Royal College of Surgeons in Ireland

repository@rcsi.com

Patient's spirituality perspectives at the end of life: a qualitative evidence synthesis.

AUTHOR(S)

Barbara Clyne, Sinéad M. O'Neill, Daniel Nuzum, Michelle O'Neill, James Larkin, Mairin Ryan, Susan Smith

CITATION

Clyne, Barbara; M. O'Neill, Sinéad; Nuzum, Daniel; O'Neill, Michelle; Larkin, James; Ryan, Mairin; et al. (2020): Patient's spirituality perspectives at the end of life: a qualitative evidence synthesis.. Royal College of Surgeons in Ireland. Journal contribution. https://hdl.handle.net/10779/rcsi.12952139.v1

HANDLE

10779/rcsi.12952139.v1

LICENCE

CC BY-NC-SA 4.0

This work is made available under the above open licence by RCSI and has been printed from https://repository.rcsi.com. For more information please contact repository@rcsi.com

URL

https://repository.rcsi.com/articles/journal_contribution/Patient_s_spirituality_perspectives_at_the_end_of_life_a_qualitative_evidence_synthesis_/12952139/1

Understanding patients' perspectives of spirituality to inform care at the end of life: a qualitative evidence synthesis

Barbara Clyne [1,2], Sinead M O'Neill[1], Daniel Nuzum[3], Michelle O'Neill[1], James Larkin[2], Mairin Ryan[1], Susan M Smith[1,2]

[1]Health Research Board – Collaboration in Ireland for Clinical Effectiveness Reviews (HRB-CICER), Health Information and Quality Authority (HIQA)

[2]Health Research Board Centre for Primary Care Research, Department of General Practice, Royal College of Surgeons in Ireland

[3]Pastoral Care Department, Marymount University Hospital and Hospice, and Department of Obstetrics and Gynaecology, College of Medicine and Health, University College Cork, Cork University Maternity Hospital.

Corresponding Author: Barbara Clyne, Health Research Board Centre for Primary Care Research, Department of General Practice, Royal College of Surgeons in Ireland, Dublin 2, Ireland

barbaraclyne@rcsi.ie

ORCID: https://orcid.org/0000-0002-1186-9495

Word Count: 5040

ABSTRACT

Background: Understanding patient perceptions of their spiritual needs when approaching the end of life is essential to support the delivery of patient-centred care.

Aim: To conduct a qualitative evidence synthesis on spirituality and spiritual care needs at the end of life in all health care settings from the patients' perspective.

Design: Studies were included where they were primary qualitative studies exploring spirituality in patients with a life expectancy of 12 months or less in any setting. Two reviewers independently screened titles, extracted data, and conducted methodological quality appraisal. A thematic synthesis was conducted. GRADE-CERQual was used to summarise the certainty of the evidence.

Data sources: Six databases (Medline, Embase, Cochrane, CINAHL, PsycINFO, Applied Social Science Index and Abstracts) were searched from inception up to January 2019.

Results: Fifty papers (42 unique datasets), incorporating data from 710 patients were included. Studies recruited from a mix of inpatient, outpatient, hospice and community settings across 12 different countries. Three overarching themes were generated: the concept of spirituality, spiritual needs and distress, and spiritual care resources. Relationships were an intrinsic component of spirituality.

Conclusion: Meeting patients' spiritual needs is an integral part of end of life care. This work emphasizes that supporting relationships should be a central focus of spiritual care for patients at the end of life.

PROSPERO: The protocol for this systematic review was registered on PROSPERO, CRD42019122062

1 INTRODUCTION

Spiritual care is considered an intrinsic domain of palliative care internationally.[1] Spirituality is a broad concept that can include or exclude religion.[2] The US consensus definition delineates spirituality as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."[3]

Spirituality at the end of life is important to patients,[4, 5] and family carers,[6] and has a positive association with patients' quality of life, physical health and social well-being.[2, 7] Patients report being comfortable with healthcare providers inquiring about spiritual needs,[8] however, spiritual and social issues are discussed less often by healthcare providers than other end-of-life issues such as physical symptoms.[9] Guidelines and standards highlight the importance of spiritual care, for example, The Irish Palliative Care Competence Framework highlights that health and social care professionals across health care settings should understand the significance and respond to the spiritual needs of people with life-limiting conditions.[10] However, where national end of life quality indicators exist, only a small number of indicators measure spiritual care.[11] Spiritual care is often neglected by healthcare providers,[4, 5] and barriers to the provision of spiritual care reported by healthcare providers include lack of time, personal, cultural or institutional factors, and professional educational needs.[8, 12]

The evidence base for the provision of spiritual care by healthcare professionals is less well developed than other domains in palliative care research,[2] and it has been highlighted that there are notable limitations to the current body of research informing spirituality training in palliative care.[13] Given the focus on person-centred care, it is important that patient views and experiences inform the development and delivery of care. Qualitative research can offer insights into how patients at the end of life, in all health care settings, view spirituality and experience spiritual care. The aim of this qualitative evidence synthesis is to explore the concept of spirituality and the experience of spiritual care from the perspective of adult patients in the last year of life, in all health care settings. The review findings will inform the development of a National Clinical Effectiveness Committee (NCEC) national clinical guideline for care of the dying adult in the Republic of Ireland.

2 METHODOLOGY

2.1 Study design

A thematic synthesis of qualitative studies exploring the concept of spirituality and the experience of spiritual care from the perspective of adult patients in the last year of life in all healthcare settings was conducted. The synthesis is reported following the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guidance.[16] The systematic review protocol has been registered on the PROSPERO database of systematic review questions and meta-analyses (CRD42019122062).

2.2 Search strategy

A comprehensive search was conducted using six electronic databases (Medline, Embase, Cochrane, CINAHL, PsycINFO, Applied Social Science Index and Abstracts) from database inception to 10th January 2019. Using combinations of keywords and Subject Headings (MeSH), the searches were adapted for different databases including the use of qualitative filters (appendix 1). Reference lists of included articles were also searched for titles which met the inclusion criteria. The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type)[17] framework informed the review question, search terms and inclusion and exclusion criteria.

2.3 Study selection

All potentially eligible citations identified were exported to Endnote (Version X7) where duplicates were removed. Two people independently reviewed the titles and abstracts of the remaining citations as per the inclusion and exclusion criteria (Table 1) using Covidence. The full texts were obtained and independently evaluated by two reviewers. Any disagreements were resolved by discussion, or if necessary, a third reviewer.

