and triggers different reactions in the scientific community. It is indicated that spiritual care helps patients to cope better with their illness. It provides a sense of direction, new hope and inner peace, allowing patients to accept and cope with problems that cannot be solved (6). Although spiritual aspects of clinical care are important, the subject should be approached carefully because it is misleading to say that it will benefit a patient in every situation (7). Based on a study of addiction care (8), it was concluded that spirituality can be a strong reason to reject certain forms of care. With respect to the relationship between spirituality and health, the placebo effect is mentioned (9), in which effects are based on ‘believing’ in something. The different views and outcomes call for further scientific study. The reason is obvious, because despite the different views, spirituality is increasingly being recognized and acknowledged as an aspect of clinical care, which plays a role concerning illnesses and should therefore be considered by caregivers in their professional practice (4).

A recent review (10) describes research on this topic in nursing. It stated that most of the respondents in these studies acknowledged that the spiritual dimension was an important part of their lives, providing a source of strength, hope and well-being, especially during illness, loss and/or hospitalization. The studies focussed on different patient groups and took place in different care settings and cultural contexts. The author concludes, although research has been small in scale and results cannot be generalized, the spiritual dimension is invaluable and highlights areas for

Correspondence to:
R. R. van Leeuwen, Christian University Ede, P.O. Box 80, 6710 Ede, Netherlands.
E-mail: rvleeuwen@che.nl
Further investigation. She recommends the need to continue to explore and describe facets of spirituality and spiritual care.

In emphasizing the importance of spirituality among patients, it is pointed out that spirituality is culturally determined. Each patient is a unique individual whose needs are influenced by cultural convictions and values and spirituality is expressed and shaped by the accepted practices and beliefs of a particular culture (3, 10). This raises the question whether there are differences in experiencing and expressing spiritual needs during illness between patients and caregivers in different countries. This was the reason for studying the phenomenon of spirituality in the context of Dutch health care. This current study focuses on aspects of spirituality, that play a role for oncology, cardiology and neurology patients and took place in the period May–December 2004.

The concept of spirituality lacks clarity in nursing literature. In a review of definitions of spirituality it is argued, that because there are myriad of definitions with different layers of meanings, spirituality can imply different things depending upon an individual’s personal interpretation or worldview (11). In this study, the so-called functional approach of the concept of spirituality is used (12). This approach represents the claim that human beings express their common function of spirituality in different forms and contents. The following description of ‘spirituality’ was used as a point of departure: ‘the ideological or religious functioning of a person, including questions of finding and experiencing meaning’ (13). This definition emphasizes the fact that spirituality can be explained in a religious as well as in a nonreligious way. This is a relevant factor in health care, given the fact that patients also have different spiritual backgrounds. The aim of this study was to determine whether and how spirituality plays a role for patients who have physical complaints within the context of Dutch clinical somatic health care, and how this may influence the practice of caregivers. To gain more insight, the experiences of patients, nurses and hospital chaplains in oncology, cardiology and neurology were examined.

### Methods

This study is part of a larger study of spiritual aspects of illness and spiritual care. The results of this extensive study are reported in separate articles. The first article describes aspects of spiritual care in nursing (14). This article focuses on the spiritual aspects of illness. The research method used in this study is similar to the method we described in our earlier paper. Therefore we now only give a brief description.

The current study involved the use of focus groups (15) that consisted of patients, nurses and hospital chaplains who were selected from the specialist fields of cardiology, oncology and neurology. The participants were selected across a certain geographical area. Selection criteria were: recent hospital admittance (patients) and work experience (nurses and hospital chaplains). Selection took place according to the method of purposive sampling. The patients were recruited from patient organizations by making an announcement on their websites. Nurses were recruited from nursing organizations and by approaching hospitals in different regions. Hospital chaplains were also recruited from hospitals in different regions. They had a religious and a humanistic background. Groups were formed containing a maximum of 5–6 people (Table 1). The hospital chaplains were assigned to three groups. Some participants cancelled their interviews because of illness, transport problems or personal reasons. The ideological background of the participants was consistent with the Jewish-Christian and humanistic roots that largely characterize Dutch society.

