Selman, L., Brighton, L., Sinclair, S., Karvinen, I., Egan, R., Speck, P., ... Hope, J. (2018). Patients’ and caregivers’ needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Journal of Palliative Medicine*, 32(1), 216-230. https://doi.org/10.1177/0269216317734954

Publisher's PDF, also known as Version of record

License (if available):
CC BY-NC

Link to published version (if available):
10.1177/0269216317734954

Link to publication record in Explore Bristol Research
PDF-document

This is the final published version of the article (version of record). It first appeared online via Sage at http://journals.sagepub.com/doi/10.1177/0269216317734954. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: http://www.bristol.ac.uk/pure/about/ebr-terms
Patients’ and caregivers’ needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries

Lucy Ellen Selman1, Lisa Jane Brighton2, Shane Sinclair3, Ikali Karvinen4, Richard Egan5, Peter Speck2, Richard A Powell6, Ewa Deskur-Smielecka7, Myra Glajchen8, Shelly Adler9, Christina Puchalski10, Joy Hunter11, Nancy Gikaara12 and Jonathon Hope13; the InSpirit Collaborative

Abstract

Background: Spiritual distress is prevalent in advanced disease, but often neglected, resulting in unnecessary suffering. Evidence to inform spiritual care practices in palliative care is limited.

Aim: To explore spiritual care needs, experiences, preferences and research priorities in an international sample of patients with life-limiting disease and family caregivers.

Design: Focus group study.

Setting/participants: Separate patient and caregiver focus groups were conducted at 11 sites in South Africa, Kenya, South Korea, the United States, Canada, the United Kingdom, Belgium, Finland and Poland. Discussions were transcribed, translated into English and analysed thematically.

Results: A total of 74 patients participated: median age 62 years; 53 had cancer; 48 were women. In total, 71 caregivers participated: median age 61 years; 56 were women. Two-thirds of participants were Christian. Five themes are described: patients’ and caregivers’ spiritual concerns, understanding of spirituality and its role in illness, views and experiences of spiritual care, preferences regarding spiritual care, and research priorities. Participants reported wide-ranging spiritual concerns spanning existential, psychological, religious and social domains. Spirituality supported coping, but could also result in framing illness as punishment. Participants emphasised the need for staff competence in spiritual care. Spiritual care was reportedly lacking, primarily due to staff members’ de-prioritisation and lack of time. Patients’ research priorities included understanding the qualities of human connectedness and fostering these skills in staff. Caregivers’ priorities included staff training, assessment, studying impact, and caregiver’s spiritual care needs.

Conclusion: To meet patient and caregiver preferences, healthcare providers should be able to address their spiritual concerns. Findings should inform patient- and caregiver-centred spiritual care provision, education and research.

Keywords

Spirituality, pastoral care, palliative care, religion and psychology, focus groups, qualitative research

1Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK
2Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, King’s College London, London, UK
3Faculty of Nursing, University of Calgary, Calgary, AB, Canada
4Global Health Programme, Diaconia University of Applied Sciences, Helsinki, Finland
5Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand
6MWAPO Health Development Group, Nairobi, Kenya
7Department of Palliative Medicine, Poznan University of Medical Sciences, Poznan, Poland
8Director of Medical Education, MJHS Institute for Innovation in Palliative Care, New York, NY, USA
9Other Center for Integrative Medicine, University of California, San Francisco, San Francisco, CA, USA
10The George Washington University’s Institute for Spirituality & Health (GWish), School of Medicine & Health Sciences, The George Washington University, Washington, DC, USA
11School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa
12Independent Consultant in Palliative Care Research, Kenya
13Patient Representative, UK

Corresponding author:
Lucy Selman, Population Health Sciences, Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, UK.
Email: lucy.selman@bristol.ac.uk
What is already known about the topic?

- Spiritual distress is prevalent among patients with advanced disease and is associated with poor quality of life and increased healthcare costs.
- An international survey of palliative care clinicians and researchers identified the need for research into the spiritual care needs, preferences and experiences of patients and their caregivers.
- However, the survey did not include patients and caregivers, whose research priorities in spiritual care remain unknown.

What this paper adds?

- Patients and caregivers in nine countries across four continents described many spiritual concerns, but reported spiritual care to be lacking.
- Participants' preferences highlighted the need for all interdisciplinary team members to address spiritual issues.
- Patients’ and caregivers’ research priorities included understanding the qualities of human connectedness, communicating sensitively about spirituality, staff education, spiritual care assessment, making spiritual care appropriate for diverse populations, studying the impact of spiritual care, and caregivers’ spiritual care needs.

Implications for practice, theory or policy

- All staff caring for people with incurable, progressive disease should have a basic level of competency in spiritual care.
- Clinical education aimed at improving spiritual care should draw on the findings from this study regarding patient and caregiver needs, experiences and preferences regarding how spiritual care is provided.
- Identified research priorities can help ensure future spiritual care research is patient- and caregiver-centred.

Background

Through international consensus, spirituality has been defined as ‘a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred’.1 Spiritual distress is suffering related to this dimension of personhood and includes existential components (e.g. meaninglessness and hopelessness) as well as religious concerns. Spiritual distress is prevalent among patients with advanced disease2–4 and is associated with poor quality of life,5 end-of-life despair,6 requests for physician-assisted suicide7 and dissatisfaction with care.2 Family caregivers report high levels of spiritual distress and unmet needs,8,9 particularly in the context of a life-limiting illness.10–12

Spiritual care, that is, support from healthcare providers that aims to ameliorate spiritual distress, is neglected in clinical practice,2,13–18 with only 6%–28% of patients receiving spiritual care from their healthcare teams.2,5,19,20 This is contrary to patient wishes21,22 and policy guidance internationally.23–25 Evidence suggests that a lack of spiritual support by healthcare teams is associated with poor quality of life, dissatisfaction with care, less hospice utilisation, more aggressive treatment and increased costs, particularly among some ethnic minority groups and patients with high levels of religious coping.5,26–28 Spiritual care specialists such as chaplains (usually, and in the context of this study, a member of the clergy or religious leader) and pastoral care providers, who provide specialist spiritual support but may not be religious, possess advanced training in addressing spiritual concerns. However, it is increasingly recognised that all healthcare providers working with patients with serious illness are responsible for providing basic spiritual care, referring to specialists when needed. Despite this, evidence to inform spiritual care provision and training is limited.29–33 A Northern and Western hemispheric bias is also evident, with most research conducted in the United States and Western Europe. To redress this deficit, an international evidence base is required to guide clinicians in the provision of spiritual care, to ensure patients’ and family members’ support needs are met.

Selman et al.34 conducted an online survey via the European Association for Palliative Care (EAPC) to identify spiritual care research priorities among palliative care clinicians and researchers (n = 971), and found that understanding spiritual care needs and preferences in multi-faith, multi-cultural populations was a priority area. However, the survey did not consult patients and caregivers regarding their own research priorities in this domain, which is essential if the international research agenda is to be centred on service users’ genuine needs.1 The goal of this study was to explore patients’ and caregivers’ needs, experiences, preferences and research priorities in spiritual care internationally.

Methods

Study design

This is a qualitative focus group study, conducted in 2013–2014.
Box 1. Topic guide for patient focus groups.

Preamble: Usually medical care focuses on the physical dimension of health, like controlling pain and other symptoms, but in this discussion, our interest is focused on those aspects of illness that affect you as a person and might cause you to consider the deeper questions of life. In this study, we define questions relating to meaning, purpose and how we cope with difficult aspects of life as spiritual questions, but this might not be the word you use. Please use whatever language you want in this discussion.

