

Review Article

What Can We Learn About the Spiritual Needs of Palliative Care Patients From the Research Literature?

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Abstract

Context. Spirituality is a distinctive subject within palliative care practice and literature, but research to date is relatively undeveloped in this field and studies often throw more light on conceptual and methodological issues than producing reliable data for clinical practice.

Objectives. To determine what is known about the spiritual needs of palliative care patients from the evidence presented in published research.

Methods. Specialist online databases were interrogated for primary empirical studies of patients with a chronic disease unresponsive to curative treatment. Studies that only used a proxy for the patient or reported expert opinion were excluded. Each study was critically appraised for quality and the strength of its evidence to determine if any data could be pooled.

Results. Thirty-five studies were identified, equating to a total of 1374 patients. Study populations were typically people with advanced-stage cancer, older than 60 years, who were English speaking, and with a Christian or Jewish religious affiliation, reflecting the predominance of Anglo-American studies. Studies fell into two groups: those that investigated the nature of spiritual experience and those that examined the relationship of spirituality with other phenomena. The evidence was insufficiently homogeneous to pool.

Conclusion. Relevant accounts of what spirituality means for palliative care patients and evidence of how it operates in the lives of people with life-limiting disease can be derived from research. Studies to date are limited by reductive representations of spirituality and the conduct of research by health professionals within health care communities demarcated from disciplines and interpretive traditions of spirituality. *J Pain Symptom Manage* 2012;43:1105–1119. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words

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Introduction

The practice of palliative care and the specialty of palliative medicine emerged from the modern hospice movement and its foundational philosophy of treating the whole person. This holistic approach recognized that the needs of dying patients were complex and multifaceted and, therefore, required going beyond a conventional biomedical understanding of the disease and its treatment. One of the most influential concepts supporting this wider view of the dying person was that of “total pain”¹ developed by Cicely Saunders, the founder of St. Christopher’s Hospice, which embraced the physical, mental, social, and spiritual problems of a patient.² This integrated multidimensional concept of human personhood became pervasive in palliative care and remains a normative philosophy evident in the descriptors and definitions of learned societies and professional bodies,^{3,4} national policies and strategies,^{5,6} and major texts on the practice of palliative care.^{7,8}

Saunders’ approach was rooted in her Christian faith and developed during a period in which the modern Christian ecumenical movement was flowering. Spiritual care in this historical context was, therefore, strongly related to exercising a Christian vocation in serving human needs.⁹ The contemporary context is different again, with a decline (in Western Europe) in the influence of traditional forms of Christianity and the emergence of new forms of religion and spirituality.¹⁰ Consequently, current discourses and practices in the spiritual dimension of palliative care have tended to shift away from socially oriented religious faiths and a vocational ethos of care towards subjective forms of belief, the personal search for meaning and wholeness, and the professionalization of care.^{11,12}

Despite the unfolding meaning and forms of “spirituality,” it persists as a prominent term within the palliative care literature,^{13–15} inquiry,^{16,17} and guidance.^{18,19} Although there is general acceptance of spirituality, it has been criticized in terms of its purported universal utility and validity,^{20,21} its confusion with

existential issues,^{22,23} its lack of roots in a substantive tradition and practice,²⁴ and its implicit ambiguity and imprecision.²⁵ Accordingly, attempts have been made to construct descriptive models^{26,27} and achieve greater definitional clarity and nuance in terminology.^{28,29} More specific has been the pursuit of valid and reliable instruments to measure spirituality. One of the earliest, from the 1980s, was a scale to measure spiritual well-being,³⁰ and since then, a raft of scales and instruments have been developed.^{31,32} Many of these were not developed specifically for palliative care but are considered relevant,³³ and a subset assesses the aspects of quality of life and well-being related to spirituality.^{34,35} Spirituality instruments also allow for relational studies between spiritual variables and measures of other factors including coping,^{36,37} despair,³⁸ and depression.^{39,40} Research to date is relatively undeveloped in this field, and studies often throw more light on conceptual and methodological issues than producing reliable data that can be synthesized and translated into clinical practice.^{41,42}

There are currently insufficient and coherent primary research data to support the systematic review of spiritual interventions in palliative care, although a Cochrane review of “Spiritual and religious interventions for adults in the terminal phase of disease” is in the protocol phase at the time of writing.⁴³ However, a small number of systematic literature reviews have been published that report on the state of research into spirituality in palliative care,^{44,45} provide a thematic and conceptual analysis,^{46,47} and present evidence of the concepts, tools, and models that support spiritual care in practice.⁴⁸ There is only one literature review to date that has attempted a meta-data analysis and synthesis: a sociologic meta-study of 19 qualitative studies using an ethnographic method.⁴⁹

