

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’.¹—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.”²

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,^{3–5} 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.^{6–11} 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.^{12,13} 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.”⁶

Spirituality, historically, was considered a process that unfolds within a religious context with established institutions designed to facilitate spirituality.¹⁴ 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.^{5,15} 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.¹⁶

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).¹⁷ 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).¹⁷ Spirituality is most often viewed, colloquially, as something that is experienced within or outside formal institutional settings and

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