A topic list was used for the focus group interviews and each participant received the definition of the concept of spirituality (see Introduction) prior to their interview to create the same frame of reference across group members. By reading this definition participants could prepare themselves on the theme of spirituality. At the start of the interview the moderator gave an additional explanation if requested by participants. For some of the participants, the theme of spirituality became more clear during the interview, because of the experiences that other participants put forward. Then they were more able to tell their own

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<th>Group</th>
<th>Number of groups</th>
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<th>Specialism</th>
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<td>Patients</td>
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<td>25</td>
<td>Cardiology 7</td>
<td>Male/female ratio 9/16</td>
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<td>Average age 58 (range: 44–82)</td>
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<td>30</td>
<td>Cardiology 10</td>
<td>Male/female ratio 2/19</td>
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<td>Neurology 9</td>
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experiences and could become more concrete. This phenomenon showed the appropriateness and relevance of this research method.

The interviews were recorded on audiotape, which were processed into fully typed transcripts which were the basic material for analysis. These results were included in the analysis. The qualitative analysis consisted of open coding and the determining of topics, followed by the subsequent attachment of substantial dimensions and characteristic fragments (15, 16). Analysis was performed with the computer program KWALITAN (17), which was also used to analyse the groups and the relationship between the groups. Measures taken to guarantee the reliability and validity of the research included separation between reporting/observing and taking the interview, trial interviews and constant briefing in the research group, ‘peer debriefing’ with a professional in the field of research and spirituality, data triangulation, the keeping of a journal and application of ‘thick description’, enabling outsiders to assess the generalization quality of the research results (18, 19).

Immediately after each focus group meeting a debriefing took place between the researcher and the research assistants to discuss the first verbal and nonverbal remarks. The outcomes of the debriefing became part of the qualitative analysing process and generated indicators for the next meetings.

After concluding the analytical phase of the study, the topics identified in the interview texts were ordered with the aid of a modification of Fitchett’s spiritual dimensions model (13, 20). This model is an example of the so-called functional approach of spirituality. On the basis of many interviews with patients Fitchett distinguished different dimensions in the functioning of patients. Another reason for using this model was the fact that this model was successfully used in the Netherlands in a research about spiritual needs among patients in palliative care (13).

Ethical dimensions of this research

All respondents participated voluntarily in the research. Before the focus groups started, the participants received written information about the purpose and content of the study and what was expected from them during the focus group meeting. They could withdraw from the study at any time. Results were presented without any opportunity to identify the response of individual group members.

Results

In describing the results of the focus group interviews, we will focus on the spiritual aspects concerning illness in general and on the differences between groups of patients. The general themes in this section are described within the spiritual categories from the modified Fitchett model of spiritual assessment (13, 20). These themes are summarized in Table 2. It is emphasized that this categorization took place after the process of analysis was completed. The Fitchett model played no role during the interviews and interpretation processes.

Spiritual themes in relation to illness in general

Belief and view of life. Themes according to belief and view of life were both positively and negatively loaded. Positive in the sense that some of the patients during illness and treatment were trusting in God, were not afraid to die because of their faith, believed in miracles and found strength in themselves, their faith and nature:

Patient: what I read in the Bible gave me a lot of faith and rest. Yes, I could leave it in Gods hands easily. It has deepened my faith, my illness has enriched my life.

Patient: I have experienced that I received an unbelievable power, and I thought, this is nature. When my relatives collapsed I became stronger. Some respondents talked about faith and view of life in a negative way by saying that they were angry at God, had fear of dying and facing God or could no longer draw any strength from their faith. Patients are also confronted with so-called questions of life and death such as questions why they got this illness or doubts about their belief:

Patient: I feel there must be something over there, but for me it is no longer God. Too much has happened in my life. My mother died, my mother-in-law died and now I am ill myself.

Patient: I am not religious any more. I stepped out. The reason for that were the many deaths of young people in my family. And then I was thinking when someone wishes the best for the world, then he is very wrong.

Goal in life and life balance. Confrontation with their own vulnerability and mortality influences the patients’ balance of life. Some of the respondents experienced the illness as an experience of loss, because they could not go on living as they did before the illness. They were confronted with their limitations. Some patients experienced their situation as a fate, in which they could find rest or in which they could give their illness a place in their life. For some of them it had to do with the end of life and the acceptance of death or having no fear of dying:

Patient: but eeeh, that cardiac arrest, then I realized that I had been dead, If you know what I mean, that was the most confronting for me during my illness.

Patient: everybody gets his turn. Everyone has his own cross to bear. Everyone gets it in his own way on his own time. Let’s make something of it.