The purpose of this literature review was to critically examine the data on the spiritual needs of palliative care patients available in published empirical studies. Experts, health care professionals, and caregivers are used in some studies to speak on behalf of patients,⁵⁰

or the distinctive perspective of the patient is subsumed within a larger data set or analysis and combined with the data from carers or health care professionals.⁴⁹ This review focused on studies that contain data derived directly from patients and not represented solely by proxies. From 2006, there is an extant analysis of the qualitative literature on the spirituality of adults at the end of life,¹⁷ but this review has included studies using quantitative and mixed methods and literature from 2007 to 2010.

Methods

The objective of this study was to identify published literature that reports evidence of the spiritual needs of palliative care patients. The search strategy was based on online bibliographic sources supplemented by a wider search of the gray literature, reference lists of landmark articles, topic-specific editions of journals, selected subject-specific journals, and the advice of colleagues. Bibliographic sources included the specialist academic databases, AMED, ATLA, CINAHL, PsycINFO, and PubMed; the library catalogue, COPAC; and a search engine of selected health-related sources, NHS Evidence. In addition, Google Scholar was used as an adjunct to the other sources, with the anticipation that it might retrieve references beyond the biomedical corpus and conventional publications.^{51–53}

Inclusion and Exclusion Criteria

The population being studied was adults with a disease unresponsive to curative treatment. Therefore, studies of patients with advanced- and end-stage chronic disease reporting primary empirical research data of spiritual needs derived from qualitative methods (e.g., narrative interviews), quantitative methods (e.g., measurement tools), or mixed methods were included. The literature with no empirical data and based on expert opinion, the results of focus groups of professionals and/or caregivers, commentaries, and personal reflections, was excluded. Specifically, the literature that only used a proxy for the patient (e.g., a caregiver) and the literature about the spiritual needs of professionals and caregivers were excluded.

Search Terms

The databases and search engines accessed do not share a consistent method of running a search inquiry; therefore, a specific set of terms had to be developed for the search of a particular source. Most databases have some form of controlled vocabulary to describe subjects and subject headings, but these are not consistent. The search strings developed for each literature source are given in Table 1. The intention of the search was to achieve an inclusive definition in this stage and filter out the literature in subsequent stages.

Screening of Literature

All literature identified was subject to a first-stage screening that used the title and, where available, the abstract or synopsis of the work so that it could be assessed for eligibility against the inclusion criteria. Many of the searches, for example, identified a significant number of studies involving staff or caregivers as a proxy for patients and were not eligible for selection. The resulting literature was then retrieved and the full article, book, or thesis read and subjected to a second-stage screening against the inclusion and exclusion criteria (Fig. 1).

Appraisal of the Literature

The literature included in this study was critically appraised with the objective of evaluating the quality of the studies and the strength of the evidence reported to determine if any of the data could be pooled for meta-synthesis and meta-analysis. The quality of a study typically

Table 1
Search Strings for Specific Literature Sources

Source	Search String
AMED	spirituality AND palliative care
ATLA	Keywords: spiritual* AND palliative [mp=abstract, title, series, related work title, heading words, formatted contents note, note]
CINAHL	Spirituality [Word in Major Subject Heading] AND Palliative Care [Word in Major Subject Heading]
COPAC	Spirituality AND palliative care
Google Scholar	“palliative care” in title:spirituality
NHS Evidence	“palliative care” AND spirituality
PsycINFO	spirituality AND palliative care
PubMed	Spirituality [MeSH Major Topic] AND Palliative Care [MeSH Major Topic]

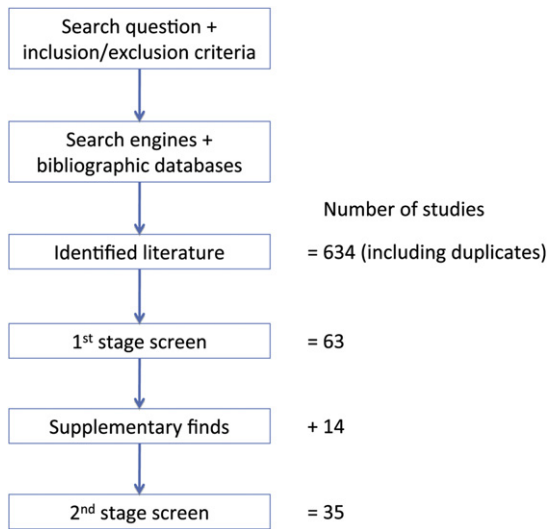


Fig. 1. Literature screening process.

refers to the rigor of the research and validity of results, with methodological quality defined as “the extent to which a study’s design, conduct, and analysis has minimized selection, measurement, and confounding biases;”⁵⁴ this relates to four study design types: systematic reviews, randomized controlled trials, observational studies, and studies of diagnostic tests.

