

## ***Special Section: Report from a Conference on the State of the Science of Spirituality and Palliative Care Research***

# State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes



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### **Abstract**

*The State of the Science in Spirituality and Palliative Care was convened to address the current landscape of research at the intersection of spirituality and palliative care and to identify critical next steps to advance this field of inquiry. Part I of the SOS-SPC two-part series focuses on questions of 1) What is spirituality? 2) What methodological and measurement issues are most salient for research in palliative care? And 3) What is the evidence relating spirituality and health outcomes? After describing current evidence we make recommendations for future research in each of the three areas of focus. Results show wide variance in the ways spirituality is operationalized and the need for definition and conceptual clarity in research in spirituality. Furthermore, the field would benefit from hypothesis-driven outcomes research based on a priori specification of the spiritual dimensions under investigation and their longitudinal relationship with key palliative outcomes, the use of validated measures of predictors and outcomes, and rigorous assessment of potential confounding variables. Finally, results highlight the need for research in more diverse populations. J Pain Symptom Manage 2017;54:428–440. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

### **Key Words**

*Spirituality, outcomes, assessment, interventions, design*

### **Introduction**

From its inception, spirituality has been at the core of the definition of whole-person palliative care.

Where a desolate sense of meaninglessness is encountered by the person at the end of life, one finds the essence of ‘spiritual pain’.<sup>1</sup>—Dame Cicely Saunders

More recently, the World Health Organization definition of palliative care shows the centrality of spirituality: “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable

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assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>2</sup>

However, while on equal footing conceptually, the field has not given equal attention, clinically or empirically, to operationalize the construct of spirituality and understand how to measure and evaluate its influence on health outcomes. As a result, the evidence base of spirituality in palliative care has been the least well developed, among domains of the bio-psychosocial spiritual model.

Both conceptual and practical factors have impeded the development of a rigorous evidence base. Scholarship in this domain has not advanced a common language or a shared understanding of the standard dimensions of spirituality to be investigated. Without common definitional parameters, researchers have been challenged to use common measures that could be tested and named as gold standard. As a result, a variety of measures are used, limiting comparison and systematic growth of the evidence base. Furthermore, we have not had a systematic accounting of the body of evidence linking spirituality, as currently measured, with health care outcomes. Important reviews of the larger literature on spirituality and health exist,<sup>3–5</sup> yet have not been extended into palliative care. Such a review in palliative care would identify gaps in evidence and recommendations for new research that would strengthen an empirically based understanding of the role of spirituality in palliative care. The purpose of this article is to review the current state of the literature with regard to three questions: 1) What is spirituality?, 2) What are the key measurement and methodologic issues in spirituality research?, and 3) What is the evidence regarding the relationship of spirituality and key outcomes in palliative care? After describing central issues in each area, we offer recommendations to guide future work (Table 3).

## What Is Spirituality?

### *Definitions, Operationalization, and Taxonomy*

To measure, screen, or intervene on a phenomenon, one must have a clear operational definition of the construct. Moreover, to understand the complexity and nuanced relationships within and between dimensions of that construct, a taxonomy is required.

Reviews within the spirituality and palliative care literature have identified challenges to and a lack of consistency in 1) operational definitions, 2) identification of dimensions that constitute the construct of spirituality, and 3) specification of the relationships between those dimensions and outcomes of interest.<sup>6–11</sup> In the palliative care literature, spirituality often is operationalized with a single item that

serves overarching reference to dimensions of spirituality as diverse spiritual or religious beliefs, rituals and practices, coping, distress, relationship with the transcendent, sense of meaning, or life purpose. The lack of definition and taxonomy inhibits clear study design, increases potential for confounding constructs, and impedes independent investigations from systematically informing one another.

*Evolving Definitions.* *Religion* has Latin derivations from words referring to that which “binds together,” inferring connections to deity, other persons, or one’s beliefs and values. Although the term *religion* in the past (and in present theological scholarship) has been used to capture *both* institutional and individual dimensions of experience, contemporary references to religion increasingly imply institutional, social, doctrinal, and denominational characteristics of experience.<sup>12,13</sup> For example, “An organized system of beliefs, practices, and symbols designed to facilitate closeness to the transcendent or the Divine and foster an understanding of one’s relationship and responsibilities with others living in community.”<sup>6</sup>

*Spirituality*, historically, was considered a process that unfolds within a religious context with established institutions designed to facilitate spirituality.<sup>14</sup> Only recently has spirituality been separated from religion as a distinct construct. This trend is rooted in movement away from the authority of religious institutions in modern social life, together with a growing emphasis on individualism, particularly within Western cultures. These combined social forces have fostered beliefs and practices that are less tethered to traditional, communal practices, and belief systems and more linked to individual experience and expression.<sup>5,15</sup> As a result, the terms religion and spirituality now are more frequently seen as referring to separate phenomena. Data of U.S. populations demonstrate a majority is both spiritual and religious, thus for many religion and spirituality are overlapping constructs.<sup>16</sup>

