

Article

History, Culture and Traditions: The Silent Spaces in the Study of Spirituality at the End of Life

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Abstract: Recent increase in the number of studies on spirituality manifests growing recognition of the importance of spirituality, as well as mounting interest in studying spirituality in healthcare. Most studies on spirituality in end of life care focus on identifying specific features of spirituality and often represent an individualistic understanding of spirituality. They seldom engage in a historical–cultural exploration of the contextual meanings of those features of spirituality. This paper aims to demonstrate the absence of contextual factors in studying spirituality at the end of life and to highlight the growing recognition of the importance of history, culture and traditions as resources to enrich our understanding of spirituality. An exploration of the concept of spirituality, an overview of the trajectory of the study of spirituality and a review of existing methodological stances reveal the silent space in current approaches to understanding spirituality at the end of life. Recognition of the importance of these contextual factors in understanding spirituality is growing, which is yet to influence the conceptualization and the conduct of spirituality research. Contextual understandings of spirituality that incorporate insights from the history, culture and traditions of specific contexts can inform effective means for providing spiritual support in clinical practice.

Keywords: spirituality; history; culture; tradition; end of life

1. Introduction

The study of spirituality has been gathering momentum in the past few decades. Growing numbers of studies and publications on the subject indicate the increasing recognition of the importance of spirituality in various aspects of life and research interest is being generated in several academic disciplines. Medicine and healthcare is one particular field where the study of spirituality has taken hold and gained support. Here researchers have employed several approaches to understanding the notion of spirituality in people with particular health conditions and how spiritual care may be provided to them. The interest in spirituality in healthcare is often seen as resulting from concepts such as “whole person care” and “person centered care”, which have become prominent themes in contemporary healthcare discourse. Among the healthcare disciplines, palliative and end of life care have been particularly active in developing research on spirituality and spiritual care, and this is the special focus of this paper.

This article reviews the trajectory of the study of spirituality in the field of end of life care focusing on the existing approaches to understanding spirituality. An analysis of methodological issues in the field demonstrates the limitations of current approaches to articulate the multifaceted and complex nature of spirituality. Furthermore, the review illustrates the emerging recognition of the importance of culture, history and traditions in the understanding of spirituality in the study of spirituality.

2. Spirituality at the End of Life: The Gap between the Concept and Research

It is well established that patients with advanced and life limiting illnesses often experience spiritual distress and existential despair along with the physical suffering caused by the illness [1]. Several studies among palliative care patients and healthcare professionals involved in the care of the dying have demonstrated the significance of spirituality for patients facing death [2–6]. The philosophy of palliative care recognises the criticality of spirituality at the end-of-life and includes it as part of the suffering. A multidisciplinary approach is often recommended to provide the four aspects of care—physical, psychological, social and spiritual—to address the complex needs of palliative care patients and their families [7]. Although in theory there seems to be broad agreement on the importance of spirituality and spiritual care at the end of life, in practice, a hierarchy of four aspects of care seems to exist, starting from the physical to the spiritual. Spiritual care, therefore, receives the least attention and remains the least developed component of the total care palliative care promises to provide [1,8]. Larkin rightly observes that spiritual care is often “subsumed under the concept of ‘psychosocial care’ and [is] therefore lacking the attention needed to understand and adequately support complex spiritual issues” ([9], p. 336).

The way spirituality is defined offers critical insight into how spirituality is represented in healthcare. Literature on the subject of spirituality in healthcare reveals that defining “spirituality” has been a challenging task. Scholars have found that the notion of spirituality either does not seem to neatly fit into any one definition or it tends to lose significance when broadened to include the wide range of elements it incorporates [10,11]. Despite such differences, defining spirituality is considered important if healthcare professionals are to recognize and appropriately care for patients in this context [12]. Most commonly used definitions describe spirituality as the inner essence of life, a dimension of the whole person, that is integral to and interacts with all other aspects of life, both physical and psychosocial [13–16]. Equally popular is the understanding that spirituality provides meaning and purpose to life and facilitates self-transcendence [2,12,17,18]. Spirituality involves relationship with God, others, nature and oneself [19–21]. A consensus conference proposed the following definition of spirituality, which attempts to bring these various dimensions together:

“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.” ([22], p. 646).