1. In terms of your own illness experience, what are the deep questions you find yourself asking these days?
2. Would you describe any of these deep questions as spiritual? If so, why? If not, why not?
3. What does ‘spirituality’ mean to you?
4. What does ‘spiritual care’ mean to you?
5. Do you think spiritual care should be provided in healthcare? If so, why? If not, why not?
6. In the healthcare setting, what sort of people could best support you with any deep emotional or spiritual questions you have?
7. In your opinion, what should be the role of different people in providing spiritual support in healthcare? Discuss each of nurse, doctor, GP, chaplain, social worker, psychologist, volunteer and community faith leaders. Prompts: How could these people best support you? Who should initiate discussions of spirituality in healthcare? Why?
8. Based on your own understanding of spirituality, what in your experience are the most helpful things a healthcare provider can do if a patient has spiritual concerns? Can you share an example of a caregiving interaction where you felt your spirituality was addressed?

Prompts: If yes, by whom? (Were they from palliative care?) When in your illness? What happened? What worked well?
If never experienced, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
9. What are the least helpful things a healthcare professional can do if a patient has spiritual concerns? Can you share an example of a caregiving interaction in a clinical setting where your spirituality was not addressed or where you were adversely affected?
10. In your opinion as a patient, what are the most important areas of research to improve spiritual care? Prompts: What do you think would really improve the quality of spiritual care or help to better meet your needs?
11. Is there anything we did not talk about which you think it would be useful to know?

Participating sites

The study was conducted across 11 sites in nine countries: South Africa (Cape Town), Kenya (Nairobi), South Korea (Seoul), the United States (San Francisco, New York, Washington), Canada (Calgary), the United Kingdom (London), Belgium (Leuven), Finland (Tampere) and Poland (Poznan). All the sites provided care for patients with incurable, progressive disease, either through community or inpatient services, and had capacity to support the research. We aimed to recruit across a range of countries and regions to produce a broad, descriptive account of patients’ and caregivers’ needs, experiences, preferences and research priorities across diverse settings.

Sampling and recruitment

We aimed to recruit 4–12 participants per focus group, utilising purposive sampling to ensure diversity in diagnoses, age, gender and religion/beliefs where possible. A group of 4–12 was felt to be optimum to generate discussion while remaining manageable. Separate focus groups for patients and caregivers were conducted so that participants had shared experiences of illness/caregiving and would feel able to speak freely. Inclusion criteria for patients were having an incurable, progressive disease and being an adult (18 years or older). Caregivers were adults with experience of caring for someone with incurable, progressive disease. Participants were recruited via one of the clinicians at the site introducing the study, with follow up by the researcher; via posters displayed in participating sites, which informed potential participants of the date of the focus group(s) and how to find out more about the study; and/or via letters of invitation sent to potential participants with a study information sheet. We aimed to achieve data saturation, that is, to collect data until analysis resulted in no new themes emerging.

Data collection

At each site, a researcher with qualitative experience (Appendix 1) conducted two focus groups (one with patients and one with caregivers), following a standardised protocol and training guidelines developed for the study (L.E.S.) based on the literature. The researchers were known to some participants, but were not involved in their care. An observer took field notes. The semi-structured focus groups followed a topic guide developed on the basis of literature and feedback from the project advisory group (Boxes 1 and 2).

Our research was in the subtle realist paradigm, in which reality is conceptualised as existing objectively, but known only from each individual’s own perspective. This approach, which posits a reality that can be separate from our knowledge of it, is appropriate in qualitative research which aims to accurately describe patient and caregiver experiences and views to inform health service delivery. Data collection was informed by an inclusive definition of spirituality and sought to understand patients’ and caregivers’ own perspectives. We described the research as focusing on ‘those aspects of illness that affect you as a person and might cause you to consider the deeper questions of life’. We defined questions relating to

...
meaning, purpose and how we cope with difficult aspects of life as ‘spiritual’ questions, but encouraged participants to use whatever language resonated with them.

The data collection documents, information sheets and consent forms were translated from English by the research team at each site where necessary. Focus groups were conducted in the most appropriate language for the location and audio-recorded. Prior to analysis, recordings were transcribed and translated into English by professional translators. The research teams at each site verified the translated transcripts against the recordings.

**Analysis**

Data were analysed thematically\(^3^9\) in NVivo v10, by qualitative researchers from the United Kingdom, Finland, Canada and New Zealand (L.E.S., L.J.B., S.S., I.K., R.E.). This descriptive methodology was appropriate given the cross-cultural, exploratory nature of the research.\(^4^0\) Analysis occurred in stages: after familiarisation with the data, two researchers (L.E.S. and S.S. for patient data; L.E.S. and R.E. for caregiver data) independently developed coding frames based on two focus group transcripts each, generating themes and sub-themes inductively from the data as well as deductively from the topic guide. Coding frames were compared and integrated to produce two overall coding frames (for patients and for caregivers), including definitions of themes and sub-themes. The coding frames were applied to the remaining transcripts using line-by-line coding (L.E.S., S.S., R.E., L.J.B., I.K.) and findings aggregated in a narrative, paying attention to non-confirmatory cases and differences between patient and caregiver views and experiences (L.E.S.). Field notes were used to contextualise the data and inform interpretation.

Anonymised data extracts are used in presenting findings (Tables 2–4). These are tagged with a unique ID code and location of the focus group.

**Ethical approval**

Approval to collect data was obtained from all sites’ local research ethics committees and for the overall study (Appendix 2). All participants gave written, informed consent.

**Results**

**Participant characteristics**

A total of 74 patients and 71 caregivers participated in 22 focus groups ranging 1–2 h (Table 1). Among

---

**Box 2. Topic guide for caregiver focus groups.**

Preamble: Usually medical care focuses on the physical dimension of health, like controlling pain and other symptoms, but in this discussion, our interest is focused on other aspects of illness and caregiving that affect you and the person you look after and might cause you to consider the deeper questions of life. In this study, we define questions relating to meaning, purpose and how we cope with difficult aspects of life as spiritual questions, but this might not be the word you use. Please use whatever language you want in this discussion.

1. What are the deep questions your loved ones ask themselves these days? Prompt: would you describe these as spiritual? Does your loved one discuss these concerns with you?
2. What about you – what are the deep questions you find yourself asking these days?
3. Would you describe any of these deep questions (either your loved one’s or yours) as spiritual? If so, why? If not, why not?
4. What do you understand by the word ‘spirituality’?
5. What do you understand by ‘spiritual care’?
6. Do you think spiritual care should be provided in healthcare? If so, why? If not, why not?
7. In your opinion, what should be the role of different people in providing spiritual support in healthcare? Discuss each of nurse, doctor, GP, chaplain, social worker, psychologist, volunteer and community faith leaders.
   Prompts: How could these people best support you? Who should initiate discussions of spirituality in healthcare? Why?
8. Based on your own understanding of spirituality, what in your experience are the most helpful things a healthcare provider can do if a caregiver has spiritual concerns? Can you share an example of a caregiving interaction where you felt your spirituality was addressed? Prompts: If yes, by whom? (Were they from palliative care?) When in your loved one’s illness? What happened? What worked well?
   If never experienced, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
9. What are the least helpful things a healthcare professional can do if a caregiver has spiritual concerns? Can you share an example of a caregiving interaction in a clinical setting where your spirituality was not addressed or where you were adversely affected?
10. In your opinion, do you think clinical care for your loved one has addressed his or her spirituality or needs for spiritual support? Prompts: If yes, by whom? (Were they from palliative care?) When? What happened? What worked well?
   If no, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
11. In your opinion as a caregiver, what are the most important areas of research to improve spiritual care? Prompts: What do you think would really improve the quality of spiritual care or help better meet your needs?
12. Is there anything we did not talk about which you think it would be useful to know?
Age, gender, country, religion, fairly/very spiritual, fairly/very religious, and patient diagnosis are shown in Table 1. Patients, the median age was 62 years, 48 were women, and 53 had cancer. Caregivers’ median age was 61 years and 56 were women. Two-thirds of participants in both groups identified themselves as Christian, with 68% identifying themselves as fairly to very religious and 69% as fairly to very spiritual. Each focus group lasted approximately 90 min.