Over time, definitions of spirituality have expanded from language solely referring to a deity or higher power to language more broadly encompassing the search for the “significant,” “sacred,” or that which holds ultimate meaning or purpose (e.g., relationships with others, the transcendent, nature, or the self).<sup>17</sup> This evolution has been described as moving from underlying constructs that are *theistic* (belief in a supreme being) to *religious* (including shared customs and practices) through *phenomenological* (based on lessons learned from life experience) and *existential* (the search for meaning and purpose) to the *mystical* (relationship between the transcendent, interpersonal, and transpersonal).<sup>17</sup> Spirituality is most often viewed, colloquially, as something that is experienced within or outside formal institutional settings and

traditions and often includes the assumption that there is more to life than what can be grasped empirically or fully understood. It evokes concerns, compassion, and a sense of connectedness to something greater beyond ourselves.<sup>18,19</sup>

*Moving Toward Consensus.* Building on this evolution, the most notable efforts to gain consensus on a definition of spirituality in palliative care were advanced by both U.S. and international committees and delineate spirituality as a search for meaning and purpose, which may or may not include reference to the divine. Both offer useful foundational language describing spirituality, including acknowledgment of its multidimensionality and diversity of expression.

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.

U.S. Consensus Committee (2009)<sup>20</sup>

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.

International Consensus Conference (2012)<sup>21</sup>

*Operationalizing Spirituality.* Spirituality, like other constructs is not a single “thing” but rather is a latent construct made up of multiple distinct dimensions that contribute to the whole. The field has been challenged by this fallacy of monism (that spirituality is one thing) when the goal is to identify, theoretically and empirically, the essential components of spirituality. Furthermore, scholars warn against reducing spirituality to merely one aspect of human experience but rather suggest conceptualized as a holism that infuses all aspects of being human.<sup>22</sup> These challenges must be examined empirically.

*Definitions in Context.* Conceptual clarity in part results from the mixed and sometimes competing goals of defining spirituality for clinical and research contexts. In a clinical setting, the goal is to honor individuality, promote conversations, capture the breadth of experience of spirituality, and emphasize similarities rather than distinctions.<sup>6,23</sup> In clinical care, constructs may overlap with other constructs; for example, spiritual and emotional concerns are often related, and conversation of one elicits expression of another. However, language that is useful in clinical settings

may have less applicability in research settings where discriminative abilities of measurement are necessary.<sup>6,9</sup> In a research context, operational definitions must be unambiguous, and constructs must be distinct and unique.<sup>6,9</sup>

Hence, recommendations regarding definitions (Table 3) include that research within spirituality and palliative care should be based on a clearly conceptualized definition of spirituality fitting to the research question and context. Additionally, the specific dimensions of spirituality under investigation should be articulated, operationalized, and matched with appropriate measures.

### *What Is Unique About Spirituality?*

The primary objective of research in spirituality and palliative care is not to measure the ineffable or determine the existence of a realm that is beyond empirical investigation. Rather, the role of research in this domain is to develop measures, observations, and understandings of human experience of the spiritual, as distinct from and relating to other determinants of human well-being. Therefore, research in this area should seek to explore whether there is something unique about spiritual experience as well as the nature of its relationship to emotional, psychological, and social experience. Key questions include: Are topics such as meaning and peace, or the human virtues of forgiveness, and gratitude primarily spiritual or do they refer to positive mental states? Is the support patients and families receive from spiritual communities equal to other forms of social support, or does it have unique qualities? And, while in a Western context spirituality often may be operationalized as an aspect of individual experience, inquiry into the fullness of this domain offers compelling opportunities to examine the ways well-being, treatment, and decision making are experienced within and influenced by community and social relationships.

Finding language for this aspect of human experience is a persistent challenge. Some scholarship refers to this core attribute of spirituality as *the sacred* that refers, “not only to God, a higher power, or the divine, but also to aspects of life that take on spiritual character and significance.”<sup>24</sup> Common qualities of the sacred from this perspective include “transcendence,” “boundlessness,” “ultimacy,” and “deep connectedness.” Investigations in this area have examined how people (religious and nonreligious) attribute sacred qualities to many aspects of life, including nature, time, relationships, strivings, and virtues. For some, the term *sacred* resonates as a means to express these aspects of life that are set apart from the ordinary; and for others the terminology of *sacred* is intertwined with theistic notions of spirituality that foster noninclusiveness. Hence, there is no consensus on the

optimal language that harkens to that which makes spirituality unique, thus refining both conceptualization and its lexicon remains a critical necessity.

### **How Should Spirituality Research Approach Measurement and Methods?**

After considering definitional clarity, researchers must use rigorous practices for choosing measures to properly capture, model, and test hypotheses about the role of spirituality in palliative care. Several important reviews exist to guide researchers.<sup>6,9</sup> Koenig's *Spirituality and Health Research* (2011)<sup>6</sup> provides a comprehensive review of measures and salient issues within spirituality and health research. Within palliative care, Selman et al.<sup>9</sup> offer a comprehensive review of measures that include spiritual items and their related dimensions and recommendations for measurement use and development. The review draws attention to key limitations of measures including the lack of population diversity in tool development and testing (e.g., significant sample bias using primarily Western, Christian populations). Supplementing spirituality measurement reviews, the work of Higginson et al.<sup>25</sup> offers best practices for health outcomes and palliative care generally and spirituality in particular. Key points are included in the following summary.