The three main aspects covered in these definitions, namely, the essence of the human person and human life, understanding of meaning and purpose of life and relationships with transformative power, are heavily influenced by historical and cultural factors in particular contexts. Similarly, descriptions of spiritual care often involve “being with” and assisting the person in his/her journey towards spiritual healing as well as facilitating those things or practices that will help the process [23,24]. Spiritual care is about providing a safe space and building a trusting relationship where patients are encouraged to ask deep and disturbing questions and to explore ways of finding meaning in their experiences. Providing spiritual care, therefore, requires immense sensitivity and care. Murray and colleagues [25] argue that attempts to provide spiritual care without adequate attention to patients’ sense of identity and self-worth can indeed cause, rather than alleviate, spiritual distress.

Several models of spirituality have been developed for application in the healthcare context. Haug [26] analyses the various elements of spirituality through which people find meaning and purpose for their lives. Her analysis suggested four dimensions of spirituality, namely: cognitive, affective, behavioural and developmental. The notion of meaning and purpose of life and the various elements of the four dimensions of spirituality, as described by Haug, underline the importance of the context of the person concerned. Wright has developed a model that represents the complex and dynamic relationship between the self, others and cosmos and remarks that it is in these relationships that individuals search and find meanings in their lives [27]. However, such a multidimensional and

complex elements are not always found in studies of spirituality. The key phrases most commonly used in existing studies and models of spirituality are: “spiritual distress”, “spiritual assessment”, “spiritual care”, “spiritual intervention” and “spiritual well-being” [19,28–30]. They all seem to neatly fit a medical model: a condition (spiritual need/pain/distress) that needs assessment and diagnosis (spiritual assessment) followed by treatment (spiritual care/intervention) aimed at a cure/relief (spiritual well-being). Approaching the study of spirituality within a medical paradigm in this way runs the risk of excluding some critical elements concerned with historical, cultural, philosophical and theological factors that are indeed foundational to the notion of spirituality.

It is evident that the recognition of spirituality at the end of life, the attempts to define spirituality and spiritual care and the conceptual models developed to understand the notion of spirituality all indicate the importance of historical and cultural aspects of spirituality. However, such recognition rarely appears in research studies carried out to understand spirituality at the end of life. Most of these remain at the level of identifying and classifying the specific elements of spirituality, to an extent, devoid of their context. For example, in a major review of research literature on spiritual needs at the end of life, Cobb [31] concludes that most studies do not pay attention to the theological and philosophical content and the socio-cultural context of spirituality. Without the theological, philosophical content and socio-cultural context such understandings of spirituality can display a lack of cultural sensitivity and therefore remain limited in their applicability to clinical contexts [32,33].

While conceptual models and frameworks of spirituality are important, therefore; their usefulness relies on the articulation of how the theological, philosophical content relevant to particular socio-cultural contexts gives practical shape to theoretical models. Such articulation requires the use of history, culture and traditions as resources, which otherwise remain the “silent spaces” in the study of spirituality at the end of life.

3. Configuring the Place of Spirituality in End of Life Care

Two distinct approaches can be identified in the understanding of spirituality in healthcare. The first approach acknowledges the spiritual distress patients experience and considers spiritual care as one of the components of care provided for the whole person [34]. It demands a spiritual care plan to be part of the treatment plan for every patient. In the field of end of life care, Cicely Saunders, the founder of the modern hospice movement emphasised this in recognising spiritual pain as a significant part of the suffering patients experience at the end of life, which she conceived as “total pain” [35,36]. In order to address the various aspects of this total pain, palliative care offers the framework of “total care”, which has four components: the physical, psychological, social and spiritual [37]. Thus, in healthcare the need to understand spirituality seems to arise from the necessity to outline the content of “spiritual care”, part of the care package offered to patients in the whole person care approach.

The second approach considers spirituality as being at the core of medical and healthcare practice, not just as constituting one aspect of care. Arguing that illness and death are spiritual events happening to all of us as spiritual beings, Sulmasy calls for a perception of medical practice as a spiritual practice [38]. Such claims are particularly prominent in the specific context of caring for the dying, Hardwig [39] demands the “demedicalization” of death by returning to the old traditions, which have spiritual care at the centre of the care provided. Hardwig proposes that spiritual care should be the core of the caring process, where all other aspects of care contribute to the spiritual wellbeing of the person. Similarly, McGrath [40] argues that a spiritual perspective on death and caring for the dying offers “protection to the formalizing and dehumanizing demands of routinization”. The foundations of these positions are that human beings are spiritual beings; and that death is not just a medical problem, but a spiritual event.