Table 1 Study inclusion and exclusion criteria

Sample	Adults (aged ≥ 18 years) with advanced life limiting illness, likely to die within the next 6-12 months (e.g. advanced (stage III or IV) cancer of any subtype), in any healthcare setting. Articles merging experiences of different populations (i.e. healthcare professionals, carers) were included only when the patients' perspective was reported separately. Studies in children and young people (aged < 18 years) were excluded.
Phenomenon of interest	Spirituality (defined as a search for meaning and purpose, which may or may not include reference to the divine)[2] at the end of life
Design	Qualitative design, using methods of data collection and data analysis which are recognised qualitative methods such as interviews, focus groups, thematic analysis, or content analysis.
Evaluation	• Views • Attitudes • Opinions • Experiences.
Research type	Original qualitative research articles (e.g. Grounded theory, ethnography, phenomenology). Only the qualitative results of mixed-method studies were included. English language only. Editorials, commentaries, opinion pieces, abstracts in proceedings were excluded.

2.4 Data extraction

Data on study characteristics (e.g., setting, duration), participant demographic characteristics (e.g., age, life expectancy, religious affiliation), theoretical perspective and the methodology employed were extracted independently by two reviewers. Data for the thematic analysis were extracted from

the results section only (not discussion) of papers, and included both author interpretations and participant quotations.

2.5 Appraisal of studies

The Critical Appraisal Skills Programme (CASP) tool for qualitative studies was used to appraise the quality of the included studies by two reviewers independently and the overall judgement for each of the CASP questions was agreed upon by consensus.[18] The CASP checklist consists of 10 questions that are designed to help researchers appraise qualitative studies systematically. The answers 'Yes', 'No' or 'Cannot tell' were selected for each paper to indicate whether the CASP question had been addressed, been addressed partially or not been addressed.

2.6 Synthesis of results

Thematic-synthesis, as described by Thomas and Harden,[19] was used in this study. Thematic-synthesis consists of a three step process; step one consists of line-by-line coding of the data of the findings of primary studies. The second step involves organisation or grouping these codes into related areas to construct 'descriptive' themes. In step three, the descriptive themes were iteratively examined and compared to refine the relationship between them and generate analytical themes that is, themes that go beyond the descriptive themes to provide new insights related to the review question. All studies were imported into NVivo 12 (QSR International) for coding and analysis. Following multiple readings of the included papers, data-analysis was carried out by one reviewer following the three steps outlined above. In order to increase confirmability of the analysis, all studies were independently read by a second reviewer to crosscheck the coding structure and themes developed. The main analysis was conducted by one researcher (BC), who has a background in health services research and has a more humanistic or existential conceptualisation of spirituality.

2.7 Certainty of the evidence

The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach was used to summarise confidence in the evidence.[20] Four components contribute to an assessment of confidence in the evidence for each key finding: methodological limitations, relevance, coherence, and adequacy of data. The confidence in the evidence for each key finding was graded by two reviewers as high (highly likely that the review finding is a reasonable representation of phenomenon of interest), moderate (likely that the review finding is a reasonable representation of phenomenon of interest), low (possible that the review finding is a reasonable representation of phenomenon of interest), or very low (not clear whether the review finding is a reasonable representation of phenomenon of interest).

3 RESULTS

3.1 Search results

The search identified 17,216 citations with four additional citations from other sources. After removal of duplicates, 9,118 titles and abstracts were screened with 8,814 references excluded. 304

full-text articles were assessed for eligibility with 254 excluded (Appendix 2). A total of 50 papers were included (Figure 1).

[insert Figure 1.]

Characteristics of included studies

Fifty studies, representing 42 unique datasets, were included (Appendix 3). Data from 710 unique patients, ranging in age from 19 to 100 years, was incorporated across the 42 datasets. The majority of studies were conducted in North America (n=26),[21-46] with 11 from Europe, [47-57] seven from Oceania,[4, 58-63] and six from Asia.[64-69] Participants were sampled from hospice settings (inpatient and hospice at home) in 27 studies,[4, 21, 27, 28, 30-37, 40-42, 47-49, 55, 56, 58-60, 62-64, 68] acute and long-term care settings in nine,[24, 29, 46, 57, 61, 65-67, 69] general practices settings in three,[44, 50, 54] cancer centres in four,[25, 26, 38, 39] a mix of settings in three studies,[23, 51, 52] and palliative care centres in two studies.[45, 53] One study provided no details on where participants were recruited from.[43] One study used a case study approach, analysing the content of a prayer journal written in the patient's home and a cancer camp.[22]

The majority of studies recruited patients on the basis of their limited life expectancy. For 10 datasets, studies were included where they reported that the majority of patients (i.e. ≥ 50%) had died within a year or before study completion.[25, 26, 28, 29, 33, 36, 38, 41, 48, 61, 63] Twenty-one datasets included participants with a mix of chronic conditions,[21, 23, 27, 30-35, 41-47, 49-52, 55, 56, 58-60, 63] 18 datasets included only participants with cancer,[4, 22, 25, 26, 28, 29, 36-39, 48, 53, 54, 61, 62, 64-69] and one dataset included participants with only neurodegenerative diseases.[57] Two datasets did not specify participants' conditions.[24, 40]

Twenty-two studies focused on issues of spirituality at the end of life,[4, 21, 22, 24, 27, 30, 34, 35, 40, 41, 46, 49-51, 55, 56, 58-60, 62, 64, 65] while the remaining studies provided insights into spirituality within the broader context of patient needs and experiences at the end of life.[23, 25, 26, 28, 29, 31-33, 36-39, 42-45, 47, 48, 52-54, 57, 61, 63, 66-69] In the studies that reported religious affiliation, patients included Christians (predominantly Catholics, Protestants, Baptists and Methodists), Muslims, Jews, Sikhs, Buddhists, Confucian or Taoists, charismatic denominations, and those with no specific religious affiliation.

Fourteen of the 50 papers reported using a phenomenological methodological approach,[22, 25, 26, 36, 38, 40, 41, 45, 58-60, 63-65] three papers used a grounded theory approach,[28, 54, 61] two an ethnographic approach,[29, 44] and one used objective hermeneutics as an approach to creating case studies.[21] The remainder of the studies did not specify a particular paradigm. All but two studies analysed data from transcripts of interviews. One study used a case study approach, analysing the content of a prayer journal[22] while another study analysed oral responses collected as part of a larger study.[27] Five studies described using a mix of interviews and participant observation.[55, 56, 65-67]

3.2 Quality appraisal

A summary graph of the appraisal of included studies is presented in Figure 2.

[insert Figure 2.]

The majority of studies provided a clear statement of the study aims, adequately described the study design, data collection and used a rigorous analytical approach, provided a clear statement of the research findings, and addressed ethical issues. The potential for bias in data collection, analysis and interpretation arising from the relationship between the researcher and the participants was only adequately reported in six of the 50 studies.[33, 42, 45, 51, 52, 64] Appropriate recruitment strategies was another area of poor reporting with 34% of studies providing either insufficient information [22, 24, 27, 30-32, 34, 35, 46, 48, 55-57, 61, 69] or reporting sufficient information but outlining an approach that was inconsistent with the study design, for example using saturation as reason to stop recruitment with a phenomenological design.[25, 26]

3.3 Thematic synthesis

Three overarching themes were generated – the concept of spirituality, spiritual needs and distress, and spiritual care resources. While presented as discrete themes they are interrelated (Figure 3). Direct quotations from study participants are presented in italics. Generated themes were common across all studies, regardless of setting, participant age, condition, or proximity to death.