- 1) Identify the purpose of the investigation and establish whether the goal is to conduct a *clinical assessment* (e.g., screening), *research* (e.g., focused on observational description or comparison), *quality improvement* (e.g., to refine a clinical process), or *accountability* (e.g., tracking patient satisfaction for organizational accountability).
- 2) Specify a conceptual model: Research should identify, *a priori*, the particular dimensions of interest, the specific measures suitable to assess those dimensions, and the hypothesized relationships between chosen dimensions and proposed outcomes. Additionally, moderators and mediators of those relationships and potential mechanisms linking dimensions to outcomes should be specified.

In developing a conceptual model, palliative care researchers may acquaint themselves with the extensive developments that have been occurring in the social scientific study of religion. These include major theoretical advances integrating spirituality into attachment theory, meaning-making theory, coping theory, and self-regulation theory, as a few examples.<sup>14</sup> Research from these theoretical perspectives has yielded important results and those findings

could and should be extended to the palliative care realm.

- 3) Identify the specific dimensions to be assessed, based on the conceptual model. Although often not all potentially relevant dimensions can be assessed due to time constraints in research, particularly in palliative care populations, assessment of the most salient dimensions should be used. Although there is no gold standard set of dimensions and corresponding measures, the reviews above guide readers toward best evidence to date. Outside palliative care, panels have been convened to identify key dimensions of spirituality by the National Institute for Healthcare Research in 1997 and the National Institute of Aging and the Fetzer Institute in 1999 (Table 1).<sup>26</sup> Dimensions were operationalized in the Multi-dimensional Measurement of Religion and Spirituality with scales for each of the identified dimensions (Table 1) and the widely used 38-item Brief Multidimensional Measure of Religiousness/Spirituality. The Multidimensional Measurement of Religion and Spirituality was not developed specifically for palliative care and, thus, requires modifications to include issues salient during life-limiting illness.<sup>9</sup>

Within palliative care, several literature reviews, both theoretical<sup>27</sup> but most often relying on inductive approaches, have sought to identify primary dimensions of spirituality specific to the context of serious illness (Table 1).<sup>11,28,29</sup> For example, Stephenson and Berry<sup>11</sup> identified five commonly defined attributes of spirituality noted in studies of spirituality and palliative care: meaning, beliefs, connecting, self-transcendence, and value. These findings overlap with other reviews that include interpersonal, transpersonal, and transcendent aspects of spirituality.<sup>28,29</sup>

A second approach to identify dimensions of spirituality has been through reviews of extant spirituality measures within palliative care (Table 1).<sup>9,30</sup> For example, Selman et al. conducted a systematic review of 85 tools to identify those which met criteria of 1) psychometric validity, and 2) population diversity, in development or testing. In addition to assessing the rigor of tools meeting these criteria, the authors identified dimensions of spirituality queried by the instruments. Monod et al.<sup>30</sup> in their systematic review likewise derived a classification of spiritual dimensions based on extant measures. Notably, the authors do not claim the identified dimensions to be comprehensive or most salient but rather that they represent the current state of measurement.

Previous work notwithstanding, there remains a lack of clarity regarding what dimensions should be



Table 1  
Empirically-Derived Dimensions of Religion and Spirituality in Serious Illness

	Alcorn et al. <sup>29</sup>	Stephenson and Berry <sup>11</sup>	Vachon et al. <sup>31</sup>	Monod et al. <sup>30</sup>	Selman et al. <sup>9</sup>
Fetzer/NIA Multidimensional Measurement of Religiousness and Spirituality <sup>26</sup>	<ul style="list-style-type: none"> <li>- Beliefs</li> <li>- Communities</li> <li>- Coping</li> <li>- Practices</li> <li>- Spiritual transformation</li> </ul>	<ul style="list-style-type: none"> <li>- Beliefs</li> <li>- Connection</li> <li>- Meaning</li> <li>- Self-transcendence</li> <li>- Value</li> </ul>	<ul style="list-style-type: none"> <li>- Attitude toward death</li> <li>- Beliefs and faith</li> <li>- Hope</li> <li>- Meaning and purpose</li> <li>- Self-transcendence or transcendence with a higher being</li> </ul>	<ul style="list-style-type: none"> <li>- General spirituality</li> <li>- Spiritual well-being</li> <li>- Spiritual needs</li> <li>- Spiritual coping</li> </ul>	<ul style="list-style-type: none"> <li>- Beliefs (e.g., practices and experiences)</li> <li>- Indicators of spiritual well-being (e.g., peace)</li> <li>- Outlook on illness</li> <li>- Outlook on life</li> <li>- Relationships (to others, to God)</li> <li>- Spiritual resources (meaning and purpose)</li> </ul>
	<ul style="list-style-type: none"> <li>- Organizational religiousness</li> <li>- Private religious practices</li> <li>- Religious preference</li> <li>- Religious support</li> <li>- Religious/Spiritual Coping</li> <li>- Religious/spiritual history</li> <li>- Values</li> </ul>				

included in spirituality and palliative care research. Based on our review, we have offered preliminary core dimensions of spirituality within palliative care (Table 2) investigators may wish to consider.