These two approaches to spirituality represent different ways of conceptualizing spirituality in healthcare in general and in end of life care in particular. The first seeks to understand spirituality that assists the formulation of models of spiritual care that contribute to the health and wellbeing

of individuals. The second demands a radical shift in the understanding of healthcare. It seeks an understanding of spirituality that influences the way healthcare and end of life care are understood. The differences these two approaches raise seem to be triggered by the differing views of the culture and history of caring in particular contexts of providing care.

Giving the example of the modern hospice movement, Ann Bradshaw [41] demonstrates the dynamic relationship between spirituality and the historical and culture context of caring for the dying in the UK. Cicely Saunders' work in initiating the modern hospice philosophy was in essence a revival of the traditional Christian attitude to the care of the dying, which historically was at the heart of UK's culture. However, she also recognizes the change in societal and cultural attitudes to religion in Britain which has implications for attitudes of caring for the dying [41]. This change of cultural attitudes to caring represents the dynamic and evolving nature of culture in any given society [42]. The pertinent works of Walter, Kellehear and Williams demonstrate the historical evolution of how societies perceive and respond to death, dying and care for the dying changes over time [43–45].

Historical and cultural understandings of death, caring for the dying and healthcare in general therefore make a critical contribution to the way spirituality is perceived in end of life care. The dynamic nature of the relationship between spirituality and the care of the dying demands sensitivity to the contextual factors that shape the perceptions of the care of the dying in particular contexts. Therefore, the positioning of spirituality in end of life care depends heavily on the historical and cultural context. This adds another set of contextual resources that need to be explored when attempting to study spirituality at the end of life.

4. Methodological Issues in the Study of Spirituality

Although historically and traditionally the study of spirituality has been associated with religion and theology, it has now moved beyond these boundaries [46–48]. As a result, the central focus of the understanding of spirituality is increasingly on the authentic growth of the human person as experienced here and now rather than on the soul and related otherworldly, futuristic expectations. The range of disciplines where the study of spirituality is gathering momentum testifies to this widening scope of the understanding of spirituality. These include psychology, education, business and management studies and social work, to name a few [49–52].

Several scholars have highlighted the historic connectedness between spirituality and healthcare both in the western and eastern traditions [53–55]. The root of this relationship is often located in the understanding of illness as a “spiritual event” that “grasps persons by the soul and by the body and disturbs them both” [38]. Palliative care emphatically acknowledges that serious and terminal illnesses cause much distress to the body, mind and spirit of the person. Therefore, among various other branches of medicine, palliative care remains one of the leading healthcare disciplines heavily involved in research on spirituality [56,57]. These studies have employed a wide range of social science methodologies and tools in their attempt to understand spirituality, including grounded theory, phenomenology, narrative based and other qualitative approaches [58–62]. In addition, others have used quantitative methods in the study of spirituality in healthcare and in end of life care [3,30,63,64].

This variety of approaches has provoked some discussion regarding the appropriateness and usefulness of using empirical research methods to the study of spirituality. Several authors confirm that empirical studies have contributed to the increased awareness and understanding of spiritual issues and have fostered a potentially positive impact on patient care [65,66]. Others have argued that due to the complexity and subjective nature of spirituality, a comprehensive understanding of spirituality may not be possible through empirical methods of study [17]. This apprehension about empirical studies is stronger when considering quantitative studies on spirituality. The proponents of quantitative studies emphasise the contribution quantitative studies make to the understanding of spirituality in terms of demonstrating positive associations between spirituality and health outcomes and quality of life as well as in evaluating the prevalence of various aspects of spirituality. However, critics of such methods have warned against the “naturalistic fallacy” of quantitative studies in spirituality [67,68]. They argue

that the various components of spirituality such as meaning and hope cannot be quantified and that such studies can only produce a fragmented understanding of spirituality.