Studies in spirituality and palliative care span the natural and social sciences, and therefore, validity in some studies (e.g., those using narrative methods) may refer more to the congruity among the experience of participants being investigated, its representation in the findings of the study, and the way conclusions are substantiated.

Evidence is defined in this study as the explicit empirical findings derived from a planned and systematic process of inquiry. The strength of evidence is related to its application (e.g., practice guidelines) and the level of certainty required for this purpose.⁵⁵ Consequently, nine criteria were derived from published evaluation frameworks and assessment criteria:^{56–59}

- 1) clarity of research aims, 2) exposition of the main assumptions and concepts, 3) justification and rationale for the study design, 4) description of context and population, 5) rigor of data collection, 6) formulation of analysis (described and constructed), 7) derivation and interpretation of findings from data, 8) extent to which its findings can be generalized to similar population, and 9) reflexivity of the account.

The first author evaluated the studies in this review against these criteria using a simple nine-point system, with one point being awarded per criterion where there was evidence of it in the published study.

Results

Characteristics/Morphology of the Literature

Thirty-five studies survived the two-stage screening process (Table 2), comprising 34 studies published between 2000 and 2010 across 24 journals and one study published exclusively in a book.⁶⁰ Common reasons for exclusion of literature were the following: populations of non-palliative care patients, non-advanced stage disease (e.g., Karnofsky Performance Status >80),⁶¹ correlational studies with no patient data, proxy reports of patients’ spirituality through carers or health care professionals, and studies validating the psychometric properties of tools that did not report any data on patients’ spiritual needs. The quality of the remaining 35 studies ranged from five to eight on a nine-point scale, with studies commonly failing to provide an exposition of their theoretical and conceptual backgrounds, not explaining how findings had been interpreted or not providing any reflexive considerations. No study made any claim that its data could be generalized beyond its particular population, and the strength of evidence was generally consistent with the restricted claims of the studies and their recommendations.

Four out of five studies were conducted in countries where English is an official language, with just more than two-thirds of the studies conducted in the U.S. or U.K. (24 of 35). Study sizes ranged from case studies of one patient to a sample of 120 patients (mean = 39), equating to a total of 1374 patients. About two-thirds of the studies (23 of 35) used qualitative methodologies for data collection such as semi-structured interviews, and the remaining studies used either quantitative (8 of 35) or mixed (4 of 35) methods. The latter used a range of measures of spirituality, including the Fetzer Multidimensional Measure of Religiousness/Spirituality,⁶² Religious Coping Scale,⁶³ Spiritual Well-Being Scale,³⁰ Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale,⁶⁴