**Findings**

Five themes were identified: patients’ and caregivers’ spiritual concerns, understanding of spirituality and its role in illness, views and experiences of spiritual care, preferences regarding spiritual care, and research priorities. Data saturation was achieved, that is, coding the later transcripts did not result in the identification of new themes in the data.

**Patients’ and caregivers’ spiritual concerns.** Patients and caregivers were asked to describe and discuss the ‘deeper questions of life’ which arose for patients with advanced disease (Table 2). Caregivers were also asked to describe their own deeper questions (Table 3). A wide range of spiritual questions, problems and concerns were reported, arising in four categories: existential, psychological, religious and social/relational. There was striking similarity across sites in the concerns and problems reported, as demonstrated in the data extracts (Tables 2 and 3), although these were framed differently in different contexts; for example, worry about the future for one’s family was often compounded by economic concerns in Kenya. Four caregivers (from Poznan, Tampere, London and San Francisco) reported that the patient they cared for did not have, or had not expressed, any ‘deeper’ questions (Table 4, Q1).
Table 2. Patients’ spiritual concerns, as reported by patients and carers.

| Category                        | Question or concern                          | Exemplifying data extracts                                                                                                                                                                                                                                                                                                                                 |
|---------------------------------|----------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Existential                     | Asking ‘why me?’                              | I wondered why I was born to have this kind of disease which made my life so much harder. If I have a disease that can be cured, I would not think negatively. Now that I have a bad disease, a flood of thoughts passes through my mind. (SP6, Seoul)                                                                                                                                                       |
|                                 | Meanings/cause of illness                     | My belief [is] that God will put a sickness onto you, most of the time, to bring you nearer to Him. (CTP6, Cape Town)                                                                                                                                                                                                                                         |
|                                 | Questioning life’s purpose                    | It was at the moment when I got to know that I could not be cured, that I looked back on my life and whether I have lived my life well without regret. I wondered myself if I did anything that would harm others or not. (SP4, Seoul)                                                                                                                                         |
| or priorities                   | Meanings/cause of illness                     | My belief [is] that God will put a sickness onto you, most of the time, to bring you nearer to Him. (CTP6, Cape Town)                                                                                                                                                                                                                                         |
|                                 | General existential questions                 | One night by myself I posed the question, ‘Do you want to live?’ And I realized the answer was ‘Yes’. (CP2, Calgary)                                                                                                                                                                                                                                              |
| Psychological                   | Questioning self-worth                        | I think you have to get down to the heart of what makes you worthwhile, where is your worthiness found? And everything that I probably didn’t know I found in it had been quite stripped away, so it left my ‘self’ confused. (CP2, Calgary)                                                                                                                                  |
|                                 | Difficulties with acceptance                  | I have always thought we are born to die, because this is a babe in arms and this is one of the things I think about an awful lot. As time has gone on, I have accepted it a lot better than I did the first year, which I found very hard. (LP5, London)                                                                                                  |
|                                 | Questioning self-resilience/ability to cope  | My fears were around just what I was going to cope with what was coming, a tremendous fear about being, uh, was I going to be severely disabled, um, was I going to not be able to drive anymore, um, where was I going to live? (CP2, Calgary)                                                                                                     |
|                                 | Stress, fear                                  | I am just finding ways at the moment of well, not combating but being compassionate towards the fear that comes up when you are on your own at night time, for example. And when the mind is going round and round, you can’t sleep. (LP4, London)                                                                                                     |
|                                 | Guilt, feeling a burden                       | [My mother] pretends in front of the doctors that she doesn’t need anything, she doesn’t say what’s bothering her. She doesn’t want to say anything; she thinks they have enough things to do … Sometimes she doesn’t ask for help, because she doesn’t want to be a burden. She’s telling me all the time that if she’s too much work, they’ll throw her out [of the hospice]. (PC2, Poznan) |
|                                 | Helplessness, loss of control                 | That helplessness that you feel, the moment you can’t do it yourself … you have to leave everything to others. (LP7, Poznan)                                                                                                                                                                                                                                    |
|                                 | Religous                                      | He decided that if this is God’s plan for his life, he doesn’t want this God. (LC4, London)                                                                                                                                                                                                                                                                   |
|                                 | Religious questions                           | I asked, ‘Why doesn’t God put me among all other people who are healthy, why isn’t God coming to my rescue in this illness?’ (NP1, Nairobi)                                                                                                                                                                                                                       |
|                                 | Questioning God                               | My husband and I are both from different backgrounds, different religions. And he has never brought up religion before. We are both sort of non-practicing, and he is now in times of, dark times, he is now questioning what God is doing to him. And that’s the only time I have heard him talk about religion really. He is now questioning what’s happening to him. (LC5, London)                                                                                             |
|                                 | Questioning personal faith                    | You have no hope; no money; so, you keep asking yourself in your heart, ‘What will I do? You are left asking yourself that question; you respond to it yourself; you ask yourself again and again. (NP6, Nairobi)                                                                                                                                                                          |
|                                 | Worry about the future/family                 | My daughters were not married, so I was thinking that they should have somebody who would offer them a shoulder to cry on. I was thinking only about them, about my children. (PP3, Poznan)                                                                                                                                                                         |
|                                 | Social and relational                         | I don’t think she is the least bit concerned with what happens to her after she dies. She is very concerned about what happens to me and her family after she dies. (SFC1, San Francisco)                                                                                                                                                                                                 |
|                                 | Relationships, including dealing with stigma  | My family discriminated against me – my siblings and also including my own mother; I was admitted here in [hospital] for three months and none of them came to visit me. So, I asked myself, ‘Why this, God? Do you want to show me that even my family doesn’t love me because I am sick? If my family has abandoned me, what about those that live around me, how will they perceive me?’ (NP8, Nairobi) |
|                                 | and reconciliation with others                | One of the members [of the patient’s Christian church], very prominent in the church, told me that God’s given me cancer to punish me because I am too proud. And it was really hitting below the belt you know and it, it really, really hurt and it took me a long, long time to get over it. (LP7, London)                                                                                                 |
Table 3. Caregivers’ spiritual concerns, as reported by caregivers.