Patients told in the interviews that coping with their illness is a process one ultimately has to go through on
one's own and that gives sometimes a feeling of loneliness. They emphasized that this confronted them with the question how to live on with that illness. They expressed that with questions such as ‘how long do I still have to live’, ‘what is left to do for me in my life’ and ‘what is still important for me now I am ill?’ It seems that by the confrontation with a severe illness, the patient is becoming more aware of his personal history. Patients told that they are looking back on their life more and made up a kind of balance. Some of them took hope and strength out of earlier difficult life experiences that helped them to fight against setback now:

Patient: before the accident my work was my life. I have got a brain damage and after a period of time I realized that most of the people who had such damage will not recover. Then I asked myself the question: how do I have to go on with my life?

Hospital chaplain: when the patient got that bad message, he started looking back: ‘what have I done with my life when I reached this age now’.

The balance of life is also related to themes that were put forward and that were called ‘ending life’ and ‘dying’. Many respondents (especially nurses) associated the theme of spirituality in first instance with questions about dying. When the interviews proceeded they also related it with illness. The remarks respondents made about dying dealt with questions about death, dying, a last wish and the wish to die:
Patient: and then I thought, I prefer to be dead, because this is not life what I am experiencing.
Nurse: he was terminally ill and then we arranged that he could go for one night to his boat to be with his dog. We took all the medical equipment with him. It was his last wish.

Experience and emotions

During their illness patients have feelings of anxiety that were described by the respondents as (existential) fear, concern, anger, rebelliousness and grief. The (existential) fear was about fear of dying, for the uncertainty and for God. Respondents told that the patients are concerned about the loss of relations, because of dying and because of possible fatal consequences of an operation. The anger and rebelliousness were directed against the sickness itself or against God, expressed by so-called ‘why questions’. Grief can play a role when the patient faces the consequences of the illness:

Nurse: a boy awoke at night and told me that he wanted to talk because he had feared. He told me that it has become more severe when a colleague of mine asked him ‘and when you will have your bone marrow transplant, do you realize that things can go wrong?’. Patient: I was full of anger. I thought, I have got this life-threatening disease and there are lots of criminals walking around who’s life is nice and easy and someone like me who does not hurt anybody, is eeh...........

Different respondents also mentioned the impact of physical aspects. In one of the interviews breast cancer patients participated. They told about their feelings of shame when they were confronted with their own body after the breast operation. Different respondents said that physical contact is experienced by patients as supportive on difficult moments during their illness.

Some of the patients had experienced special images and visions. They were mainly religious from origin, for example one talked about a visible contact with mother Mary or with angels. Some patients saw a great light, what they called near death experience. All the respondents called this positive experiences which gave them some kind of rest:

Patient: a near death experience....., yes what did see......there was a tunnel and I saw a light and my grandfather, who was waiting for me. Since that time I don’t feel I am alone.

Courage, hope and growth

‘Acceptance’ and ‘letting go’ were important themes mentioned in the interviews. It entails that patients can give meaning to their illness, that they can surrender themselves to the new situation and seek new perspectives in life. The way in which patients handle this new situation differs for every person. Some patients could accept their situation rather easily, while others had more difficulty with it or could not accept it at all (at the moment):

Patient: in my rehabilitation they were all focussing on the way I had to cope with the new situation and that I had to accept it. But I said ‘I can only accept it when I am sure that I need not go on in the way I did before’.

Hospital chaplain: many patients are seeking, but on the long term many of them realized that the solution had to come out of themself.

The following mechanisms were mentioned that had helped patients to cope with their illness: humour, positive thinking, to be open about their feelings, experience of comfort and keep fighting. It turned out that the way patients used these mechanisms depends on the way that they fit for every person. The need of comfort was mentioned by several patients, meaning not only the comfort the patient got for example from relatives, but also that the patient was able to encourage and comfort his relatives:

Patient: I want to get the positive out of it. After all I have dealt with it during my illness, I still see a message for myself and the possibility to develop myself in a certain way.

Nurse: I realized that when I let the patient talk about his or her life, that it was comforting for that patient.

Patient: I keep fighting. I will make something of my life. I keep fighting. I am doing that for all my life.