- 4) Select relevant measures of those dimensions: As noted, existing practice in measurement often relies on single or a few items describing one dimension, such as spiritual well-being or peace, and often does not adequately capture even that single dimension of spiritual experience. Few measures have been evaluated for responsiveness to change, predictive validity, or discriminative value.<sup>7,9</sup> Furthermore, most measures have not been developed within culturally diverse settings and, hence, may lack identification of key dimensions of spirituality that may be deeply embedded within certain cultural groups.<sup>7,9</sup> Foundational observational work on spirituality in palliative care is limited and offers a significant opportunity for advancement of the field.<sup>11,28,31</sup> Based on these current limitations in measurement, the following principles should be applied when choosing a measure from another setting to be applied to palliative care: (1) establish the instrument's reliability and validity in a palliative care population, (2) test the tool in diverse cultural contexts, (3) determine its applicability across specific care settings, (4) establish its responsiveness to change over time, (5) ascertain whether the tool captures clinically meaningful data (this is most relevant in QI and audit contexts), and (6) ensure it is easy to administer to the particular patient population.<sup>7,9,32</sup>

These principles also should be applied to new tool development and should be augmented by the charge to create tools in collaboration with patients, families, and interdisciplinary and spiritual care provider colleagues. Interdisciplinary collaboration, such as among psychometricians, spiritual care providers, medicine and nursing clinicians, patient-family representatives, and social workers, would improve the likelihood that tool content is relevant to patient and family needs, is actionable by providers, and includes aspects unique to spirituality that may not be easily amenable to measurement.

- 5) Consider potential confounding constructs: In spirituality research, there is often evidence of confounding relationships between independent variables and dependent outcomes. This is usually the result of a lack of clarity about the content and construct validity of many existing measures.<sup>6</sup> For example, many items assessing spirituality are evaluating constructs, such as outlook, meaning, or

Table 2  
Preliminary Set of Core Dimensions of Religion and Spirituality in Palliative Care

Core Dimensions of Spirituality in Palliative Care	Description of Dimension
Importance of spirituality and religiousness	Overall importance and extent to which spirituality and religion are central features of patient's daily life experience, values, and approach to illness
Religious affiliation Religious/spiritual coping, positive or negative	Religious tradition/community affiliation and extent of participation Religious/spiritual coping with the stress of illness, including positive (e.g., partnering with God in illness) and negative (e.g., illness is God's punishment, spirituality caused crisis) reappraisals
Spiritual experiences, positive (resources), or negative (needs)	Sense of deep connection, peace, meaning, purpose, forgiveness, love (resources), or lack thereof (needs)
Religious/spiritual values and beliefs related to illness	Religious or spiritual framework for understanding illness experience, such as beliefs about life sustaining technologies, miracles, role of physicians in healing (e.g., God's instrument)
Religious/spiritual practices	Personal and corporate religious/spiritual rituals and other practices (e.g., meditation, reading of sacred texts, prayer, contemplative exercises)

purpose, that overlap with positive mental states. If a study is modeling the effect of spirituality operationalized by such positive mental states on outcomes, such as anxiety or depression, findings will be confounded as similar constructs are necessarily correlated with one another.<sup>6</sup> Attention to confounding variables is particularly relevant to studies attempting to model causal relationships and is of less concern in other settings, such as studies focused on screening and quality improvement.<sup>9</sup> Further work is needed that includes measurement of multiple dimensions of spirituality concurrent with potentially overlapping psychosocial dimensions to determine the similarities and distinctions between psychosocial and spiritual states (Table 3).

### What Is the Relationship of Spirituality to Health Outcomes and Outcome Disparities?

Having reviewed the key definitional and methodologic considerations in spirituality and palliative care research, we next review the evidence base investigating the relationship between spirituality and palliative care outcomes, with specific attention to disparities. Reviewing the outcomes landscape aids in framing future research endeavors, such as those aiming to better define the relationships of spiritual dimensions to outcomes and to guide interventions. Although not exhaustive, this summary describes foundational work while also naming key research gaps that inform research priorities in this area of inquiry.

#### Patient Spiritual Dimensions and Outcomes

A large body of research in spirituality and palliative care examines the relationship between dimensions of patient spiritual experience and patient-centered outcomes, including QOL and physical health outcomes, medical care at the end of life, and end-of-life care

disparities. Figure 1 provides a visual display of the dimensions of spirituality found in the evidence base, the nature of study design, and the direction of the relationships between those dimensions and health outcomes.