Table 2
Studies Included in the Literature Review

First Author	Date	Publication	Population	Sample	Measures (Full- or Subscales)
Alcorn ⁸¹	2010	<i>J Palliat Med</i>	Randomly selected patients with diagnosis of an advanced-stage incurable cancer; active receipt of palliative radiation therapy (Boston, MA)	68	Fetzer Multidimensional Measure of Religiousness/Spirituality, RCOPE (Pargament et al. ⁶⁴)
Buxton ⁸⁶	2007	<i>Br J Nurs</i>	Purposive sample of terminal and nonterminal patients (Birmingham, U.K.)	7	N/A
Chao ⁶⁹	2002	<i>J Nurs Res</i>	Purposive sample of terminally ill patients of a hospice ward of a teaching hospital (Taiwan)	6	N/A
Fegg ⁹²	2010	<i>J Pain Symptom Manage</i>	Palliative care patients treated in an inpatient palliative care unit and in a palliative care consult service (Munich, Germany)	100	Schedule for Meaning in Life Evaluation
Grant ⁷⁰	2004	<i>Palliat Support Care</i>	Purposively recruited patients with a range of advanced-stage malignant and nonmalignant illnesses from a variety of religious and social backgrounds (Edinburgh, U.K.)	20	N/A
van Laarhoven ⁷⁶	2010	<i>J Pain Symptom Manage</i>	Consecutive patients in a group of palliative cancer patients who were no longer receiving antitumor treatments and facing death (The Netherlands)	68	Images of God Scale; COPE-Easy abbreviated version (Carver et al., 1989) ¹⁰³
Hanson ⁸⁵	2008	<i>J Palliat Med</i>	Subjects were recruited from palliative care, family medicine, or geriatric medicine inpatient services and oncology clinics with attending physician judged that it would not be surprising if the patient died within the year + family caregivers for patients (North Carolina)	38	A validated two-item screen for depressive symptoms
Hart ¹⁰⁴	2003	<i>Am J Hosp Palliat Care</i>	Terminally ill patients enrolled in two hospice programs (Seattle, WA)	16	N/A
Hebert ⁷⁷	2001	<i>J Gen Intern Med</i>	Patients hospitalized with a life-threatening illness (Baltimore, MD)	22	N/A
Hermann ⁹⁰	2001	<i>Oncol Nurs Forum</i>	Terminally ill hospice outpatients, cancer and other conditions (U.S.)	19	N/A
Hermann ⁶⁸	2007	<i>Oncol Nurs Forum</i>	Patients in inpatient and outpatient hospices, cancer, and heart failure (U.S.)	100	Spiritual Needs Inventory (Hermann) ¹⁰⁵ and Cantril Ladder of quality of life
Hills ⁷³	2005	<i>J Palliat Med</i>	Patients referred to the palliative care consult service. All patients had a life-threatening diagnosis requiring aggressive symptom management and end-of-life care planning (Chicago, IL)	31	Brief RCOPE (Pargament et al. ⁶⁴), FACIT-Sp, FICA (Puchalski), ¹⁰⁶ National Comprehensive Cancer Network Distress Management Assessment Tool, and Profile of Mood States—Short Form
Ireland ¹⁰⁷	2010	<i>Br J Nurs</i>	A woman with breast cancer (Grampian, U.K.)	1	N/A
Kawa ¹⁰²	2003	<i>Support Care Cancer</i>	Patients with cancer who were inpatients at palliative care units (Japan)	11	N/A
Kernohan ⁷⁹	2007	<i>Palliat Med</i>	Patients admitted to the inpatient unit or attending day hospice sessions (Northern Ireland, U.K.)	62	N/A
Kub ⁷⁵	2003	<i>Appl Nurs Res</i>	Patients diagnosed with ALS, advanced-stage cancer, or congestive heart failure (U.S.)	114	N/A

(Continued)

Table 2
Continued

First Author	Date	Publication	Population	Sample	Measures (Full- or Subscales)
Mako ⁷²	2006	<i>J Palliat Med</i>	Patients with advanced-stage cancer admitted to a palliative care hospital (New York, NY)	57	Nonvalidated scales to measure physical pain, spiritual pain, religiosity, severity of illness, and level of depression
McGrath ¹⁰⁸	2004	<i>Support Care Cancer</i>	Hospice patients with a terminal cancer diagnosis with less than six months to live + hematology survivors (Australia)	14	N/A
Miller ⁸⁴	2005	<i>J Sex Res</i>	African-American gay men living with end-stage AIDS (Manhattan and Brooklyn, NY)	1	N/A
Mishra ¹⁰¹	2010	<i>Am J Hosp Palliat Care</i>	Patients with advanced-stage cancer admitted to a pain and palliative care unit (New Delhi, India)	100	N/A
Mok ⁸³	2010	<i>J Adv Nurs</i>	Patients with incurable cancer and referred to the inpatient palliative care service (Hong Kong)	15	N/A
Murphy ⁹³	2000	<i>Neurology</i>	Patients with ALS (U.S.)	46	FACIT-Sp, preferences and use of technology, Beck Depression Inventory, Beck Hopelessness Scale, Attachment to Life, and Revised Collett-Lester Fear of Death Scale
Murray ⁸⁹	2004	<i>Palliat Med</i>	People dying of lung cancer or heart failure (Edinburgh, U.K.)	40	N/A
Norum ⁸⁷	2000	<i>Support Care Cancer</i>	Hospitalized patients with advanced-stage cancer, no present therapy (only palliation) (Tromsø, Norway)	20	N/A
Osse ⁸⁸	2002	<i>Patient Educ Couns</i>	Cancer patients with metastasized disease and their most important relative (The Netherlands)	40	A 97-item checklist of items covering a range of dimensions including spiritual
Park ⁷¹	2008	<i>Palliat Support Care</i>	Patients with severe congestive heart failure who were ineligible for transplantation (Cincinnati, OH)	111	FACIT-Sp subscales, Longevity Estimate Scale (Sulmasy et al. 1998), ¹⁰⁹ clinical indices, subjective functioning indices, depressive symptoms CES-D (Radlof), ¹¹⁰ Satisfaction With Life Scale (Diener et al.) ¹¹¹
Penman ⁷⁸	2009	<i>Aust J Adv Nurs</i>	Palliative care clients and palliative care caregivers. Participants selected for this study had been diagnosed with a life-limiting condition, or were caring for, or had cared for a loved one with a life-limiting condition (Australia)	4	N/A
Scobie ⁷⁴	2005	<i>Internet J Pain Symptom Control Palliat Care</i>	Advanced-stage terminally ill patients within two specialized care hospices (Scotland, U.K.)	120	McGill Quality of Life Questionnaire—Scottish version
Stanworth ⁶⁰	2004	Oxford University Press	Hospice patients (London, U.K.)	25	N/A
Stephenson ⁸⁰	2003	<i>J Hosp Palliat Nurs</i>	Hospice patients (Ohio)	6	N/A
Sulmasy ¹¹²	2006	<i>JAMA</i>	A patient with metastatic pancreatic cancer (U.S.)	1	N/A
Tamura ¹¹³	2006	<i>Palliat Support Care</i>	Cancer patients admitted to a general hospital (Japan)	2	N/A
True ⁸²	2005	<i>Ann Behav Med</i>	Patients diagnosed with advanced-stage lung or colon cancer (U.S.)	68	Fetzer (adapted) + Daily Spiritual Experience Scale (Underwood and Teresi, 2002 ⁶⁷)
Watts ⁹⁴	2008	<i>Illn Crisis Loss</i>	A patient with multiple myeloma (U.K.)	1	N/A
Yardley ⁹¹	2009	<i>Palliat Med</i>	Inpatient, outpatient, or day care hospice (U.K.)	20	