[insert Figure 3.]

3.3.1 Concept of spirituality

Spiritual definitions were both explicitly discussed by participants and articulated implicitly through author interpretations across the studies. A wide variety of interpretations were presented and spirituality was expressed in three broad sub-themes: religious understandings, relationships, and existential or humanistic understandings (Table 2). Only a limited number of studies included participants who reported to have no spiritual beliefs.[32, 47, 50, 55, 56] Regardless of how spirituality was conceptualised, participants recognised the important role it played at the end of their lives: "*I think it's important, but especially important in the situation I'm in. It would be very difficult if I didn't have any sense of spirituality."*[4] Spirituality was a source of support and comfort to help patients deal with their illness and current situations.[28, 29, 33-35, 38, 41, 48, 50, 56, 57, 59, 61] It also promoted peace of mind[4, 22, 30, 48, 64, 65, 67] and a sense of well-being[8, 21, 22, 27, 51, 62, 65] for many participants.

Table 2 Concept of Spirituality

Sub-themes	**Illustrative quotation**
Religious	"From firmly within a Christian paradigm, a middle-aged male artist named his spirituality as synonymous with religion, '*It is fairly conventional. I am a Christian'*".[62]
Relationships	"*It's one of those things you want to spend a little more time with them (his grandchildren), take them fishing or, you know, just throw rocks in a pond. I guess that's part of spirituality to me."*[24]
Existential or humanistic	*"It's a long and broad subject. Spirituality to some can be religion. Spirituality can mean the science of being human. What does that involve? What's your driving force within?....For me, spirituality is the science of learning what it is to be human and what our abilities and capabilities that we rely on to help us get through our day to day living".*[46]

3.3.2 Spiritual needs and distress

Reflecting the broad conceptualisations of spirituality identified, there was a wide variety of spiritual needs and sources of spiritual distress expressed. The identified spiritual needs and sources of distress have been grouped into four main sub-themes: relationships, managing remaining life, dealing with dying and after death and finding meaning. While they have been presented as discrete themes they represent an interrelated continuum and arise out of the context of the diverse conceptualisations of spirituality identified (Figure 3). Selected illustrative quotations are presented in Table 3.

3.3.2.1 Relationships

Relationships were identified as a core aspect of the conceptualisation of spirituality, and incorporated both human and beyond human connections.

The need to connect with family and friends was keenly expressed repeatedly across included studies.[23, 24, 27, 30, 36-39, 43, 45, 47, 60, 65, 68, 69] Receiving support was a key need but participants also expressed the need to participate in relationships and reciprocate by taking care of loved ones in return.[30, 33, 36, 42, 51, 54, 69] This was done by demonstrating affection and love, but also through taking care of the more materialistic future needs and security of family and friends for their own peace of mind.[25, 54, 55, 60]

Considering the centrality of relationships, losses in those relationships were a core driver of spiritual distress for participants, contributing to a sense of loneliness and isolation. In some cases, it was the complete loss of relationships that was the source of distress.[30, 35, 39, 43, 46, 48, 50, 51, 58, 60, 68, 69] In other cases, it was the loss of relational identity, who they had been in their relationships, that was the source of distress.[25, 26, 30, 33, 50, 51, 60, 65]

Some participants felt the need to seek closeness and connection with God.[22, 23, 28, 35, 39] A loss of this relationship with God created further distress approaching the end of life for many patients.[22, 25, 26, 33, 46, 50, 56]

3.3.2.2 Managing remaining life

"I'm using my flexibility not to devote my time toward how I am going to die and praying, etc. ...I'm using my flexibility in time management to do things that the living do, not the dying."[26]

Staying focused on being alive and "maintaining a lifeworld"[43] was an important need expressed.[26, 33, 38, 39, 42-44, 53, 55, 61, 68, 69] The need to maintain relationships and stay connected, as described above, was one component of living. Other components of living included looking "*for the positive instead of the negative*",[30, 31, 33, 37-39, 42-44, 47, 53, 60, 63, 68] "*just taking each day as it comes*",[25, 30, 31, 33, 36, 38, 42, 46, 47, 50, 55, 60, 69] maintaining hope[28, 37-39, 47, 51, 67, 68] and appreciating nature.[27, 30, 31, 33, 36, 44, 46, 53, 64]

The importance of identity and sense of self was expressed strongly.[23, 25, 33, 44, 63] Remaining in control of medical care and medical decision making,[25, 37, 39, 40, 54, 63, 69] staying independent for as long as possible[30, 33, 39, 53, 54, 61] and staying active were some of the ways participants maintained their sense of self. Passing on a legacy, beyond material aspects, as a means for continued existence

in the future was important.[25] This involved passing on values and traditions,[23, 41, 45, 55, 65, 69] passing on wisdom[25, 36, 40, 69] and creating good memories.[31, 33, 37, 38]

It was however clear across the included studies that despite a positive attitude and embracing the moment, living with the reality of illness, symptoms and suffering caused extreme distress. A recurring source of distress identified was a loss of sense of self, encapsulated by participants losing their independence, ability to do things and feelings of uselessness.[4, 21, 31, 33, 36, 38, 39, 43-45, 47, 48, 50, 51, 54, 60, 66, 69] An important contributor to this loss of self was increased dependency on family and friends due to their physical conditions.[21, 23, 25, 26, 40, 48, 60, 66, 69] Being dependent and becoming a burden on family was a threat to independence and overall sense of self, and was difficult for many people to accept.[21, 23, 25, 26, 40, 44, 48, 54, 60, 66, 69] For some, this suffering prompting a loss of the will to live.[21, 26, 39, 44, 48, 50, 51, 66]

3.3.2.3 Dealing with dying and after death

"Dying is no easy thing; there's a lot to it."[38]

A minority of studies referred to patients actively avoiding thinking about death.[21, 27, 40, 44, 54, 55] However, for the majority of participants, accepting death was an important consideration. Death was conceptualised as a natural part of the life cycle.[21, 36, 39, 44, 55, 60, 69] Accepting death provided an opportunity for patients to prepare and plan for dying and for after death. Common themes patients planned for included how and where they would die, their wills and their own funerals,[54, 55, 60, 64, 65] and getting their affairs in order by tending to legal and financial matters.[21, 30, 39, 41, 54, 60] Preparing to die also prompted participants to reflect on their lives and confront their demons.