**Quality of Life Outcomes.** In the setting of serious illness, numerous studies demonstrate positive associations between measures of patient spirituality and QOL and its varied subdomains.<sup>33–45</sup> Studies examining spirituality and QOL, although consistently showing positive associations (Fig. 1), are largely cross-sectional and include varied measures of spirituality. Studies have used single-item measures of patient spirituality<sup>36</sup> and validated, multidimensional scales, such as the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being<sup>33,38,40–42</sup> and the Spiritual Well Being Scale.<sup>35,39</sup> Although characterized by similar methodologic limitations, associations have also been observed between spirituality and psychological aspects of quality life and mental health outcomes, such as depression,<sup>39–41</sup> anxiety,<sup>39</sup> and hopelessness.<sup>38</sup> A small number of studies suggests a positive relationship between spirituality and physical health<sup>43,46</sup> and social well-being.<sup>44</sup>

In contrast, research to date has not shown a positive relationship between quality of life and patient-reported religiousness or other religious dimensions, such as religious coping.<sup>33,40,47,48</sup> Furthermore, in the setting of serious illness, religiousness has not been associated with patient survival.<sup>46,49</sup> However, in a prospective study examining two-year mortality among medically-ill elderly patients, religious struggle was associated with an increased risk of mortality.<sup>50</sup> Positive religious coping, assessed with Pargament's validated RCOPE,<sup>51</sup> one of the more frequently investigated dimensions, has, in general, not been a significant correlate of QOL.<sup>47,48,52,53</sup> Conversely, negative religious coping has consistently demonstrated association with decrements in patient QOL.<sup>47,48,52,53</sup>

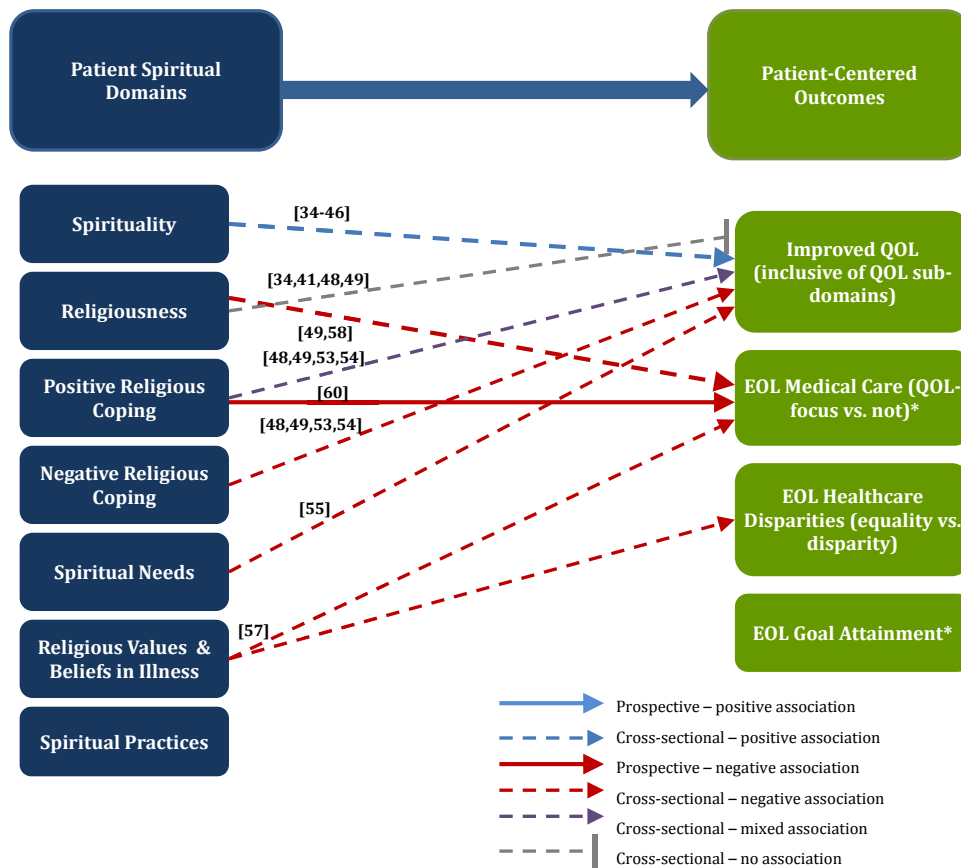


Fig. 1. Patient spiritual domains and their relationship to patient-centered health care outcomes. “\*,” Quality-of-life focused end-of-life medical care, for example, receipt of hospice care and lack of heroic, aggressive measures at the end of life, for example, resuscitation, ventilation, and death in an intensive care unit. Notably, this does not, however, take into account patient goals of end-of-life care, also a key, inter-related outcome for patients. EOL = end of life; QOL = quality of life.

Similarly, greater religious and spiritual needs are associated with poorer patient psychological QOL.<sup>54</sup> One prospective study examining the influence of religious values and beliefs (such as the religious belief that one’s illness is under divine control)<sup>29</sup> on anxiety/depression within illness revealed no significant relationship.<sup>55</sup>

In general, these data suggest a positive relationship between spiritual dimensions, such as self-identified spirituality and QOL outcomes. However, there are important methodologic limitations that must be addressed to strengthen the evidence base. The variety of measures used challenges common comparisons among studies, and the use of single or few items means spirituality is rarely assessed in a multidimensional manner. Cross-sectional designs leave questions of causality and the directionality of relationships unclear. For example, we do not know whether spirituality leads to improved quality of life or if poorer quality of life results in a diminished experience of spirituality. Or, if both processes are operating, they could diffuse effects and lead to nonsignificant findings. Furthermore, this

research often is plagued by the potential for confounding of spiritual predictor domains and QOL outcomes. Without multiple assessments of spiritual and religious predictors over time, and their relationships to QOL outcomes, it is impossible to disentangle changes in spiritual/religious dimensions longitudinally and evaluate whether observed differences are the result of developmental processes or cohort differences in spirituality.