| Category            | Question or concern                              | Exemplifying data extract                                                                 |
|---------------------|--------------------------------------------------|------------------------------------------------------------------------------------------|
| Existential         | Questioning ‘why them?’                          | It is the unfairness of it. In fact, I probably deserve all sorts of things going on with me. But he is slim, exercises, never smoked, drinks in moderation … And this happens to him. (LC8, London, UK) |
|                     | Questioning ‘why me?’                            | I also ask myself, “Why was I given this burden?” We were born eight of us and we are all alive, but my sister’s burden falls on me since her operation last year … I ask myself why this has to be me; even when my mother was sick the same thing happened; she also died in my arms. (SC2, Seoul, Korea) |
|                     | Looking for meaning                              | I ask myself this question: what is the meaning of a man’s suffering, especially mental … I grab various answers to this question … One of the answers that there is, is that suffering ennables. The other says that suffering toughens us up. Other version I heard says that the road to hell is paved with suffering. So I’m just weighing what’s the truth here. (PC5, Poznan, Poland) |
|                     | Psychological guilt                              | I am hugely afraid and terribly angry and, uh, very sad. Um, and I don’t see a point. I don’t see any reason to this except the biological reason, uh, that everybody dies. Um, I absolutely refuse to do the stuff that they call coming to terms with it. (SFC1, San Francisco, USA) |
|                     | Stress, feeling overwhelmed                      | When you’re taking care of someone, like I say, I’m dealing with my mother and that’s almost full-time, it takes away from caring for my husband because he’s ill also. But at the end of the day I’m pushing myself, pushing myself, pushing myself, and sometimes it gets overwhelming. I don’t know what I’m going to do. I can’t, I’m going here and there. (NYC4, New York, USA) |
|                     | Questioning ability to cope                      | My question is how am I going to do this, you know. Where do find the strength to do this? As we have said, I am not necessarily, I feel that I am spiritual, but, um, I am not that. I just don’t rely on it, and that may be a background of perhaps the science thing has, uh, wormed its way in there and that I am very logical and organised, and, uh, look at the practice stuff more than anything, the hows and the logistics almost of things. (WC3, Washington, DC, USA) |
|                     | Worry about the future, including role as carer  | How will it end … How will it go on from here? If things don’t go well at a certain moment … You wonder how it will continue. (LC1, Leuven, Belgium) |
|                     | Difficulties with acceptance                     | I just don’t want to watch my husband suffer. I don’t want prolonged suffering, and we are not spiritually on the same page. And that makes it a difficult … Because I will be in charge of his care, and I am not sure he would like me to do what I feel is the appropriate thing. I think for me there are moral and ethical dilemmas involved in this … moral issues, you know. When. What do you do? … It is like there [are] no answers that anybody is going to be allowed to have except me at the end, and I – that is something that I really need guidance for. (SFC3, San Francisco, USA) |
|                     | Isolation, loneliness of caregiving              | So I ask myself, ‘God, because you found it fit for us to carry this burden, help us because now I have been left alone; no one wants to get close to us in case we ask them to help us carry our burden’. (NC9, Nairobi, Kenya) |
|                     | Feeling insufficient, not knowing what to do     | He [patient] just literally was looking at the wall, didn’t want to do anything, didn’t want to eat or anything. I was struggling. He didn’t know what to do. I didn’t know what to do. (LC5, London, UK) |
| Religious           | Anger at God/ questioning God                   | I am an Episcopalian, and I can’t change the fact that I believe in God and a particular manifestation of God. Um, I am extremely angry with God. I haven’t gone to a service, um, in years, um. I definitely feel that God kind of went over the edge on this one … this is clearly more than people should have to deal with. (SFC1, San Francisco, USA) |
| Social and relational | Relationships, including change in relationship with the patient | Now that [mother’s] sick, [I am] trying to understand what she’s going through, she’s not a very talkative person either; if she needs something I have to like think for her or see whether she’s got a frown on her face, she’s got a pain now, she won’t tell me I’ve got pain, so I have to do the thinking and everything for her. (CTC3, Cape Town, South Africa) |

Understanding of spirituality and its role in illness. Many patients either described a religious conception of spirituality as related to belief in God (Table 4, Q2) or found the concept difficult to understand or define (Q3 and Q4). Others talked about a deeper dimension of life that was a source of transcendence and meaning, and a coping resource (Q5–Q7), or described spirituality in relational terms (Q8). Caregivers largely understood spirituality to be a religious concept, but many also stressed that spirituality was distinct from religion (Q9). Relational conceptions of spirituality were common (Q9 and Q10), as well as the view that spirituality means different things to different people (Q11).
### Table 4. Exemplifying data extracts, by theme.