Accepting the inevitability of death was facilitated in many cases by a belief in God and God's control:[21, 23, 35, 40, 48, 64, 65, 67] "*I've turned things over to God and I'm ready to go. When He says He's ready, I'm ready*"[27] and a belief in an 'afterlife' which provided some comfort and reduced the fear and uncertainty of what came next, after death.[21, 27, 28, 35, 44, 48, 50, 55, 56, 59, 64]

For some, having a terminal illness served as a 'momento mori', a sharp reminder of mortality which in turn triggered suffering,[48] rather than acceptance. For some that suffering was caused by fear of dying: *"One thing I dread is being on my own. I am not frightened to die, but I am frightened of dying, I don't want to go through all this pain*."[4] For others the suffering came from the uncertainty of what happens during the dying process and the uncertainty of what comes after.[4, 33, 34, 40, 44, 46, 50, 54, 55, 58, 59]

3.3.2.4 Finding meaning

The two core areas where patients needed to find meaning were finding meaning in life and finding meaning in their illness.

Participants viewed meaning in life and purpose through relationships in many instances, reflecting the core of relationships in spirituality.[4, 28, 34, 36, 41, 42, 50, 51, 64] Others found meaning and purpose through their belief in a god or higher power.[21, 22, 27, 36, 59, 60] The need to remain involved in life was identified strongly across the included studies as the meaning in life, as described above.

Many participants were able to find meaning in their illnesses also. For some, their illness had changed and challenged them in positive ways. Their illnesses provided the opportunity for reflection, personal growth and developing wisdom,[31, 38, 39, 42, 44-46, 53, 60, 69] much of which resulted in an increased acceptance of themselves.[39, 42, 45, 64] For some, illness represented an opportunity to find or renew their spirituality through creating closer relationships with loved ones,[36, 44, 60] or through finding or renewing religious beliefs.[24, 33, 35, 36, 39, 41, 48, 56, 59]

The opposite view was also expressed however, and participants had difficulty in constructing any meaning in life from their current situation.[21, 50, 51] They worried about the pain caused to family[40, 48, 51, 65, 66] and could see no transformative effect or meaning in their current situations: *"You can get tired of pain. And everything that comes with it, and all the upset to people who love you…they tell you pain is a teacher. I question that."*[45] Many only saw a negative meaning within their illness,[21, 39, 50, 57] it was a punishment from God[21-23, 39, 41, 46, 56, 57, 59, 67] and an unwelcome test of faith.[22, 44, 66]

Table 3: Selection of illustrative quotes of spiritual needs and distress

Sub-themes	**Illustrative quotation**
Relationships	
Need to connect with family and friends	"*You need help. You have to have some support from people in your families...spiritual help from your family as well as friends and relatives. I've got a lot of them*. In describing spiritual help, he stated, *more or less just somebody to lean on. Somebody to help...somebody to talk to*".[30]
Taking care of loved ones	"*you know, we'll be sitting here on the couch watching TV and she says, "Would you rub my neck?"...so I do. She's hurting. I'm hurting. I care; we empathize. I still try and give her relief in her shoulder and neck...she has worked all day...and I do it lovingly and caringly*"[36] "*It is maybe a bit weird to say, to organize these materialistic things now, but you worry about it. I don't think I'm the only one who wants to leave everything behind as good as possible."*[54]
Loss of relationships	*"When they know you've got cancer, you've got secondary, they all shy away from you. They don't have a clue how to talk to you. And you can feel it just in their body motions as they are coming to you that they don't want to say anything. And people that I was really depending on for support...who had helped so much for many years, didn't even come over. And it really hurt*."[60]
Loss of relational identity	"*Although I feel lonely and scared because of my declining health (during the evening and night in particular), I was embarrassed to ask for my children's comfort and companionship because I used to be their leader and protector."*[65]
Loss of relationship with God	"*I actually believed that there was something, but then when you approach God and nothing happens and no matter what you do, you can't...Then I don't think that you can keep that faith. Because that goodness that God is supposed to have, like...Then it doesn't make sense, then it's more cruel, yes."*[56]
Managing remaining life	
Maintaining a lifeworld	*"There are, of course, many negative things about it, but yes, life is still very much worth living."*[53]
Sense of self	*"I've accepted everything that came along and incorporated it in*

	my living. But my illness is not who I am."[33]
Feelings of uselessness	*"I'm depressed, very much so, because I can't live. I can't live and I can't die. I can't do anything. I can't get interested in anything. I used to enjoy movies and bingos and things. I've lost all enjoyment in them. So it's just a matter of living from day to day waiting to die, and that's no good. It's just no good, it's making me sick, and they can't tell me anything when I ask them, you know. How long they think it'll be, they have no idea."*[45]
Being dependent and becoming a burden	*"I cannot come to terms with the changes in my life, from being a capable person to an incapable one. I cannot accept it. [I] have lost the value of being a human … lost my dignity as a human being … and as a mother, I feel sorry for my son. But as I am ill, and not having any other person to help me, I have to rely on my son…Last night, I woke my son up because I was in pain, asking him to massage my legs…asking him to do physical therapy exercises on me. When he woke up to massage me, his eyes remained closed…that really made me feel deep pain. He is so young…only 17 years old, still in the process of growing up, so he needs longer rest. Having to look after me, he has only 5 hours to rest at night, while other boys might have 8 hours. I feel sorry for my son that he has to wake up in the middle of the night to look after me, but what else could I do? I cannot control my body. I feel worthless. Nowadays, I feel like my life is worth nothing. I am suffering a lot* [from the whole situation]."[66]
Dealing with dying and after death	
Avoiding thinking about death	"*At any rate I don't think about dying...it's pushed away...yes, it is placed—it's clarified...it's how it is, and when it comes, then, that's the way it is*"[55]
Uncertainty	*"Is it real; is there life after death, where am I going? What happens if I am wrong and there is something after all?"*[50]
Finding meaning	
Meaning through relationships	"*I am always concerned about the health and happiness of my children and grandchildren. Sometimes I felt stressed that there are so many family members and friends I need to care for. Nevertheless, that is the meaning of my life. If I did not have anyone whom I need to care about, I would feel my life was absurd.*"[64]
Meaning through belief in a god or higher power	"*God put me here for a purpose. I believe that prayer of St. Francis Assisi—to change what you can and accept what you can't.*"[27]
Meaning in illness - renewing religious beliefs	*"What is the meaning of suffering? That's the kind of question you ask yourself now. A big question. I came up with an answer. The meaning of my suffering is that it has deepened the faith of everyone around me, their spirituality. And it's brought them closer to each other. I think it's important to say that I'm not going through this suffering for no reason. There's a reason for this suffering."* [44]
No meaning	"*What is the point of life—years of happiness followed by a few years of misery and then out?"*[50]

3.3.3 Spiritual care resources

As described above, patients at the end of life demonstrate an array of spiritual needs which were met and unmet to varying degrees. Across the included studies, two main categories of spiritual care resources were identified that were used by participants to meet these spiritual needs: personal resources and resources related to the professional support that patients received.