RCOPE = Religious Coping Scale; COPE = Multidimensional Coping Inventory; N/A = not applicable; FACIT-Sp = Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale; FICA = Spiritual Assessment Tool; ALS = amyotrophic lateral sclerosis; CES-D = Self-Report Depression Scale.

the Ironson-Woods Spirituality/Religiosity Index,⁶⁵ the Spiritual Needs Inventory,⁶⁶ and the Daily Spiritual Experience Scale.⁶⁷

Content of the Literature

Studies commonly made positive assertions about the role of spirituality in palliative care and pointed to extant literature to justify their claims, for example, “the beneficial effects of spirituality have been reported in numerous studies.”⁶⁸ Most studies were designed to gather data that could be used to understand the spiritual needs of patients, improve patient assessments, develop interventions, and improve outcomes. Research questions, therefore, typically were constructed around exploring the meaning and role of spirituality in the lives of patients⁶⁹ and the extent to which spiritual needs were met.⁷⁰ Studies that used quantitative methods addressed questions about the relationship of spirituality with various factors, including depression,⁷¹ pain,⁷² quality of life,⁶⁸ distressing symptoms,⁷³ and coping strategies.⁷⁴ Two studies had a particularly religious focus, one focusing on the religiosity of patients⁷⁵ and the other on religious coping in relationship to an individual’s image of God.⁷⁶

The literature frequently used the term *spiritual* along with *religious*, often differentiating the two⁷⁷ and sometimes conjoining them: “spirituality/religiosity.”⁷⁴ There were a few examples of studies referring to *existential* aspects of spirituality.⁷⁰ It was unusual for the authors of studies to provide more than a brief explanation or background as to how they were using this terminology, but some included succinct literature reviews in the introduction to their studies.⁷⁸ Simple statements were often the norm: “Spiritual care responds to both religious and humanistic needs by meeting the requirements of faith and the desire for an accompanying person to ‘be there’, ‘to listen’, and ‘to love’.”⁷⁹ However, some studies were designed to elucidate what patients understood by the terms and, therefore, did not preempt this with their own definitions.⁸⁰

The demographics of the study populations were typically people older than 60 years, English speaking, and with a religious affiliation to either Christianity or Judaism,⁸¹ reflecting the predominance of Anglo-American studies (72% of patients). More extensive reports of demographic characteristics were

included in studies using quantitative methods in which variables such as gender, socioeconomic status, and educational achievement could be analyzed as confounding variables.⁶⁸ One study, for example, examined differences in the use of spiritual coping between African-American patients and their white counterparts with advanced-stage cancer.⁸² Sociocultural and philosophical differences were acknowledged in studies conducted in Japan, Taiwan, and Hong Kong,⁸³ but there was only one study that addressed the issues of sexual identity.⁸⁴