| Theme                                                                 | Extract                                                                                     |
|----------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| 1. Patients’ and caregivers’ spiritual concerns                      | Q1: "No, we didn’t have anything like that; we both had a very balanced mind." (TC3, Tampere) |
| 2. Understanding of spirituality and its role in illness             | Q2: "Spirituality is that our hearts are filled with the Holy Spirit. When we are full of the Holy Spirit, what is it? God comes into our hearts." (SP5, Seoul) |
|                                                                      | Q3: "Are spirituality and religion combined or are the two totally separate things? How do you strive for the two? I find it very difficult to sort of put it into a context ... I mean if you ask me am I religious, I mean religious, do you go to church three times a week, whatever? What is spirituality? ... um I grew by sitting outside practically in the garden ... is that spirituality?" (CTP2, Cape Town) |
|                                                                      | Q4: "This word, 'spiritual', I have never really understood it, what it means. If someone could explain to me, it might help me in the future. I don't know." (LP3, London) |
|                                                                      | Q5: "Spirituality gives me the strength to continue living." (NP10, Nairobi)                 |
|                                                                      | Q6: "I have to accept my humanity with its limitations, and this is what spirituality means to me. It lifts me above the things that I can see and feel and touch." (LP2, London) |
|                                                                      | Q7: "I believe we are connected to a much greater form and connected to each other. For me, spirituality means being able to feel hope, but not necessarily hope we will be healed but hope for kindness, generosity and freedom from pain." (NYP1, New York) |
|                                                                      | Q8: "[Spirituality] is how you react to others, to other people, to other people and close ones and to, to have good relations, whatever it means to everyone, but it is a very broad concept." (TP3, Tampere) |
|                                                                      | Q9: "I feel too that there was definitely, um, a power and energy out there that we just don’t understand at all. Um, and that we can accept or not accept whatever we decide, and, um, for a long time I thought it was really a part of religion because I guess I heard the word first at church and didn’t understand it. Um, but I, you know, I have gone beyond that a little bit now." (CC2, Calgary) |
|                                                                      | Q10: "It means to me more how you treat people, you know. Not going to church, that’s not a spiritual person. You can go to church and be evil. It is more of how you, what you, how you treat people, animals, you know." (CC1, Calgary) |
|                                                                      | Q11: "I think when we use this word ‘spiritually’, it has so many different meanings for different people. For me, it will be everything connected with faith. For somebody else, it would be chanting to music and meditating." (LC4, London) |
|                                                                      | Q12: "I think this disease is spiritual because if it was not spiritual, it would be a disease just like any other and I would already have died; this illness is spiritual and its purpose is to facilitate my knowledge of God." (NP1, Nairobi) |
|                                                                      | Q13: "I used to ask myself, ‘Why should I get sick [when I] am a widow and the one who fends for my children and all their needs?’ And then another spirit tells me, ‘There is no one who would have carried that burden in this home apart from you.’ So I continued to pray and God has really helped me." (NP11, Nairobi) |
|                                                                      | Q14: "I started to wonder in my head, is it what I have done? ... Because of what the preacher [said] and everything I have been hearing about sin and stuff, I started to believe okay, maybe it is what I have done ... That’s why I am in this condition ... What kind of sin would I have committed that would make me have this kind of disease?" (LP2, London) |
|                                                                      | Q15: "It is that I have refused to do your [God’s] work or I have refused to follow your ways as you would like?" (NP3, Nairobi) |
|                                                                      | Q16: "I tend to think that lately I may have lots of sins. Therefore, I am not sure about my mind; it just blows hot and cold. When I had a confinement, I said to the priest that my sin was that I did not make my children go to the Catholic Church." (SP9, Seoul) |
|                                                                      | Q17: "You know when you have a sick person, you have very many questions in your heart; but when God gets into your heart it removes the humaness in that person; when spirituality gets into me, it guides me not to make wrong moves; I get back on my knees and pray and continue with the journey of taking care of my patient; and the fatigue goes." (NC10, Nairobi) |
|                                                                      | Q18: "We believe in Buddhism. When we do not feel good, we read ‘Cheonsugyeong’ [The Thousand Eyes and Hands Sutra] and it made our mind to be calm." (SC1, Seoul) |
|                                                                      | Q19: "I believe in Buddhism. When we do not feel good, we read ‘Cheonsugyeong’ [The Thousand Eyes and Hands Sutra] and it made our mind to be calm." (SC1, Seoul) |
|                                                                      | Q20: "I think this disease is spiritual because if it was not spiritual, it would be a disease just like any other and I would already have died; this illness is spiritual and its purpose is to facilitate my knowledge of God." (NP1, Nairobi) |
|                                                                      | Q21: "I used to ask myself, ‘Why should I get sick [when I] am a widow and the one who fends for my children and all their needs?’ And then another spirit tells me, ‘There is no one who would have carried that burden in this home apart from you.’ So I continued to pray and God has really helped me." (NP11, Nairobi) |
|                                                                      | Q22: "I started to wonder in my head, is it what I have done? ... Because of what the preacher [said] and everything I have been hearing about sin and stuff, I started to believe okay, maybe it is what I have done ... That’s why I am in this condition ... What kind of sin would I have committed that would make me have this kind of disease?" (LP2, London) |
|                                                                      | Q23: "It is that I have refused to do your [God’s] work or I have refused to follow your ways as you would like?" (NP3, Nairobi) |
|                                                                      | Q24: "I tend to think that lately I may have lots of sins. Therefore, I am not sure about my mind; it just blows hot and cold. When I had a confinement, I said to the priest that my sin was that I did not make my children go to the Catholic Church." (SP9, Seoul) |
| 3. Views and experiences of spiritual care (including perceived barriers to its provision) | Q25: "I think this disease is spiritual because if it was not spiritual, it would be a disease just like any other and I would already have died; this illness is spiritual and its purpose is to facilitate my knowledge of God." (NP1, Nairobi) |
|                                                                      | Q26: "I used to ask myself, ‘Why should I get sick [when I] am a widow and the one who fends for my children and all their needs?’ And then another spirit tells me, ‘There is no one who would have carried that burden in this home apart from you.’ So I continued to pray and God has really helped me." (NP11, Nairobi) |
|                                                                      | Q27: "I started to wonder in my head, is it what I have done? ... Because of what the preacher [said] and everything I have been hearing about sin and stuff, I started to believe okay, maybe it is what I have done ... That’s why I am in this condition ... What kind of sin would I have committed that would make me have this kind of disease?" (LP2, London) |
|                                                                      | Q28: "It is that I have refused to do your [God’s] work or I have refused to follow your ways as you would like?" (NP3, Nairobi) |
|                                                                      | Q29: "I tend to think that lately I may have lots of sins. Therefore, I am not sure about my mind; it just blows hot and cold. When I had a confinement, I said to the priest that my sin was that I did not make my children go to the Catholic Church." (SP9, Seoul) |
|                                                                      | Q30: "You know when you have a sick person, you have very many questions in your heart; but when God gets into your heart it removes the humaness in that person; when spirituality gets into me, it guides me not to make wrong moves; I get back on my knees and pray and continue with the journey of taking care of my patient; and the fatigue goes." (NC10, Nairobi) |
|                                                                      | Q31: "We believe in Buddhism. When we do not feel good, we read ‘Cheonsugyeong’ [The Thousand Eyes and Hands Sutra] and it made our mind to be calm." (SC1, Seoul) |
|                                                                      | Q32: "I think this disease is spiritual because if it was not spiritual, it would be a disease just like any other and I would already have died; this illness is spiritual and its purpose is to facilitate my knowledge of God." (NP1, Nairobi) |
|                                                                      | Q33: "I used to ask myself, ‘Why should I get sick [when I] am a widow and the one who fends for my children and all their needs?’ And then another spirit tells me, ‘There is no one who would have carried that burden in this home apart from you.’ So I continued to pray and God has really helped me." (NP11, Nairobi) |
|                                                                      | Q34: "I started to wonder in my head, is it what I have done? ... Because of what the preacher [said] and everything I have been hearing about sin and stuff, I started to believe okay, maybe it is what I have done ... That’s why I am in this condition ... What kind of sin would I have committed that would make me have this kind of disease?" (LP2, London) |
|                                                                      | Q35: "It is that I have refused to do your [God’s] work or I have refused to follow your ways as you would like?" (NP3, Nairobi) |
|                                                                      | Q36: "I tend to think that lately I may have lots of sins. Therefore, I am not sure about my mind; it just blows hot and cold. When I had a confinement, I said to the priest that my sin was that I did not make my children go to the Catholic Church." (SP9, Seoul) |
|                                                                      | Q37: "You know when you have a sick person, you have very many questions in your heart; but when God gets into your heart it removes the humaness in that person; when spirituality gets into me, it guides me not to make wrong moves; I get back on my knees and pray and continue with the journey of taking care of my patient; and the fatigue goes." (NC10, Nairobi) |
|                                                                      | Q38: "We believe in Buddhism. When we do not feel good, we read ‘Cheonsugyeong’ [The Thousand Eyes and Hands Sutra] and it made our mind to be calm." (SC1, Seoul) |
Q27: In hospitals or during those times when we meet here or any other place where patients are meeting, spiritual care should be provided. (NP8, Nairobi)

Q28: Spiritual care means the whole world, it's more than money, it's more than diamonds ... you cannot weigh it, there's no depth, there's no height, there's no width, you know, that is what spiritual care is all about. (CTP2, Cape Town)

Q29: I need [spiritual care] more than they [the patients] do. They're being taken care of. Everything's been done for them but nobody's helping me. (NYC2, New York)

Q31: My husband wanted to tell about his story to the doctors, but they did not have time to talk; he was dissatisfied with it. It would be great if they listened to patients' stories and what they really want. (SeC3, Seoul)

Q32: [The doctor] ended up spending half an hour with me, which is in a hospital like this you don't have time for, you know, and she said to me, 'Look, we don't normally ...' and I said, 'No, you need somebody to talk to' and at the same time she could talk to me. It does give you a certain amount of joy, you sort of go out of there afterwards and you forget about little things, little worries that you had on your mind. (CTP3, Cape Town)

Q34: I used to be a nurse myself, and I honestly feel if you want to do it, then you can find the time ... they are just not inclined to. You are there to have your wound dressed or your stitches taken out. Let me get on with that. Your other bits and pieces, I don't really want to know. (LP7, London)

Q35: It definitely mustn't come from a religious angle, it mustn't be like Roman Catholic or Islamic or whatever. (CTP4, Cape Town)

Q36: How is it communicated to the patient? What are the words? What is the semantics? What is the invitation? Because the ... it. How is it marketed to the patient? And does that affect whether the patient signs up or not, um, for spiritual care? (CP1, Calgary)

Q42: Create a metal detector for empathy ... And you will probably have the most successful spiritual care department that ever existed. (CP2, Calgary)