*Health Care Outcomes and Health Care Disparities.* Another small group of studies examines spiritual dimensions and their relationships with types of health care received at the end of life and can be parsed into those 1) factors preceding end-of-life care (e.g., end-of-life treatment preferences<sup>48,56,57</sup> and advance care planning),<sup>57</sup> and 2) end-of-life care received by patients (e.g., hospice care, intensive care unit days).<sup>58</sup> In examining correlates of treatment preferences, studies have shown that religious factors, including religiousness<sup>48,57</sup> and religious beliefs about EOL care,<sup>56</sup> are associated with preferences for more

aggressive medical interventions at the EOL. To our knowledge, only one study, *Coping with Cancer 1*, addresses the relationship of patient religious dimensions and actual medical care received at the EOL<sup>59</sup>; this multisite prospective cohort study of advanced cancer patients found that patients exhibiting high positive religious coping at baseline were more likely to receive aggressive interventions in the last week of life (e.g., care in an intensive care unit, resuscitation) even after controlling for confounding factors including race and other coping characteristics. Notably, no studies to date evaluate the relationship between spiritual or religious factors and patient goal attainment in medical care (e.g., dying in the patient's preferred setting).

A small but growing number of studies examine the role religious factors may play in influencing differences in EOL outcomes. For example, the largest racial/ethnic minority groups in the U.S., African-American and Latino patients, are typically more religious<sup>48,60</sup> and receive more aggressive EOL interventions than white patients.<sup>61</sup> Studies examining the relationship of race/ethnicity and medical decision making in the U.S. suggest that African-American and Latino patients have greater endorsement of religious beliefs about medical care<sup>56,57</sup> and religious coping.<sup>57</sup> Both religious beliefs and religious coping are associated with greater preference for and receipt of aggressive EOL interventions<sup>56,57</sup> and lower rates of advanced care planning,<sup>57</sup> after adjustment for potential confounding factors, such as trust, in the health care system. To our knowledge, no studies to date provide prospective data relating race/ethnicity, these religious dimensions, and EOL care received. Conceptually, studies in this area wrestle with identifying whether differences in outcomes, as described earlier, represent distinct preference vs. disparities spawned by inequitable care.

Studies examining spiritual and religious predictor domains and their relationships to EOL outcomes and outcome disparities are few; findings thus far offer preliminary sketches of these relationships specific to U.S. patient populations. Greater research is required, in particular, focusing on how spiritual and religious factors may influence decision-making and treatment outcomes, including outcome disparities in a variety of religiocultural settings. Furthermore, within studies examining EOL disparities, it is important to simultaneously assess key variables that may be associated with religious dimensions and medical decision making, such as socioeconomic factors and trust in the health care system.

*Family Spiritual Dimension and Outcomes.* Few studies in palliative care explore the relationship of family caregiver spiritual dimensions and outcomes

(Fig. 2), with extant data suggesting a similar relationship to QOL outcomes as those seen for patients.<sup>62,63</sup> One cross-sectional study of 1229 family caregivers of patients with dementia (the Resources for Enhancing Alzheimer's Caregiver Health [REACH] study<sup>62</sup>) demonstrated that the majority of caregivers consider faith/spirituality to be important to them. Additionally, the study found that importance of faith, spiritual practices (e.g., prayer/meditation), and attendance of religious services were, in adjusted analyses, each associated with reduced depressive symptoms and less complicated grief. Another cross-sectional study of family caregivers of cancer patients in India found greater post-traumatic growth among those caregivers exhibiting higher religious coping.<sup>63</sup> An additional cross-sectional study found that caregivers of advanced cancer patients reporting spiritual pain have greater anxiety, depression, and worse QOL.<sup>64</sup>

This small body of research suggests the importance of family caregiver spiritual dimensions as contributors to QOL outcomes, although data are limited by cross-sectional designs with inconsistent control for confounding factors. To date, we found no studies addressing the role of caregiver's spirituality in medical decision making (e.g., when acting as a surrogate decision maker).