3.3.3.1 Personal resources

Many participants actively engaged in regular personal spiritual practices. For many that was in the form of traditional religious practices such as participating in religious services and rituals (for example communion, confession) or reading the bible. The most frequent activity (for both religious and non-religious participants) was praying.[21-23, 27-30, 35-37, 39, 41, 50, 51, 53, 54, 56, 59, 67, 68]

As described above, the most salient spiritual activity was engaging in meaningful relationships and connections with family and friends. Family and friends provided much needed support, physically, emotionally and spiritually:

"I just can't imagine how anyone does this without the support system that I have. There are so many people who've helped me in huge ways. That's how I've gotten through this with my family and friends. What I'm looking for is to be able to take this with a little more grace. I am not a brave little soldier, never pretended to be. I would just like for all of us to be sure that we all know how much we love each other, and how important that love is in a person's life. All you need to get you through this life is love."[44]

3.3.3.2 Resources related to professional support and health system

Experiences of spiritual care were explicitly explored in 11 studies,[24, 32, 38, 41, 46, 49, 50, 53, 57, 63, 68] however, the themes were apparent across many of the included studies. Only one study reported that patients did not consider spirituality as part of their healthcare needs or that patients were unaware of this aspect of care.[32]

Across studies a broad sense of spirituality was expressed and likewise, views on who should provide spiritual care were generally quite broad. Spiritual care encompassed anyone with whom patients felt heard and understood, which in turn, left them with the sense of connection, otherwise missing in spiritual distress.[46] This included family, friends, and healthcare professionals.

Genuine caring, compassionate and honest relationships with healthcare professionals were meaningful to participants. This included both medical care and small gestures such as learning patients' names, engaging in honest conversations, listening, being respectful, showing compassion, paying attention to the patients' overall well-being and smiling at patients.[24, 28, 37-39, 41, 46, 47, 49-51, 53-55, 60, 63, 65, 69, 70] Tying in with the need to maintain a life, maintaining a sense of identity and self "Being treated as individuals who were important, rather than diseases, made the most difference to how people felt on a day-to-day basis: *My G, the most important thing that he does—well he assures me that I'm not away yet. He always listens*".[50]

Patients reported suffering was increased by the way healthcare providers spoke to them, poor bedside manner, a lack of information, reluctance to engage and poor understanding of religious

beliefs and practices.[45, 47, 52, 54, 55, 62, 69, 71] Areas identified for improving the quality of spiritual care delivered from the perspectives of patients are summarised in Table 4.

The physical environment, for those in hospital or hospice settings was highlighted as an important resource to facilitate the use of personal resources. This included privacy, comfortable rooms for visitations, tranquillity, beautiful views, appropriate dietary provision, appreciation of feng shui and prayer facilities. [24, 52, 55, 61, 63, 69]

Table 4: Areas identified within studies for improving the quality of spiritual care

Area	Illustrative quotation
Talking to patients	"*I think it would be good if you could always get to talk to someone when you are feeling really down or not well… even if they only talk to you to put your mind at rest*."[49] "*If I was sitting talking to a member of staff…then I wouldn't mind in the slightest if they were giving their own opinions of things because we are not talking preaching… we are talking about something we are both interested in*"[49] "*How can I help today?*"[46] "*It's nice, somebody stops in and sounds sincere when they say how you doing*."[24]
Asking about spiritual needs	"*I'd ask them if they were alone. If they felt alone*. (patient 6)" [46] "*someone could chat with you and ask you those questions in an informal way to get the background really… I would want to know more about what they were searching for but I wouldn't mind answering any questions like that*"[49] "In regard to sample questions (to initiate spiritual care discussions) that were shown to patients, they felt that three might be particularly useful: '*What principles do you live by?' 'Do you have a personal faith?' 'Have you ever prayed about your situation?*'"[49] "*It would be nice if something was offered. And maybe not specifically, but if they would, for example, if the specialist checks my breathing, checks whether my abdomen hurts etc., she could also ask if I am still feeling happy. Or if I am, I don't know, crying more, or something like that…because that is not what she is asking. It would be nice if that was asked, because then you at least have an opportunity to talk about it. It could well be that there is no-one at home talking about it with you*."[53] "*I think it's attitude, and if they approach you rather than you approaching them, you can do if you want to but what I have noticed is they make sure that they come round and speak to you individually…if you don't want to that is fine as well*" [49]
Listening	"*Just listen. You'd be surprised to know what you pick up…*"what would they be listening for?…*hints about how the person is really feeling*."[46] "*She listens. She truly listens. She does listen. You can talk all you want. There are certain doctors that are hearing what you are saying but are truly not hearing or listening. You know...she really truly listens to what you are saying*."[46] "*…the power of listening. It's so incredible*." [46] "*I do have this conversation but it's got to be with people who understand, and are not going to judge or criticize…listen to what you say…*"[46] "*They ask it every day, 'how are you feeling?' but do they take the time to stop and listen to what* [the patient] *said…*" [46] "*listening and communicating are the two biggest pieces of advice I could give … talk about everything. Don't be afraid to just say your feelings because the person knows it if you are hiding things like that. A person feels it*."[42] "*all you can do is train somebody to recognise the individual, that they have needs*

	whether they are nine or ninety they need to be listened to and they need to be valued"[49]
Giving information	"*I think you have to help me out a lot by being just plain truthful. You should tell people what they want to know...I like an honest man...I tell the truth too* [grinning]."[38] "*It is an awesome aspect to be turned loose into that system. I think they expect us* [pause], *they think we know more than we know. But, we are almost completely ignorant of the procedure or what to expect or how to do. You know if you do it every day, it becomes second nature to you. I would say the time aspect of it and to keep you a little more informed*."[38] "*Comfort the patients, informing them of improvements made and letting them know that they will try their best when the patients' condition deteriorates*." [68]
Personal attention of professional medical caregivers for patient wellbeing	"*Oh, spiritual care is just—I guess simple term I would use is just respect. It's just—yeah, just simple respect would be the first step...If you respect the reaction of the person you can reinforce where they are coming from. Which is all that really matters*."[46] "*...the doctor will probably walk in this evening, he always comes walking in and out, once a week...we drink coffee and we talk for a while...that is really great*."[53] "*Tell patients not to focus on their illness and encourage them not to give up*."[68] "*Getting patients their favourite food*."[68] "*They lower the patients' suffering when they help me run errands*."[68] "*Help patients fulfill their wishes to the best of their ability*." [68] "Typically, participants emphasized the provision of compassion and kindness. As one participant stated, *Kindness and compassion go a long, long way*.[42] "Another participant specified the importance of being present and supportive, *support them. Try to be understanding, talk, communication is the most important thing that you can do*". [42]
Practical medical care delivery	"*Provide the necessary care*."[68] "*They can help strengthen our bodies to allow easier treatment*." [68]
Participate in religious activity	"Two suggested that nurses *should just go in and say a little prayer with them*."[37] "One patient described their family doctor praying: *That wee prayer, that is more valuable than all the pills*"[50]
Improved access to chaplaincy	More frequent and longer visits from chaplains.[24]
Views on training	"*I think that* [staff developing skills via training] *is very important…it's a huge step. I guess it would be okay to turn around and say do you know I have often thought about that myself and I don't have an answer, but if you talk to this member of staff she might be able to help you a little bit more than I*" [49] "*what kind of training, well first of all a new patient comes in and you get to know the patient…First of all you would have to ask, you wouldn't impose it on them…you would ask them first*" [49] "Training was thought necessary to teach people to elicit, recognise and meet individual needs: *he [staff member] validated what I was thinking, he didn't make any judgments…and at my pace we were allowed to explore that in a little bit more detail and I have a good enough relationship…to feel I could discuss it again with him*" [49] "*I also think in terms of training that it's useful sometimes to have real patients and I think it is really important that people, staff are open and listening to criticism constructively*"[49]