Q47: A religious affiliated hospital can, on the one hand, be more 'pro' providing spiritual care, and on the other hand, they can also be more likely to assume that everybody has got what their faith tradition is. Someone walked in and the first spiritual care question was 'Would you like prayer?' That's already making a big assumption about the patient in the bed. (WC2, Washington, DC)

Q46: The most important, to me, is trust. It is good to have someone in front of you who you can trust, and to who you can talk about your concerns, that is what you need. I'm not sure if there is one general solution for that, because everyone is different. I don't think you can just learn from a book. That is knowledge, and feeling the needs of a person, like, he needs this, he needs that, that is hmm ... everyone is different. You can't just find one solution for that. (LeP6, Leuven)

Q45: A religious affiliated hospital can, on the one hand, be more 'pro' providing spiritual care, and on the other hand, they can also be more likely to assume that everybody has got what their faith tradition is. Someone walked in and the first spiritual care question was 'Would you like prayer?' That's already making a big assumption about the patient in the bed. (WC2, Washington, DC)

Q50: When somebody says no, I don't have any religion ... maybe the checklist could have a spirituality [question]? Okay, would you like somebody else to talk to? And maybe it is somebody who comes in maybe in a collar or when he comes in there, he takes the collar off. And just somebody comes in and says okay, is there something you want to talk about? There may be a way of helping people in the future that don't have a faith. (LC9, London)
For some patients, illness was inherently spiritual (Q12). Some patients drew upon their spiritual beliefs and were supported by spiritual leaders and faith communities to help them cope with and accept their illness (Q13). Conversely, framing their illness in relation to their beliefs led other patients to blame themselves or their imperfect past behaviour for their current situation (Q14–Q16). Caregivers described how their beliefs, spiritual practices (e.g., meditation, prayer) and support from their faith community helped them cope with their role (Q17 and Q18).

Views and experiences of spiritual care, including perceived barriers. Just as participants’ conceptions of spirituality varied, so did their understandings of spiritual care. Some participants understood it to be essentially religious; for example, in Cape Town and Nairobi, caregivers talked about spiritual care as prayer, while in Poland, caregivers related spiritual care to seeing a priest (Q19 and Q20). Some religious patients saw the primary purpose of spiritual care to be helping them integrate their personal faith into the illness experience (Q21). However, many participants across the sites did not consider spiritual care to be religious care, instead describing it as providing a safe space, listening and counselling. These patients emphasised the role of spiritual care in providing existential support and human connection at a difficult time (Q22 and Q23). Some caregivers understood spiritual care broadly to encompass all care that goes beyond medical intervention, hopefulness, honesty, empathy, kindness and being spiritually aware (Q42–44). Proselytisation and other prescriptive approaches to spiritual care were highlighted as insensitive and inappropriate (Q45). Participants emphasised that spiritual care needed to be individualised and that staff should avoid categorising or stereotyping (Q46).

Research priorities. When asked to consider spiritual care research priorities, patients identified a need to understand the qualities, nature and practice of human connectedness (e.g., compassion, empathy) (Q47). Patients’ other priorities included communicating sensitively about spirituality, particularly in initiating conversations about spiritual care needs (Q48); raising patient awareness of the availability of spiritual care and self-care practices; improving public discussion of death and dying; and how to provide spiritual care within the time constraints of contemporary healthcare. Research that was multi-professional and informed by patients was recommended.

Caregivers emphasised the need to develop educational interventions for staff (Q49); investigate ways to make spiritual care suitable for diverse populations, including those of no religious faith (Q50); improve the assessment of spiritual care needs (Q48); raising patient awareness of the availability of spiritual care and self-care practices; improving public discussion of death and dying; and how to provide spiritual care within the time constraints of contemporary healthcare. Research that was multi-professional and informed by patients was recommended.

Discussion

Main findings

This study provides, for the first time, a picture of patients’ and caregivers’ spiritual concerns, spiritual care experiences and preferences, and priorities in spiritual care research in an international sample. Participants described a wide range of ‘deeper’ concerns that were remarkably common across countries. These concerns were spiritual in the sense of relating to ultimate meaning, purpose, transcendence and relationships to self, others and the significant/sacred.1 Many concerns were existential, psychological and social/relational in nature rather than overtly religious, although religious distress (related to the
content of beliefs and questioning one’s faith) was also evident.

The rich descriptions of spiritual concerns in this study highlight the importance of attending to these in palliative care. However, participants reported a wide-spread neglect of spiritual care needs in practice: spiritual care was needed and felt to be important, but was frequently not addressed by healthcare providers. Participants suggested that the neglect of spiritual care was a matter of prioritisation and staff attitude as much as lack of time. Participants had wide-ranging preferences regarding who provides spiritual care, valuing both specialist and non-specialist spiritual care providers. This suggests that the most appropriate person to provide spiritual support depends on the individual patient or caregiver, as well as the type and severity of distress and the skills of the healthcare professional. Across sites, there were commonalities in the attitudes and approaches perceived as necessary to spiritual care, regardless of who provided it.

Patients emphasised the need for patient-informed multi-disciplinary research into the innate and relational qualities of spiritual care and how to foster them among staff. Their other priorities included communicating sensitively, raising patient awareness of spiritual care and self-care practices, improving public discussion of death and dying and how to provide spiritual care given time limitations. Caregivers highlighted the need to develop educational interventions for staff, make spiritual care suitable for diverse populations, improve assessment, study the impact of spiritual care and consider caregivers’ spiritual care needs, including during bereavement.

Strengths and weaknesses of the study

A strength of the study is that it was informed by an inclusive conceptualisation of spirituality, and participants were encouraged to speak about their deepest concerns and needs in their own language. There is much debate about definitions of spirituality, and adopting an inclusive definition means we captured social and psychological concerns as well as those narrowly conceived of as ‘spiritual’. We believe this reflects the complexity of human experience, which is not easily compartmentalised into ‘spiritual’, ‘social’ and ‘psychological’, and in which relationships are key. Recruiting from nine countries provides an overall picture of patients’ and caregivers’ views, experiences, preferences and priorities internationally, and we achieved data saturation. However, the study was not designed to explore differences in experiences by site or within each country: just two focus groups were conducted at each site, and we did not aim for data saturation at each site. Data should not be taken as representative of the views and experiences of patients and caregivers in that country and cannot result in site- or country-specific recommendations for improving spiritual care. Findings should also not be extrapolated beyond the nine countries involved, as patients and caregivers in other countries might have different experiences and views. A limitation of this study is that we did not have the resources to conduct back translation to check the validity of the translations. However, the local researchers at the sites (who were fluent in English as well as the local language) checked the transcripts for accuracy. Despite our intention to recruit a diverse sample, most participants had cancer and identified as at least fairly religious and Christian, although, as the data extracts show, there was a continuum of secular and religious views. These factors could limit the transferability of findings.

What this study adds

Our findings contribute to the understanding of patients’ and caregivers’ spiritual care needs, preferences and experiences towards the end of life provided by qualitative studies from New Zealand, Australia, Norway, the United Kingdom, the United States, Taiwan, Japan and India. We found that patients and caregivers experience a range of existential, psychological, religious and social concerns; these reflect both the existential concerns (e.g. threats to self-identity) emphasised in Henoch and Danielson’s review and the relational concerns that emerged as central in Edwards et al’s review of qualitative literature on understandings of spirituality.