Two-thirds of studies identified specific disease groups in their sample, with 18 studies including patients with cancer ($n = 805$), four including patients with congestive heart failure ($n = 190$), two including patients with amyotrophic lateral sclerosis ($n = 70$), one including patients with chronic obstructive pulmonary disease and motor neuron disease, and one case study of a person with AIDS. The remaining studies provided no specific data on diagnostic categories and used generic terminology about their sample, such as patients who were seriously⁸⁵ or terminally ill,⁸⁶ and one study describing its sample of patients as having “... a life-threatening diagnosis (with a usual prognosis of days to weeks) requiring aggressive symptom management and end of life care planning.”⁷³ Where specific diagnostic data were provided, some studies included related prognostic data, such as the Eastern Cooperative Oncology Group Performance Scale score,⁸⁷ Karnofsky Performance Status,⁸¹ or the New York Heart Association level.⁷⁵ Comorbidities were reported infrequently unless the study was designed to account for disease-related factors that might contribute to spiritual needs such as symptoms of pain, fatigue, and constipation,⁷³ and depression.⁸⁵

Settings for the studies were hospitals, hospices, and patient dwellings in the community, with 17 studies including patients admitted to hospitals, hospices, or palliative care facilities. The data collection was typically synchronic, but some were diachronic (i.e., data accrued over time) to enable the patients’ narratives to be built up over several sessions, and one study was longitudinal (i.e., repeated observation over time) as it aimed to examine how spirituality might change as people perceived the ends of their lives approaching.⁷¹ Not all studies restricted their participants to patients;

some combined patients and caregivers.⁸⁵ One article explained that the most important relative to the patient was usually intensely involved in the life and care of the patient and that they may be able to provide information that the patient was reluctant to disclose or unable to communicate because of impairment.⁸⁸ Another study reported that there was no difference between the spiritual experience of the client and that of the caregiver.⁷⁸ Studies investigating spirituality exclusively from the perspective of health care professionals involved in palliative care practice were excluded from this review.

Primary Findings of Studies

The heterogeneous aims of the studies in this review resulted in a set of findings that were broadly coherent at the level of demonstrating that patients with advanced-stage terminal diseases could describe and respond to questions and instruments intended to capture spiritual aspects of their experience. The data also provided evidence of sufficient weight and quality to support a general finding that there are patients in palliative care with spiritual needs for whom spiritual beliefs and practices are meaningful and active. In addition, studies could be grouped in two types: those that investigated the nature of spiritual experience and those that examined the relationship of spirituality to other phenomena.

The first set of studies typically used interpretive qualitative methods to understand spiritual phenomena in relation to the patients' experiences that generated synopses, themes, and schema to describe their findings. An example was an inquiry using in-depth interviews of the spirituality of six terminally ill patients that resulted in 10 emergent themes grouped into four categories: communion with self, communion with others, communion with nature, and communion with the higher being.⁶⁹ Some studies reported patient narratives and provided commentary and interpretive explanation,⁸⁹ whereas others developed their thematic interpretations into illustrative schemas⁹⁰ and proposed theoretical models.^{60,81} Several studies also aimed to explore how the patient understood the provision of spiritual care and the role of health care professionals. Patients

reported that they wanted to discuss their religious beliefs with their doctors,⁸⁷ and that doctors should acknowledge that spirituality and religion are important for many patients and should treat the subject with respect.⁷⁷ A study of hospice patients found a clear view that spiritual care should be integral to hospice services and is a legitimate activity for all health care professionals.⁹¹ However, another study of hospice patients reported that none of the participants expressed a desire for health care workers to perform spiritual care interventions.⁸⁰

The second set of studies included investigations of covariance between phenomena using quantitative or mixed methods. The relationship among spirituality, religious coping, and symptoms of distress is an example of this type of study that reported that "Negative religious coping (i.e., statements that suggested punishment or abandonment by God) in this group was positively associated with distress, confusion, depression, and negatively associated with physical and emotional well-being, as well as quality of life."⁷³ Other covariant studies reported different relationships, which cannot be amalgamated and must be listed individually: spirituality is more likely to be identified as an important source of "meaning in life" for palliative care patients compared with a representative sample of the population;⁹² belief in a nonpersonal (image of) God is a significant positive predictor for coping strategies in patients;⁷⁶ gender, years of education, and place of residence, but not socioeconomic status, were each significant variables in relationship with spiritual needs;⁶⁸ spirituality or religion influenced the treatment options and attitudes toward the dying process in patients with amyotrophic lateral sclerosis;⁹³ the ethnicity and spirituality of patients with cancer are related to preferences and actions near the end of life, although these associations did not always reach statistical significance;⁸² the longevity estimates of patients with chronic heart failure were related to changes in spirituality;⁷¹ the quality of life of spirituality-oriented patients is positively related to hospices with spirituality-based policies;⁷⁴ and the characteristics of spiritual care providers were not linked to better outcomes, but some types of spiritual caregiving were correlated with greater satisfaction and perceived value.⁸⁵