3.4 Certainty of the evidence

Confidence in the review findings (as assessed by GRADE-CERQual) ranged from medium to high, and there was strong consistency in the findings across countries, population groups and clinical contexts (Appendix 4).

4 DISCUSSION

4.1 Main findings of the study

This qualitative evidence synthesis identified 50 studies (42 datasets) from various healthcare settings that explored spirituality, mainly through face-to-face interviews with patients in the last year of life (n = 710). A comprehensive thematic analysis resulted in the generation of three overarching themes: the concept of spirituality, spiritual needs and distress, and spiritual care resources. The certainty of the evidence using the GRADE CERQual approach was judged to be moderate to high.

4.2 Context of other literature

In keeping with international consensus definitions, spirituality was found to be a broad concept,[2] encapsulating references to religion and higher powers, and more existential or humanistic dimensions.[2, 62] Edwards et al (2010),[14] identified that relationships were the most important dimension of spirituality in a systematic review of 11 qualitative studies of patients receiving palliative or hospice care. However, many patients die in acute and long term care settings and primary care settings, for example, up to half of all cancer deaths in high-income countries occur in acute hospitals.[15] Our synthesis further corroborates Edwards et al,[14] line of argument, through the inclusion of a larger number of studies across all health care settings. Relationships with family, friends, the self, healthcare providers and higher powers were integral to people's sense of spirituality.

Spirituality has been identified as a key asset for patients' approaching the end of life a positive association with patients' quality of life, physical health and social well-being has been demonstrated.[2, 4, 7] The studies identified in this review highlighted that participants recognised the importance of spirituality to their overall well-being and peace of mind, and expressed a wide range of spiritual needs. These needs were quite varied and encompassed many aspects of patients' lives beyond religion including the need to have relationships, manage remaining life, deal with dying and after death and find meaning. The most salient spiritual activity identified was engaging in meaningful relationships and connections with family and friends and with healthcare professionals.

Spiritual distress is common in patients with advanced, terminal conditions.[72, 73] Within the studies identified here, losses in relationships were identified as a core driver of spiritual distress; however, distress arose from a number of unmet needs such as a lack of information.

The provision of spiritual care, is considered an intrinsic domain of palliative care internationally.[1] Within this review, we identified two main categories of spiritual care resources: personal resources and resources related to the professional support received within the healthcare system. Personal resources particularly included patients' own personal religious practices (especially praying). Previous quantitative studies have found a positive association between practicing and participating in religious rituals and quality of life in the context of palliative care.[74] The provision of spiritual care can be neglected by healthcare providers.[4, 5] Across the included studies, the provision of spiritual care was not viewed as a task or a treatment given by health care providers alone. While board-certified healthcare chaplains are recognised as the formally trained spiritual carers in the healthcare setting, spiritual care, as conceived by patients could be provided by anyone (not just chaplains) with whom patients felt heard and understood, which in turn, left them with the sense of connection. One of the most salient factors to arise from this analysis was that genuine caring, compassionate and honest relationships with healthcare professionals, that should be part of good holistic patient-centred care, were meaningful to participants as they felt affirmed and valued by health professionals, which in turn supported their desire to find meaning in their remaining days and months.

4.3 Strengths and limitations of this review

This study was conducted according to the ENTREQ reporting guidelines[16] and is the protocol was registered on PROSPERO in advance of conducting the review to ensure transparency. An extensive search of the published literature was conducted using a detailed search strategy across six electronic databases. Two reviewers were involved in all stages of the review (screening, data extraction, quality appraisal and assessing the certainty of the evidence using the GRADECerqual approach), reducing bias. The cultural and religious diversity in the included studies is a strength of this review, increasing the applicability of the findings.

However, the review has some limitations including restriction to English language studies only and the inherent difficultly of identifying qualitative literature in systematic reviews.[75] The main analysis was conducted by one researcher (BC). The initial themes and the analysis were discussed with others member of the research team and were presented to the guideline development group (comprised of multidisciplinary stakeholders including palliative care professionals and patient representatives) for discussion to increase the conformability of the themes.

4.4 Implications for Healthcare Professionals

Relationships are an intrinsic component of spirituality. This work emphasizes that supporting relationships should be a central focus of spiritual care for patients at the end of life. Aspects of palliative care training of healthcare professionals that focused on person centred care, such as how to engage with patients on topics of spirituality and the importance of listening to patients were highlighted as ways of improving spiritual care. Our study strongly reinforces the need to listen openly, being guided by the patient, to allow them to explore what is important to them, which in turn may help to alleviate their spiritual distress. Meeting the spiritual care needs of patients necessitates all healthcare providers have some degree of proficiency in this regard. Existing spiritual care training programmes (such as Clinical Pastoral Education) used in healthcare chaplaincy education may have a role in broader spiritual care education for healthcare professionals. Given the importance of family and friends in the role of spiritual care, emphasis on supporting and facilitating

family to provide this care, both directly and indirectly, for example ensuring access to patients in inpatient settings, may be important. Ensuring the physical environment can facilitate drawing on personal resources by, for example, having comfortable rooms for visitations and prayer facilities would be of benefit to patients.

5 CONCLUSION

Spiritual care is an integral part of end of life care. Patient perspectives on spirituality were broad encapsulating references to religion, and more existential or humanistic dimensions. Relationships were identified as an intrinsic component of spirituality. This review emphasizes that spiritual care is not a task or a treatment given by healthcare providers alone and that supporting relationships should be a central focus of spiritual care for patients at the end of life. Training of healthcare professionals should focus on person centred care, incorporating aspects of how to engage with patients on issues of spirituality and the importance of listening to patients as ways of improving spiritual care. Given the importance of family and friends in the role of spiritual care, emphasis on supporting and facilitating family to provide this care, both directly and indirectly, for example ensuring access to patients in inpatient settings, may be important.