The finding that spiritual care is needed but neglected supports other evidence of a lack of attention to spiritual care needs. Participants’ view that lack of time was not the main reason for this neglect echoes Balboni et al.’s study, which found that neither lack of time nor space was associated with spiritual care provision in oncology. Rather, the barriers were inadequate training, clinicians not viewing it as their professional role, and worry that spiritual care is inappropriate due to power inequity between patient and clinician. Other studies have identified additional barriers: lack of expertise and the sense that others could do a better job. Among nurses, higher perceived competence in spiritual care is associated with viewing spirituality/spiritual care broadly, not just in religious terms. Taken together, these studies suggest specific areas of education to improve spiritual care; for example, deepening practitioner’s self-awareness and self-understanding to help promote human connectedness, and ensuring that spiritual care is understood not purely as religious care. However, changes to organisational culture are also needed to shift practice, for example, incentivising good spiritual care provision via quality indicators and paying staff for time spent on spiritual care. Our findings support models of palliative care which emphasise that all staff should be comfortable with, and competent to provide, a basic level of spiritual care, with more advanced psycho-spiritual and religious support provided by specialists. The virtues of openness, authenticity, non-judgement and kindness which patients described have been identified as essential
motivators in compassionate care and appear in a conceptual analysis of spiritual care in nursing.

Researchers and clinicians in the EAPC survey prioritised research into spiritual care interventions and their effectiveness, overcoming barriers in spiritual care due to staff attitudes, helping staff talk about spiritual issues (e.g. via conversation models), screening and assessment and understanding needs and preferences in multi-faith, multicultural populations. These priorities overlap with patients’ prioritisation of communication and how to provide spiritual care, and caregiver’s prioritisation of assessment and impact. However, patients were more focused on understanding the qualities or attributes of spiritual care providers than caregivers and survey respondents. This echoes findings from other studies and suggests that for patients, the quality of spiritual care depends on the quality of human connection rather than the nature of the intervention itself. Clinicians’ and researchers’ prioritisation of spiritual care interventions rather than attitudes might reflect a professional emphasis on ‘doing’, rather than the ‘being’ often emphasised in spiritual care practice.

We found that while individuals are unique in expressions of spirituality, there are commonalities that can serve as pillars for ongoing international collaboration to improve spiritual care (e.g. The Global Network for Spirituality & Health). Findings suggest that training staff and volunteers in spiritual care provision in palliative care must become an international priority. They also provide a framework for future research, providing the service user counterpart to the research priorities previously identified. Further research is needed to explore cultural differences in service users’ experiences and preferences and identify models of spiritual care that are culturally sensitive and locally appropriate.

Conclusion

Our findings provide evidence that spiritual care is an essential but neglected component of care, according to patients and their caregivers across a range of countries. Participants described human connection, person-centredness and integration in healthcare as fundamental to spiritual care. While spiritual care specialists play important roles, including staff support, participants emphasised the importance of spiritual care competency across disciplines. The priorities identified here should be used to guide future spiritual care research and clinical and educational initiatives.

Acknowledgements

The authors would like to thank all the patients and caregivers who participated, the staff at the participating sites, Suzanne O’Brien for data entry and analysis and members of the Project Advisory Group. The InSpirit collaborative includes the co-authors and the following collaborators: Mieke Vermandere, Liz Gwyther, Clint Cupido, George Handzo, Andrew Goodhead, Aquinas Nyakundi, Julianna (Jinsun) Yong, Insun Seo, Katarzyna Stachnik, Yvette Coulter and Najmeh Jafari. L.E.S. obtained funding, designed and coordinated the study, led data analysis, drafted the manuscript and takes responsibility for the content. L.J.B. assisted with data analysis, administration and drafting of the paper. S.S., I.K. and R.E. contributed to the design of the study and assisted with data analysis. S.S., I.K., P.S., R.A.P., E.D.-S., M.G., S.A., C.P., J.H. and N.G. contributed to data collection. P.S. also obtained funding. J.H. was a patient representative on the Project Advisory Group. All authors contributed to the intellectual content of the manuscript and have approved the final version.

Data sharing

Requests to access anonymised transcripts should be directed to the corresponding author (L.S.).

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethics and consent

This study was approved by the ethical review boards of the participating sites (Appendix 2). All participants provided written informed consent.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship and/or publication of this article: They thank the Sir Halley Stewart Trust and the University of Cape Town for contributing to the research costs.