The design of studies remained largely within the bounds of conventional forms and methods in qualitative and quantitative research. One study included a five-week period of participant observation on a hospice ward,⁶⁰ but most designs relied on semi-structured interviews, questionnaires, and data collection instruments. Few authors offered reflexive accounts of how they were approaching the subject, the form of data collection, or its impact on the participants. A study to understand the perspectives of hospice patients on spiritual care reported that patients want to be known as individuals and did not want spiritual assessment to be a “tick box” exercise.⁹¹ The author of a case study of a man with multiple myeloma contested that measuring spiritual needs is a form of depersonalization and concluded that spiritual needs were substantially situational and biographic and could only be met by someone with shared memories and in the context of long-standing and valued relationships, something, therefore, not possible for health care professionals.⁹⁴

Discussion

In this review of research literature, it is evident that when spirituality is scrutinized using social and scientific methods of research, it yields empirical data that may contribute to clinical knowledge and practice. Most studies and their findings can be broadly classified as exploratory in that they investigated the lived experience of palliative care patients, described phenomena, inferred explanations, and generated theoretical models. This extended to the investigation of potential contributory factors and the identification of causal relationships, for example, between spirituality and quality of life. There were no explicit claims that the sample of participants was representative and, therefore, that the findings could be generalized to similar populations; however, this was sometimes implied in the concluding sections of the literature where the strength of evidence was extended beyond its original level of certainty. Findings were typically aimed at implications for palliative care practice but seldom were issues in knowledge translation between the study and the clinic discussed.

Many of the studies reviewed were designed around the practical and economical

convenience of a local population, which in turn set a limitation recognized by most studies and led to suggestions that further research is required across different palliative care populations. Demographic homogeneity was, therefore, a notable characteristic of studies, some of which can be explained through the predominance of Anglo-American studies (leaving aside religious differences) and some may be related to most studies using populations of patients with cancer, a disease with certain demographic characteristics. This could be an advantage in research terms because it suggests some similarity in the dying process.⁸⁸ Studies infrequently accounted for sociodemographic variables including age and gender despite these being known as significant variables, particularly in terms of religiosity.⁹⁵ Similarly, many studies did not differentiate or categorize disease progression or attempt to account for death salience (with the exception of the study by Park⁷¹), although awareness of mortality was described as a motivator of spirituality. The lack of differentiation across sociodemographic, contextual, and illness variables could result in a perception of similarity, which, in reality, is not present. More importantly, a gloss of coherence may obscure more specific differences to the ways in which spirituality is experienced, expressed, and understood by patients that could result in spiritual care that is insensitive, biased, or incapable of responding to diverse needs.

The very fact that there are studies of spirituality in palliative care points to a number of assumptions about the subject, primarily that the methods of inquiry can detect and describe the spirituality of individuals. The concept of spirituality used in these studies generally went without much critical commentary. The implied assumption was that spirituality had the potential to be beneficial, and it was exceptional for ethical considerations to be discussed beyond the role of professionals. Quantitative studies may be particularly prone to this assumption because complex phenomena are typically operationalized as small sets of variables, and variables as metrics are presumed ethically neutral. Outside the mainly irenic discourse of palliative care, scholars appear both less shy of debate, such as those attracted by the proliferation of prayer studies,^{96,97} and perhaps more realistic about the potential negatives, such as Pargament's wise

caution that “‘Spirituality’ is not a synonym for ‘goodness’.”⁹⁸ (p. 129)

There remains a paucity of exposition on the presuppositions of this research field, of which these studies are no exception. Similarly, there is minimal discussion on the impact and limitations of socioscientific methods and analysis on the subject being studied, such that “What one finds is contingent upon what one looks for, and what one looks for is to some extent contingent upon what one expects to find.”⁹⁹ The treatment of spirituality in most of these studies is functionalist in that spirituality is conceived as something that may contribute to a health outcome or personal benefit.¹⁰⁰ This approach has the reductive advantage of enabling categorical comparison and the possibility of establishing objective knowledge and associations with health-related outcomes. However, it is not apparent from much of this literature whether studying function can provide a sufficient account of spirituality in relation to health care or whether the theological and philosophical content and sociocultural context of spirituality are also required.