*Health Care Teams, Faith Communities, and Outcomes.* Only a few studies examine the impact of spiritual care provision (e.g., chaplains, medical teams, faith communities) on patient/family outcomes. The *Coping With Cancer* study prospectively assessed the roles of psychosocial and spiritual factors on EOL outcomes in patients with advanced cancers. Patients reporting high support of their spiritual needs from the medical team (e.g., doctors, nurses, chaplains) at baseline were found to have better QOL at the EOL. Patients reporting high support of their spiritual needs were also found to receive greater hospice care and less aggressive interventions at the EOL (e.g., resuscitation, ventilation).<sup>58</sup> In a cross-sectional study of patient-reported receipt of spiritual care by their medical teams, patients with unmet spiritual needs reported lower ratings of quality of care and satisfaction with care.<sup>65</sup> Furthermore, a survey-based study of family members of patients dying after an ICU admission showed greater care satisfaction when families received greater spiritual care from chaplains during the ICU stay.<sup>66</sup>

A small number of studies have explored the factors that mediate the relationship between provision of spiritual care and patient/family outcomes. One cross-sectional study of 339 oncology nurses and physicians reported types of spiritual care provided by clinicians,<sup>67</sup> barriers to providing spiritual care,<sup>68</sup> and



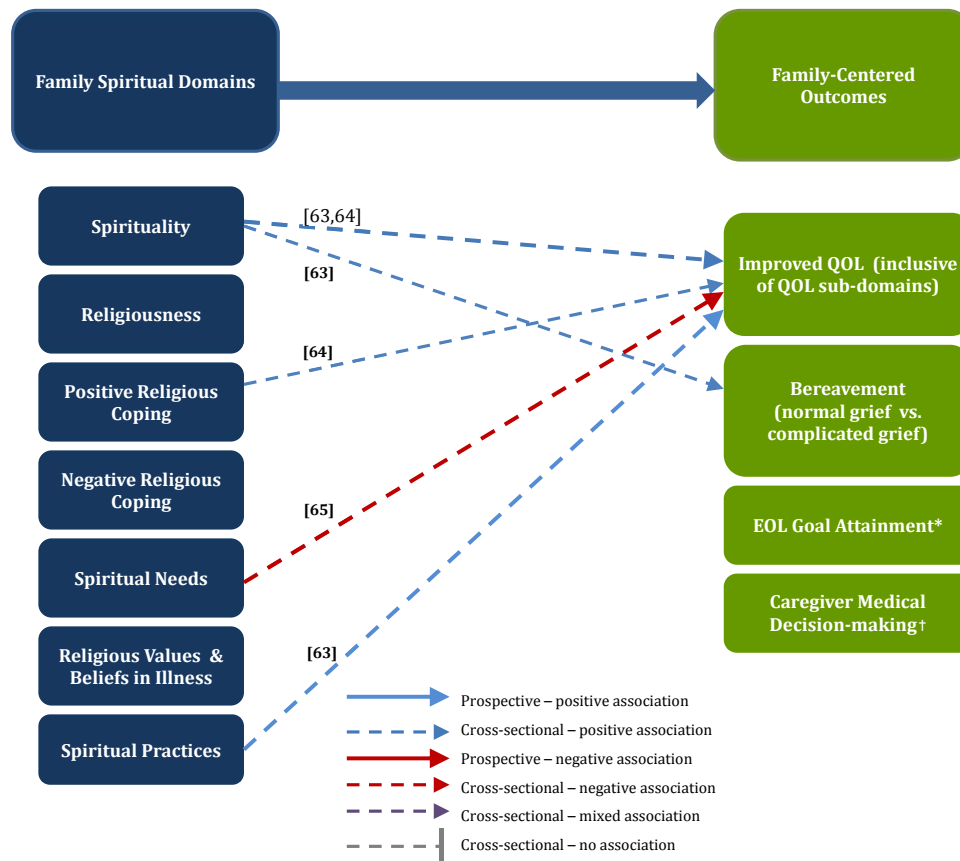


Fig. 2. Family spiritual domains and their relationships to family-centered outcomes. “\*,” Goal attainment in care received at the end of life, for example, place of death commensurate with family wishes. “†,” Medical care decision making as it involved the family caregiver, for example, when acting as a health care proxy or in preferences influencing on the patient. EOL = end of life; QOL = quality of life.

found that training was the strongest predictor of spiritual care provision by clinicians.<sup>69</sup> Other factors, such as having an integrated structure for spiritual care (multidisciplinary teams inclusive of chaplaincy), may also influence spiritual care delivery, although empirical investigation is required to explore these relationships.

Faith communities frequently play a role in providing spiritual care to patients and families,<sup>70</sup> yet data to assess their influence on patient outcomes at EOL are limited. In the Coping with Cancer study, patients reporting high spiritual support from religious communities at baseline went on to receive less hospice care and greater aggressive interventions at the EOL, particularly for African American and Latino patients.<sup>70</sup> Although high religious community spiritual support was associated with baseline patient-reported QOL, it was not significantly associated with patient QOL near death.

Limited prospective data suggest that spiritual care influences patient outcomes, including QOL and medical decision making. The source and content of spiritual care provided (e.g., spiritual care from health care teams vs. from religious communities) appears to

influence outcomes in potentially contrasting ways. The body of research informing these relationships is too limited to render definitive conclusions but suggests potentially important distinctions in impact based on the characteristics of spiritual care provided. Further data are required.

#### Research Priorities in Spirituality, Outcomes and Outcome Disparities Research

These studies suggest an association between spirituality and QOL (for patients and family caregivers), and patient medical decision making and care, with a potential role in disparities in EOL medical care for certain racial/ethnic groups. They also suggest spiritual care influences patient QOL, informs medical decision making and care at the EOL, and promotes culturally and spiritually sensitive care, particularly for groups in which spirituality plays a prominent role. Data describing relationships between spiritual domains and patient survival are too limited to draw conclusions, although further study of the impact of spiritual peace and struggle on physical health outcomes in the setting of serious illness, including elucidating mechanisms, is required.