Funding: This research was funded by the Health Research Board under grant no. HRB-CICER-2016-1871

Acknowledgements: This research was undertaken to support the development of a national clinical guideline care of dying adults in the last days of life. HRB-CICER would like to acknowledge the contributions and input from members of the guideline development group and the Clinical Effectiveness Unit, Department of Health, Ireland.

Authorship: All named authors have made an active contribution to the conception and design and/ or analysis and interpretation of the data and the drafting of the paper. All authors have critically reviewed its content and have approved the final version submitted for publication.

Data management and sharing

The search strategy and extracted data are presented and are thus available.

Conflicts of interest

No conflicts of interest have been declared.

6 REFERENCES

1. World Health Organization. Worldwide Palliative Care Alliance. Global Atlas of Palliative Care at the End of Life. World Health Organization, 2014 (accessed 1 May 2019) https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf.
2. Steinhauser KE, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI, et al. State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes. Journal of pain and symptom management. 2017;54(3):428-40.
3. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. Journal of palliative medicine. 2009;12(10):885-904.
4. Egan R, Macleod ROD, Jaye C, McGee ROB, Baxter J, Herbison P, et al. Spiritual beliefs, practices, and needs at the end of life: Results from a New Zealand national hospice study. Palliative & Supportive Care. 2017;15(2):223-30.
5. Selman LE, Brighton LJ, Sinclair S, Karvinen I, Egan R, Speck P, et al. Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. Palliative medicine. 2018;32(1):216-30.
6. Gonella S, Basso I, De Marinis MG, Campagna S, Di Giulio P. Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings. Palliative medicine. 2019;33(6):589-606.
7. Chen J, Lin Y, Yan J, Wu Y, Hu R. The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: A systematic review. Palliative medicine. 2018;32(7):1167-79.
8. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliative medicine. 2010;24(8):753-70.
9. Abarshi E, Echteld M, Donker G, Van den Block L, Onwuteaka-Philipsen B, Deliens L. Discussing end-of-life issues in the last months of life: a nationwide study among general practitioners. Journal of palliative medicine. 2011;14(3):323-30.
10. Palliative Care Competence Framework Steering Group. Palliative Care Competence Framework. Dublin: Health Service Executive, 2014.
11. Virdun C, Luckett T, Lorenz KA, Phillips J. National quality indicators and policies from 15 countries leading in adult end-of-life care: a systematic environmental scan. BMJ Supportive & Palliative Care. 2018;8(2):145-54.
12. Balboni MJ, Sullivan A, Amobi A, Phelps AC, Gorman DP, Zollfrank 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. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2013;31(4):461-7.
13. Balboni TA, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI, et al. State of the Science of Spirituality and Palliative Care Research Part II: Screening, Assessment, and Interventions. Journal of pain and symptom management. 2017;54(3):441-53.
14. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliative medicine. 2010;24(8):753-70.
15. Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. Jama. 2016;315(3):272-83.
16. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC medical research methodology. 2012;12:181.

17. Cooke A, Smith D, Booth A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. Qualitative health research. 2012;22(10):1435-43.
18. Critical Appraisal Skills Programme Qualitative Checklist [Internet]. 2017 [cited December 11th 2017]. Available from: Available at: http://www.casp-uk.net/checklists
19. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC medical research methodology. 2008;8(1):45.
20. Lewin S, Glenton C, Munthe-Kaas H, Carlsen B, Colvin CJ, Gülmezoglu M, et al. Using Qualitative Evidence in Decision Making for Health and Social Interventions: An Approach to Assess Confidence in Findings from Qualitative Evidence Syntheses (GRADE-CERQual). PLOS Medicine. 2015;12(10):e1001895.
21. Ardelt M, Koenig CS. The Importance of Religious Orientation and Purpose in Life for Dying Well: Evidence from Three Case Studies. Journal of Religion, Spirituality & Aging. 2007;19(4):61-79.
22. Bell Meisenhelder J, D'Ambra C, Jabaley T. Spiritual Coping at the End of Life. Journal of Hospice & Palliative Nursing. 2016;18(1):66-73.
23. Campbell CL, Ash CR. Keeping faith. Journal of Hospice & Palliative Nursing. 2007;9(1):31-41.
24. Chang BH, Stein NR, Trevino K, Stewart M, Hendricks A, Skarf LM. Spiritual Needs and Spiritual Care for Veterans at End of Life and Their Families. American Journal of Hospice and Palliative Medicine. 2012;29(8):610-7.
25. Coyle N. The hard work of living in the face of death. Journal of pain and symptom management. 2006;32(3):266-74.
26. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. Oncol Nurs Forum. 2004;31(4):699-709.
27. Dobratz MC. 'All my saints are within me': Expressions of end-of-life spirituality. Palliative & Supportive Care. 2013;11(3):191-8.
28. Duggleby W. Enduring suffering: a grounded theory analysis of the pain experience of elderly hospice patients with cancer. Oncol Nurs Forum. 2000;27(5):825-31.
29. Engle VF, Fox-Hill E, Graney MJ. The experience of living-dying in a nursing home: self-reports of black and white older adults. Journal of the American Geriatrics Society. 1998:1091-6.
30. Hermann CP. Spiritual needs of dying patients: a qualitative study. Oncology Nursing Forum. 2001;28(1):67-72.
31. Montross-Thomas LP, Joseph J, Edmonds EC, Palinkas LA, Jeste DV. Reflections on wisdom at the end of life: qualitative study of hospice patients aged 58-97 years. International psychogeriatrics. 2018;30(12):1759-66.
32. Nebel Pederson S, Emmers-Sommer TM. “I'm Not Trying to Be Cured, So There's Not Much He Can Do for Me”: Hospice Patients’ Constructions of Hospice's Holistic Care Approach in a Biomedical Culture. Death Studies. 2012;36(5):419-46.
33. Nelson-Becker HB. Voices of Resilience: Older Adults in Hospice Care. Journal of Social Work in End-of-Life & Palliative Care. 2006;2(3):87-106.
34. Pevey C. Death, God, Flesh, and other: Hospice Recipients Reflect on what Matters. Illness, Crises, and Loss. 2008b;16(3):203-26.
35. Pevey CF, Jones TJ, Yarber A. How Religion Comforts the Dying: A Qualitative Inquiry. Omega. 2008a;58(1):41.
36. Prince-Paul M. Understanding the meaning of social well-being at the end of life. Oncology Nursing Forum. 2008;35(3):365-71.
37. Reynolds MA. Hope in adults, ages 20-59, with advanced stage cancer. Palliative & Supportive Care. 2008;6(3):259-64.
38. Ryan PY. Approaching death: a phenomenologic study of five older adults with advanced cancer. Oncology nursing forum. 2005;32(6):1101-8.