Religious and spiritual practices and customs

Many respondents told that patients were supported by the use of one or more of the following practices and customs: prayer, meditation, reading religious or spiritual textbooks, listening to religious or spiritual music, visiting (religious) services in the hospital and visiting the hospital chapel for a moment of silence. For some patients there were custom practices they wanted to continue while they were in hospital. For some other patients these needs were felt during their stay in the hospital:

Patient: on Sunday I asked if they would bring me to the service in the hospital. At home I always visit that services. Then they brought me to it with all the medical equipment.

Patient: sometimes thoughts are running around in my head. And when I cannot stop my thoughts, then I start praying in my own way. Then I am talking with God or with myself or anyone else.

Some patients are also using various rituals and symbols, like burning candles, praying the rosary and the use of healing stones. Some of the nurses told that when the patient reached the terminal stage of illness, the relatives asked for giving the unction or, in case of Roman Catholic patients, the last rites.
Nurse: sometimes I see patients with some kind of little stones. They got them for example from their (grand) children to bring luck en get healed.

**Relationships**

Relationships are especially important for patients during illness. Patients mentioned the fear of loneliness. They said that ultimately they had to cope with the illness all by themselves. The support from and contact with fellow sufferers was mentioned by different patients as very supportive:

Patient: I discovered I had to do it all on my own. Ultimately I was thrown back upon my own resources.

Patient: I feel that I am most connected en supported by people who gone through the same I did.

Patients are also asking themselves the question if they can go to work again or they realize that they have to find a whole new life fulfilment. In this relational aspect also the experiences and feelings of the relatives of the patient have a place. They can express feelings like sorrow, concern, fear, panic and the acceptance or nonacceptance of the situation. Some relatives express the problems they have with their faith. Some respondents reported the tensions that arose in the relationship between the patient and a relative:

Nurse: sometimes ago I nursed a women who knew that she would die soon. She was very busy with making lists with practical instructions for her husband how he had to care for their little child. For her husband, this was very confronting. That stressed their relationship.

**Authority and guidance**

When patients were asked if they experienced some guidance in their life during the illness, some of them mentioned the role of their faith. In this, the religious patients showed a different view. Some of them experienced a positive guidance because they said they had felt strength and support from God. On the other hand, some religious patients said they experienced fear of God or were angry at God because he had taken all good things from them. Nonreligious patients said they had to find their own way in dealing with the illness:

Hospital chaplain: I meet patients who said that the illness has brought them very close to God. One patient said: ‘I would say, If I did not have that I do not know where I should be now. My faith has supported me very much. Because at the end you lose everything, also my wife, and who is left then?’

Some patients put forward that they were confronted with decisions about life and death and the meaning of their view of life in this context. Some patients expressed their fear of euthanasia:

Patient: the doctor said to me ‘when you become a cardiac arrest again, do we have to resuscitate you?’.

That question frightened me, that I am directing my own life and death.

**Differences between respondents**

The topics described appeared in each patient category, although they may have been expressed differently by each patient. Among cardiology patients, we can distinguish between patients with acute ailments (heart attacks) and those with chronic ailments (heart failure). The first group is characterized by a high degree of resistance, a low degree of resignation, and the (continuous) search for possible treatments, which hinders reflection on their personal situation. Self-reflection is more apparent in the other group:

Nurse: a patient in his early 60s said: ‘I want a heart transplantation; I’ll sell my house and make sure I have enough money so that you can get me a heart’. He could do nothing else. Then there was a 34-year-old woman with heart disease who was about to die. With her I saw more peace of mind and rest; she realized that the end is near. But in the category of patients who have had a heart attack or need a transplant, it’s just live, live, live!

With neurology patients, communication problems (e.g. aphasia) may be the reason why aspects of spirituality are not expressed by patients or are not recognized by caregivers. These patients indicate that as a result they appear to receive little attention from caregivers, leaving them with the impression that the caregivers are avoiding contact. Especially during the initial phase, neurology patients tend to find their situation unacceptable. Nurses speak about reactions similar to those in a mourning process:

Patient: I wonder if they even thought about whether I was dealing with it. The rehabilitation was focussed on accepting and dealing with it; they went on and on about it. And I said: I will not accept this until there is nothing else left. I wanted to get the most out of it.

In the case of oncology patients, the results show that during follow-up treatment they expressed more questions on how to find a sense of purpose and communicated more with the caregivers as compared with their first treatment, which was usually dominated by the initial shock and the consequences of the diagnosis (what can be done, what are my options?). From this we can conclude that if a patient is dealing with a long-term illness the spiritual aspects may play a more explicit role in the patient’s life and will be discussed more often with the caregivers.