The evidence base has notable limitations. Studies are largely cross-sectional, frequently have small sample sizes, often lack hypothesis-driven conceptualization of the spiritual predictor domains and their relationships to the outcome(s) of interest, frequently lack multidimensional measurement of spiritual domains with inconsistent use of validated measures, have inconsistent control for confounding factors, and are largely conducted in the setting of advanced cancers, within U.S. patient populations. Furthermore, available research often examines a single time point and, hence, does not evaluate how spiritual dimensions, dynamically, impact outcomes over time. Accordingly, we offer priorities for spirituality and palliative care outcomes research (Table 3).

## Conclusion

In summary, the state of the science in spirituality in palliative care points to notable relationships between spiritual domains and palliative care patient and family outcomes, albeit with many limitations to the findings because of critical gaps in areas of inquiry and methodologic issues hampering clarity of interpretation. As outlined in the summary in Table 3, using definitional and methodologic rigor, the field of palliative care can address these key gaps and further the understanding of how spirituality, in its diverse domains and religiocultural expressions and forms, relates to palliative care outcomes. An additional critical next step is the application of the understanding of these relationships within the care of seriously

Table 3

### Research Priorities in Spirituality and Palliative Care—Definitions, Approach to Measurement, Outcomes Research, and Health Disparities

Domain	Recommendations
Definitions and Taxonomy	<ul style="list-style-type: none"> <li>- Definitions should be clearly stated within the research design, including spirituality, religion, and related terms (e.g., spiritual care or spiritual needs).</li> <li>- Definition of spirituality should be chosen based on the application (clinical vs. research).               <ul style="list-style-type: none"> <li>• In a clinical setting, define spirituality broadly and inclusively.</li> <li>• In a research context, articulate the specific definition of spirituality, and its dimensions, to be operationalized, measured, and tested in the study of interest.</li> </ul> </li> <li>- Within spirituality research, include efforts to capture what is unique to spirituality, such as ultimate meaning/purpose, “the sacred, or significant” or other core attributes of spirituality, and how they relate to psychosocial domains of human experience.</li> <li>- Examine core attributes of spirituality in diverse populations, including in various traditional religious, non-religious groups, secular humanists, different cultures, etc.</li> </ul>
Approach to Measurement and Methods	<ul style="list-style-type: none"> <li>- Clarify the purpose of the measurement (e.g., assessment, quality improvement, observation, intervention).</li> <li>- Employ clear and explicitly stated conceptual models, grounded in the extant literature, with specification within the conceptual model of the specific relationships linking dimensions of spirituality to the outcome(s) of interest.</li> <li>- Match tools to the identified dimensions.               <ul style="list-style-type: none"> <li>• With existing non-palliative care validated tools, assess the identified dimensions of interest and modify and test in palliative care populations.</li> <li>• When using tools within the palliative care literature, examine psychometric properties of reliability and validity, the population diversity in which the tool was developed and tested, and measures of sensitivity to change.</li> <li>• When developing new tools, create and validate within culturally, religiously, and spiritually diverse populations of patients and families.</li> <li>• Develop tools with interdisciplinary colleagues, collaborating with chaplaincy to identify the most clinically salient and actionable dimensions.</li> </ul> </li> <li>- Check for confounding in modeling, to evaluate the potential overlap of spiritual, psychological, and emotional well-being, particularly in observational studies in which dimensions of spirituality serve as outcomes.</li> <li>- Apply the above aforementioned processes within diverse disease, cultural, and religious settings both within the study of patients and their families.</li> </ul>
Outcomes Research and Health Care Disparities	<ul style="list-style-type: none"> <li>- Conduct hypothesis-driven, prospective outcomes research based on a priori conceptual models of spiritual dimensions and their longitudinal relationships with key palliative care outcomes, use validated measures of predictors and outcomes, and includes rigorous assessment of potential confounding variables.</li> <li>- Conduct studies in a diversity of patient populations and settings (e.g., disease type, race/ethnicity, geography).</li> <li>- Use longitudinal research designs that characterize the dynamic nature of spiritual variables in their relationship to outcomes.</li> <li>- Give attention to the following particular lines of research for future investigation:               <ul style="list-style-type: none"> <li>• Patient/family spiritual factors (e.g., religious beliefs/values) and their relationship to patient and family EOL health care decision making, outcomes (including goal attainment), and disparities;</li> <li>• Mechanisms of the relationships of spiritual factors (e.g., spirituality, coping, spiritual needs) to patient and caregiver quality of life;</li> <li>• Health care team spiritual care provision (including elements of spiritual care and spiritual care providers) and its relationship to patient/family palliative care outcomes (e.g., quality of life, bereavement, EOL medical decision making and care).</li> </ul> </li> </ul>

ill patients, including in spiritual screening and assessment and spiritual care interventions and clinician education, addressed in Part II of this state of the science summary.

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