References

1. Puchalski CM, Vitillo R, Hull SK, et al. Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med 2014; 17: 642–656.
2. Astrow AB, Wexler A, Texeira K, et al. Is failure to meet spiritual needs associated with cancer patients’ perceptions of quality of care and their satisfaction with care? J Clin Oncol 2007; 25: 5753–5757.
3. Egan R, MacLeod R, Jaye C, et al. Spiritual beliefs, practices, and needs at the end of life: results from a New Zealand national hospice study. Palliat Support Care 2016; 15: 223–230.
4. Selman L, Siegert R, Higginson IJ, et al. The ‘Spirit 8’ successfully captured spiritual wellbeing in African palliative care: factor and Rasch analysis. J Clin Epidemiol 2012; 65: 434–443.
5. Balboni T, Vanderwerker LC, Block SD, et al. Religiosity and spiritual support among advanced cancer patients and their associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2007; 25: 555–560.
6. McClain CS, Rosenfeld B and Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet 2003; 361: 1603–1607.
7. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. JAMA 2000; 284: 2911.
8. Kim Y, Wellisch D, Spillers R, et al. Psychological distress of female cancer caregivers: effects of type of cancer and caregivers’ spirituality. Support Care Cancer 2007; 15: 1367–1374.
9. Colgrove L, Kim Y and Thompson N. The effect of spirituality and gender on the quality of life of spouses of cancer survivors. Ann Behav Med 2007; 33: 90–98.
10. Milstein JM. Introducing spirituality in medical care: transition from hopelessness to wholeness. JAMA 2008; 299: 2440–2441.
11. Lin WC and Tsao CJ. Information needs of family caregivers of terminal cancer patients in Taiwan. Am J Hosp Palliat Care 2004; 21: 438–444.
12. Keeley MP. Final conversations: survivors’ memorable messages concerning religious faith and spirituality. Health Commun 2004; 16: 87–104.
13. Kristeller JL, Zumbrun CS and Schilling RF. ‘I would if I could’: how oncologists and oncology nurses address spiritual distress in cancer patients. Psychooncology 1999; 8: 451–458.
14. Kuuppelomaki M. Spiritual support for terminally ill patients: nursing staff assessments. J Clin Nurs 2001; 10: 660–670. DOI:10.1046/j.1365-2702.2001.00534.x.
15. Cobb M. Spiritual care. In: Lloyd-Williams M (ed.) Psychological issues in palliative care. New York: Oxford University Press, 2003, pp. 135–147.
16. Ross L. Spiritual care in nursing: an overview of the research to date. J Clin Nurs 2006; 15: 852–862.
17. MCPCIL. National Care of the Dying Audit – Hospitnals: round 2. Generic Report, 2009, http://www.mcpcil.org.uk/media/16531/generic_ncdah_2nd_round_final_report[1].pdf
18. Higginson I, Wade A and McCarthy M. Validity of the support team assessment schedule: do staff ratings reflect those made by patients and families? Palliat Med 1993; 7: 219–228.
19. Balboni MI, Sullivan A, Amobi A, et al. Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. J Clin Oncol 2013; 31: 461–467.
20. Phelps A, Lauderdale K, Alcorn S, et al. Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists, and oncology nurses. J Clin Oncol 2012; 30(20): 2538–2544.
21. MacLean CD, Susi B, Phifer N, et al. Patient preference for physician discussion and practice of spirituality. J Gen intern Med 2003; 18: 38–43.
22. Best M, Butow PN and Olver IN. Do patients want doctors to talk about spirituality? A systematic literature review. Patient Educ Couns 2015; 98: 1320–1328.
23. National Institute for Clinical Excellence. Improving supportive and palliative care for adults with cancer. London: National Institute for Clinical Excellence, 2004.
24. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care, 2nd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care, 2009.
25. African Palliative Care Association. Standards for providing quality palliative care across Africa. Kampala, Uganda: African Palliative Care Association, 2010.
26. Balboni T, Balboni M, Paulk ME, et al. Support of cancer patients’ spiritual needs and associations with medical care costs at the end of life. Cancer 2011; 117: 5383–5391.
27. Balboni T, Paulk M, Balboni M, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. J Clin Oncol 2010; 20: 445–452.
28. Pearce M, Coan A, Herndon JE II, et al. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. Support Care Cancer 2012; 20: 2269–2276.
29. Candy B, Jones L, Varagunam M, et al. Spiritual and religious interventions for well-being of adults in the terminal phase of disease. Cochrane Database Syst Rev 2012; 5: CD007554.
30. Pesut B, Sinclair S, Fitchett G, et al. Health care chaplaincy: a scoping review of the evidence 2009–2014. J Health Care Chaplain 2016; 22: 67–84.
31. Kruizinga R, Hartog I, Jacobs M, et al. The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: a systematic review and meta-analysis. Psychooncology 2016; 25: 253–265.
32. Kalish N. Evidence-based spiritual care: a literature review. Curr Opin Support Palliat Care 2012; 6: 242–246.
33. Department of Health. End of life care strategy – promoting high quality care for all adults at the end of life. London: UK Government, 2008.
34. Selman L, Young T, Vermandere M, et al. Research priorities in spiritual care: an international survey of palliative care researchers and clinicians. J Pain Symptom Manage 2014; 48: 518–531.
35. Kristie Saumure LMG. Data saturation. In: Given LM (ed.) The SAGE encyclopedia of qualitative research methods. Thousand Oaks, CA: SAGE, 2008, pp. 196–197.
36. Hudson P. Focus group interviews: a guide for palliative care researchers and clinicians. Int J Palliat Nurs 2003; 9: 202–207.
37. Krueger RA and Casey MA. Focus groups: a practical guide for applied research. Thousand Oaks, CA: SAGE, 2014.
38. Hammersley M. Challenging relativism: the problem of assessment criteria. Qual Inv 2009; 15: 3–29.
39. Braun V, Clarke V and Terry G. Thematic analysis. In: Braun V, Clarke V and Terry G. Thematic analysis. In: Rohlleder P and Lyons A (eds) Qualitative research in clinical and health psychology. Basingstoke: Palgrave Macmillan, 2015; 95–113.
40. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000; 23: 334–340.
41. Edwards A, Pang N, Shiu V, et al. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliat Med 2010; 24: 753–770.
42. McGrath P. Spiritual pain: a comparison of findings from survivors and hospice patients. Am J Hosp Palliat Care 2003; 20: 23–33.
43. Rohde G, Kersten C, Vistad I, et al. Spiritual well-being in patients with metastatic colorectal cancer receiving non-curative chemotherapy: a qualitative study. Cancer Nurs 2017; 40: 209–216.
44. Murray SA, Kendall M, Boyd K, et al. Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. Palliat Med 2004; 18: 39–45.
45. Hart A Jr, Kohlves RJ, Deyo R, et al. Hospice patients’ attitudes regarding spiritual discussions with their doctors. *Am J Hosp Palliat Care* 2003; 20: 135–139.
46. Hermann CP. Spiritual needs of dying patients: a qualitative study. *Oncol Nurs Forum* 2001; 28: 67–72.
47. Chao CS, Chen CH and Yen M. The essence of spirituality of terminally ill patients. *J Nurs Res* 2002; 10: 237–245.
48. Shih F, Lin H, Gau M, et al. Spiritual needs of Taiwan’s older patients with terminal cancer. *Oncol Nurs Forum* 2009; 36: E31–E38.
49. Kawa M, Kayama M, Maeyama E, et al. Distress of inpatients with terminal cancer in Japanese palliative care units: from the viewpoint of spirituality. *Support Care Cancer* 2003; 11: 481–490.
50. Henoch I and Danielson E. Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. *Psychooncology* 2009; 18: 225–236.
51. Balboni MJ, Sullivan A, Enzinger AC, et al. Nurse and physician barriers to spiritual care provision at the end of life. *J Pain Symptom Manage* 2014; 48: 400–410.
52. Selby D, Seccaraccia D, Huth J, et al. A qualitative analysis of a healthcare professional’s understanding and approach to management of spiritual distress in an acute care setting. *J Palliat Med* 2016; 19: 1197–1204.
53. Ross L, Giske T, van Leeuwen R, et al. Factors contributing to student nurses’/midwives’ perceived competency in spiritual care. *Nurse Educ Today* 2016; 36: 445–451.
54. Van Leeuwen R and Schep-Ackerman A. Nurses’ perceptions of spirituality and spiritual care in different health care settings in the Netherlands. *Religions* 2015; 6: 1346–1357.
Appendix 1. FG facilitator characteristics.

| Site         | Occupation                        | Gender | Highest qualification                  |
|--------------|-----------------------------------|--------|----------------------------------------|
| Calgary      | Chaplain and researcher           | M      | PhD                                    |
| United Kingdom| Chaplain and researcher           | M      | PhD                                    |
| Washington, DC| Physician and researcher          | F      | MD                                     |
| Poznan       | Psychologist and lecturer         | F      | MSc                                    |
| Cape Town    | Researcher                        | F      | BA, PGDip Pall Med                     |
| San Francisco| Researcher                        | F      | PhD                                    |
| Tampere      | Researcher                        | M      | PhD                                    |
| Nairobi      | Researcher                        | F      | BA                                     |
| Seoul        | Nun and researcher                | F      | PhD                                    |
| Belgium      | General practitioner and researcher| F      | PhD                                    |
| New York     | Chaplain and researcher           | M      | BCC                                    |

Appendix 2. Ethical approvals received.

| Organisation                                                                 | Reference     | Date              |
|-----------------------------------------------------------------------------|---------------|-------------------|
| King’s College London Biomedical Sciences, Dentistry, Medicine Research      | BDM/12/13-124 | 14 August 2013    |
| Ethics Committee                                                            |               |                   |
| Ethics Committee of Pirkanmaa Hospital District, Tampere                     | R13158H       | 19 February 2014  |
| IRB of Songeui Medical Campus, The Catholic University of Korea              | MC13QISI0090  | 24 December 2013  |
| Conjoint Research Ethics Board, University of Calgary                       | REB13-0764    | 13 January 2013   |
| Nairobi Hospice Standards and Ethics Committee                              | N/A           | 6 January 2013    |
| Beth Israel Medical Center Institutional Review Board                        | #152-13       | 30 October 2013   |
| University of California, San Francisco, Committee on Human Research        | 14-13072, 081952 | 21 April 2014 |
| University of Cape Town Human Research Ethics Committee                      | 670/2013      | 9 December 2013   |
| The George Washington University Committee on Human Research IRB            | FWA00005945   | 12 February 2014  |
| Poznan University of Medical Sciences Ethics Committee                       | 724/14        | 4 September 2014  |
| Medical Ethics Committee KU Leuven                                           | SS5823        | 21 March 2014     |