39. Sherman AC, Simonton-Atchley S, Mikeal CW, Anderson KM, Arnaoutakis K, Hutchins LF, et al. Cancer patient perspectives regarding preparedness for end-of-life care: A qualitative study. Journal of Psychosocial Oncology. 2018;36(4):454-69.
40. Shockey Stephenson P, Sheehan D, Hansen D, Mayo MM. The Spiritual Nature of Uncertainty Among Hospice Patients. Journal of Hospice & Palliative Nursing. 2017;19(5):480-6.
41. Stephenson PL, Draucker CB, Martsolf DS. The experience of spirituality in the lives of hospice patients. Journal of Hospice & Palliative Nursing. 2003;5(1):51-8.
42. Wright ST, Breier JM, Depner RM, Grant PC, Lodi-Smith J. Wisdom at the end of life: Hospice patients' reflections on the meaning of life and death. Counselling Psychology Quarterly. 2018;31(2):162-85.
43. Wrubel J, Acree M, Goodman S, Folkman S. End of living: maintaining a lifeworld during terminal illness. Psychology & Health. 2009;24(10):1229-43.
44. Yedidia MJ, MacGregor B. Confronting the prospect of dying: reports of terminally ill patients. Journal of Pain & Symptom Management. 2001;22(4):807-19.
45. Kuhl D. Exploring the lived experience of having a terminal illness. Journal of Palliative Care. 2011;27(1):43-52.
46. Selby D, Seccaraccia D, Huth J, Kurppa K, Fitch M. Patient versus health care provider perspectives on spirituality and spiritual care: the potential to miss the moment. Annals of palliative medicine. 2017;6(2):143-52.
47. Buckley J, Herth K. Fostering hope in terminally ill patients. Nursing Standard. 2004;19(10):33-41.
48. Ellis J, Cobb M, O'Connor T, Dunn L, Irving G, Lloyd-Williams M. The meaning of suffering in patients with advanced progressive cancer. Chronic Illness. 2015;11(3):198-209.
49. Yardley SJ, Walshe CE, Parr A. Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements. Palliative medicine. 2009;23(7):601-7.
50. Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. Palliative & supportive care. 2004;2(4):371-8.
51. Kristiansen M, Irshad T, Worth A, Bhopal R, Lawton J, Sheikh A. The practice of hope: a longitudinal, multi-perspective qualitative study among South Asian Sikhs and Muslims with life-limiting illness in Scotland. Ethnicity & Health. 2014;19(1):1-19.
52. Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. BMJ. 2009;338:b183.
53. Warmenhoven F, Lucassen P, Vermandere M, Aertgeerts B, van Weel C, Vissers K, et al. Life is still worth living': a pilot exploration of self-reported resources of palliative care patients. BMC Family Practice. 2016;17:1-6.
54. Proot IM, Abu-Saad HH, ter Meulen RH, Goldsteen M, Spreeuwenberg C, Widdershoven GA. The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. Palliative medicine. 2004;18(1):53-61.
55. Moestrup L, Hansen HP. Existential Concerns About Death: A Qualitative Study of Dying Patients in a Danish Hospice. American Journal of Hospice & Palliative Medicine. 2015;32(4):427-36.
56. Moestrup L, Hvidt NC. Where is God in my dying? A qualitative investigation of faith reflections among hospice patients in a secularized society. Death Studies. 2016;40(10):618-29.
57. Veronese S, Gallo G, Valle A, Cugno C, Chiò A, Calvo A, et al. The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study. Progress in Palliative Care. 2015;23(6):331-42.

58. McGrath P. Affirming the connection: comparative findings on communication issues from hospice patients and hematology survivors. Death Studies. 2004;28(9):829-48.
59. McGrath P. Religiosity and the challenge of terminal illness. Death Studies. 2003b;27(10):881-.
60. McGrath P. Spiritual pain: a comparison of findings from survivors and hospice patients. American Journal of Hospice & Palliative Care. 2003a;20(1):23-1p.
61. Ying-Yu C, Donoghue J, Chenoweth L. Responses to advanced cancer: Chinese-Australians. Journal of Advanced Nursing. 2005;52(5):498-507.
62. Egan R, MacLeod R, Jaye C, McGee R, Baxter J, Herbison P. What is spirituality? Evidence from a New Zealand hospice study. Mortality. 2011;16(4):307-24.
63. McKinlay EM. Within the circle of care: patient experiences of receiving palliative care. Journal of Palliative Care. 2001;17(1):22-9.
64. Chao CC, Chen C, Yen M. The essence of spirituality of terminally ill patients. Journal of Nursing Research (Taiwan Nurses Association). 2002;10(4):237-44.
65. Shih FJ, Lin HR, Gau ML, Chen CH, Hsiao SM, Shih SN, et al. Spiritual needs of Taiwan's older patients with terminal cancer. Oncology Nursing Forum. 2009;36(1):E31-E8.
66. Nilmanat K, Chailungka P, Temsak P, Promnoi C, Tulathamkit K, Noo-urai P, et al. Living with suffering as voiced by Thai patients with terminal advanced cancer. International journal of palliative nursing. 2010;16(8):393-9.
67. Nilmanat K, Promnoi C, Phungrassami T, Chailungka P, Tulathamkit K, Noo-urai P, et al. Moving Beyond Suffering: the Experiences of Thai Persons With Advanced Cancer. Cancer nursing. 2015;38(3):224-31.
68. Hong IWM, Ow R. Hope Among Terminally Ill Patients in Singapore: An Exploratory Study. Social Work in Health Care. 2007;45(3):85-106.
69. Ho AHY, Chan CLW, Leung PPY, Chochinov HM, Neimeyer RA, Pang SMC, et al. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. Age and Ageing. 2013;42(4):455-61.
70. McGrath P. Strategies for coping with spiritual pain: a comparison of insights from survivors and hospice patients. The Australian journal of holistic nursing. 2004;11(1):4-15.
71. Chang B, Stein N, Stewart M, Hendricks A, Skarf L. Spiritual needs of veterans: Healthcare implications for returning troops. BMC Complementary and Alternative Medicine. 2012;12.
72. Gielen J, Bhatnagar S, Chaturvedi SK. Prevalence and Nature of Spiritual Distress Among Palliative Care Patients in India. Journal of religion and health. 2017;56(2):530-44.
73. Delgado-Guay MO, Hui D, Parsons HA, Govan K, De la Cruz M, Thorney S, et al. Spirituality, religiosity, and spiritual pain in advanced cancer patients. Journal of pain and symptom management. 2011;41(6):986-94.
74. Vallurupalli M, Lauderdale K, Balboni MJ, Phelps AC, Block SD, Ng AK, et al. The role of spirituality and religious coping in the quality of life of patients with advanced cancer receiving palliative radiation therapy. J Support Oncol. 2012;10(2):81-7.
75. Booth A. Searching for qualitative research for inclusion in systematic reviews: a structured methodological review. Systematic Reviews. 2016;5(1):74.