The study by van Laarhoven et al.⁷⁶ was a unique example of an inquiry into the theological content of the beliefs of palliative care patients, using a 14-item instrument that differentiates between three images of God: personal, nonpersonal, or unknowable. It is notable that the research team included a member of a Faculty of Theology that has an established approach to empirical theology. Similarly, there were few studies that acknowledged or accounted for the cultural inflections and contextual determinants of spirituality. For example, the only study from a developing nation reported that 98% of their sample of palliative care patients declared belief in God,¹⁰¹ but there was no discussion about the content of this belief, given that the patients identified themselves as Hindu, Muslim, and Sikh. This lack of contextual analysis and reflexivity on the underlying structures and propositions may suggest that researchers share a normative account of spirituality and a lingua franca that is self-evident or established. However, these studies neither explain nor question such assumptions. For example, one of the Japanese studies aimed to explore the patients’ experiences of distress associated with spirituality: “... that is, with their feelings about the

meaning and aim of life in this situation in which their personal existence was threatened.”¹⁰² However, the word *spiritual* is never used in the interviews, but the responses are interpreted within a spiritual framework. Stanworth alone presents an extensive discussion on the linguistics of spirituality and the use of nonreligious language, arguing that spirituality cannot be approached or understood using second-order propositions but through “... metaphors that disclose, mediate and structure ...” the reality of meaning for people who are dying.⁶⁰ (p. 97)

Limitations of This Review

This review of research literature has a number of significant limitations primarily related to the reliability and consistency of the terminology of spirituality, and also to the accuracy of the inclusion criteria in determining studies of palliative care patients. The key search terms did not map consistently onto the sets of standardized vocabulary used to index bibliographic databases, and this is compounded for spirituality because it is a subject that is ill defined and has an underdeveloped subject structure. The initial search returned 634 studies (including duplicates), suggesting that the terms used may have lacked sensitivity and specificity. Most of the literature identified, and none of the screened literature, was published before the year 2000. This is partly explained by the fact that the study of spirituality in health is a developing field and that *spirituality* was not introduced as a MeSH term until 2002. Second, studies involving patients with advanced- and end-stage conditions present more ethical and methodological challenges that are compounded by explorations of spirituality. Researchers and ethics committees, therefore, may be still learning about good approaches to this subject, and funders may be wary of applications. The dominance of cancer-related studies in this review possibly reflects the historic focus of palliative care, and it is only in more recent years that other terminal conditions, such as chronic heart failure and renal disease, have begun to be included within the practice and publications of palliative care. A further limitation is associated with screening the literature to ensure that the study populations fulfilled the palliative care inclusion criteria as this could result in a level of uncertainty

when studies lacked necessary descriptors or clinical information. Finally, there may be a publication bias in the studies as there is no evidence of dissent in the generally positive view of spirituality in palliative care, and it may be difficult to propose or publish studies that are not consistent with this apparent consensus.

Conclusion

The studies in this review provide accounts of what spirituality means for palliative care patients and evidence of how it operates in the lives of people with life-limiting disease. The results are substantially positive and beneficial, thus confirming the place of spirituality in the holistic construct of palliative care. However, if we consider spirituality to be a major category alongside physical, psychological, and social dimensions of personhood, then there are significant limitations to what can be learned from 35 studies representing a total of 1374 patients contained substantially within Anglo-American populations similar in terms of disease, age, religious background, and general cultural context. If the literature included in this review is representative of the study of spirituality in palliative care patients, then it is apparent at this time that we have neither a systematic knowledge nor a tightly structured discourse but signs of the emergence of a developing body of research with a shared aim, that is, to understand and address the spiritual needs of terminally ill patients.

The prevalence of inquiries into the function of spirituality is a relevant approach in health care studies, but it is unlikely to be sufficient. The reductive presentation of spirituality in many studies results from the type of methodologies used, motivated by the challenges of making complex phenomena intelligible and producing explanatory and predictive knowledge. In the case of health care research, there is an additional requirement to interpret and translate this knowledge to support evidence-based practice. Therefore, a critical question for empirical studies of spirituality is to what extent do they enlarge our understanding and increase access to the subject? The evidence constituted by these studies is limited by a range of factors including the scale of the research, the

methodologies deployed, and the unexamined assumptions on which the research is based. Finally, most research is conducted by health professionals within health care communities who are clearly demarcated from disciplines and interpretive traditions of spirituality. Perhaps one of the unintended benefits of these studies is that they become a means for opening up interdisciplinary dialogue, building shared understanding, and providing a more complete account of how the spiritual needs of patients may be understood and supported.

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