In addition, the social context of a patient plays a role (family, partner and work). On the one hand, patients may find support in their social environment, but on the other hand it may lead to questions (‘will I be able to go working again’) and tensions (family members who try to find a
Discussion

This study confirms that spirituality affects the perception of illness. Results show that patients clearly indicate this and caregivers are able to confirm it. An essential element is the personal perspective on these aspects, leading to distinguishing between many different spiritual aspects, which are presented thematically in this study.

According to the literature the spiritual needs and sources cover a wide range and include vertical, transcendent (religious) elements and horizontal existential elements. Studies show that nurses tend to view spirituality in broader terms than patients who see it more in terms of religion or expressed difficulty in defining it (10). Our study shows that both nurses and patients first tend to view spirituality in religious terms. The reason for that could be that in Dutch society people are more familiar with the concept of religion than with spirituality. The use of the functional definition of spirituality could have contributed to this view, because religion was explicitly mentioned in that definition. Participants’ responses to the initial questions usually were limited. Informants seemed to need time to feel comfortable talking about such an intimate topic. The same experience is described in a study among cancer patients (21). This raises questions about the possibility of communication on spiritual matters between the nurse and the patient. It seems that a relationship of faith and trust is needed.

This study shows that the spiritual categories of the modified Fitchett model (20) are useful for categorizing the spiritual themes that emerged from the analysis. The resulting overview (Table 2) can serve as a basic tool for caregivers in observing and signalling spiritual aspects in care practice. In a study about spirituality in nursing Bash (22) stated that he is not convinced that it is possible to develop assessment tools that are sensitive, flexible and accurate enough to identify the spirituality of all patients, or even the majority, because of the fact that a person’s spirituality may be so difficult to identify, that it will not be possible to measure it. The tool that can be derived from this study should be considered as a frame of reference that nurses can use in their relationship with the patient.

Ultimately, the nurse’s assessment of the real spiritual need of the patient, depends on the spiritual sensitivity of the nurse herself. In this, we agree with McLaren (23) who emphasizes that definitions and related concepts of spirituality can only provide a starting point from which nurses can engage in spiritual nursing. That is the reason that many authors stress the need for development of spiritual self-awareness of nurses, which is an important condition for the nurse to meet the spiritual needs of patients (3, 10, 14).

The spiritual topics play a role in different patient categories. There seems to be a difference between on the one hand patients who stay in hospital for a relatively brief period (acute ailments) or those who are in the first phase of diagnosis and treatment, and, on the other hand, patients who have been ill for a longer period and who are therefore confronted with caregivers on a regular basis. This raises the question of whether spirituality should (or can) be an area of attention for caregivers when dealing with the first group. There are studies in acute settings that all explicitly describe spiritual needs of patients in an acute care setting (24–27). Maybe caregivers should trained to be more alert in recognizing spiritual needs in that acute settings.

The study shows the relevance of spiritual aspects during illness, indicating that there is a relationship between spirituality and health. Spiritual aspects can be of vital importance to patients when they are dealing with their illness, their relationships, when making decisions, facing the prospect of death, etc. In addition, spirituality may have an obstructive effect on the normal functioning of a person. This topic does not address the question whether or not spirituality is a relevant area of attention in care, but how and to what degree it plays a role in individual patients. This is what caregivers should look for. In today’s health care essential human aspects threaten to disappear from view. These aspects can be regarded as spirituality and seem to play a relevant role in the process of illness and care.

The relationship between spirituality and health should receive more attention in research, especially in nursing. In medicine much relevant research have been done in this area (2), but in nursing this research is limited (5, 10). The exploration and description of aspects of spirituality concerning to illness should be continued, but in agreement with Ross (11) we recommend that future studies also should focus on the associations between variables of health and spirituality.

To increase attention for spiritual aspects in care, we propose that educational programmes of caregivers pay more attention to this topic. For nurses these competencies have already been described and in practice been recognized (14, 28, 29). Follow-up research should focus on further exploration of spiritual aspects in care, as well as effective education of caregivers.
Author contributions

René van Leeuwen, Lucas J. Tiesinga, Henk Jochemsen and Doeke Post performed the study design and manuscript preparation. René van Leeuwen did the data collection and analysis.

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