Departing from studying spirituality through descriptions from informants and correlations of its characteristics, several researchers have turned attention to the mind of the individual as an authentic source. Those who adopt psychological approaches to the understanding of spirituality at the end of life, they locate spirituality deep in the personal space of the human mind. Spirituality, in this approach, is characterised by a universal psychological process in which people show awareness of and respond to the situation of facing their own mortality. Some studies demonstrate clear patterns of transition, which are highlighted as transformative spiritual experiences [69,70]. These studies draw their conclusions from the analysis of conscious as well as subconscious response indicators, including that of dreams, visions and supernatural experiences [71–73].

Different methodological approaches contribute to the growing understanding of spirituality in various ways. However, the move away from theology and religious studies to social science and health studies has had considerable methodological implications for the study of spirituality. As illustrated earlier, most studies rely on interviews, surveys or observations as their sources, which suggest that the data gathered are shaped by what the informants have perceived and are able to articulate. But they often do not provide the rich mix of philosophical, cultural and historical context that provides the framework to understand why and how aspects of spirituality, identified through empirical methodologies, gain their significance and meaning. It seems reasonable to perceive that some of these meanings may remain impossible to articulate, although they are of great value and profoundly meaningful to individuals. While no one discipline or approach to the study of spirituality seems to yield an all-inclusive understanding of spirituality, a cross-disciplinary approach has the potential to offer a critical and practical perspective on the understanding of spirituality. While empirical methods can provide the content of what constitutes spirituality for a given population, historical and cultural approaches, psychological enquiry as well as theological and philosophical explorations can provide critical understandings of how and why the various elements of spirituality gain their significance and meaning in particular contexts. Such comprehensive attempts to understand aspects of spirituality at the end of life can provide insight for creation of contextually meaningful models of spiritual care in end of life care.

5. Recognition of the Importance of History, Culture and Traditions

Although the theological, philosophical and cultural articulation of the understanding of spirituality is lacking in existing studies, an emerging acknowledgement of the significance of contextual factors can be recognised in the study of spirituality at the end of life. An in-depth analysis of cultural traditions are considered having the potential to add great value to the understanding of spirituality and culturally sensitive spiritual care at the end of life [32,33]. Some consider historical traditions as powerful resources for accessing the wisdom of the past for dealing with issues pertaining to the present times. For example, it might be particularly valuable to seek out what different traditions have in common. There is a strong suggestion that rediscovering cultural and spiritual heritage can enrich the experience of life [74]. Historical aspects of particular contexts facilitate engagement of the past with the perceptions and experiences of life in the present. Gardner defines history as:

the relation of the past to present and the lives of others through time, by listening to the voices of individuals talking extensively about the events and experiences through which they have lived ([75], p. 206).

History, therefore, as a continuing influence on shaping the worldview and experiences of communities in the present, remains crucial for understanding spirituality at the end of life.

Similarly, the notion that spirituality is shaped by society and culture has also been highlighted [33]. This signifies the recognition of society and culture in understanding spirituality, although there is often much emphasis on the individualistic and personalised character of spirituality

for each person. There is increasing awareness within healthcare that care must be provided in a culturally sensitive manner. Some argue that care practices for the care of the dying need to be shaped in accordance with the specific cultural frame of the care receiver in order to be meaningful and beneficial [76]. For example, Gunaratnam [77] suggests that careful attention to the social and historical evolution of culture is required in developing culturally sensitive care practices.

The importance of cultural and contextual understanding of spirituality has been expressed in some palliative and end of life care commentary [36,78]. Martsolf [79] argues that spiritual care should base itself on the values, beliefs, norms and customary practices of the community to which the patient belongs. These values and beliefs are often deeply rooted in culture, crystalized and perpetuated across generations and through traditions. In the context of death and dying, the way one experiences death is shaped by historical and cultural meanings of death and caring for the dying [43]. Such an understanding of death and the way individuals and communities relate to death resonate with the following definition of culture:

Culture is a historically transmitted pattern of meaning embodied in symbols. a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and attitudes toward life ([80], p. 89).

The existence of the wide range of cultural and religious plurality demands an awareness of the historical-cultural aspects of life and death in different contexts in order to be able to provide culturally sensitive and meaningful care [81,82]. This creates major challenges for care givers. The lack of such knowledge has been found as a reason for dissonance between care providers and patients and is often described as a barrier to providing spiritual care [83]. In some instances, it has resulted in highlighting the value of understanding contextual meanings and practices towards when making palliative care more adapted to local cultural context [2,84]. The ideation of care often rests on the perception of good death, which is embedded in the particular community's culture [85]. Therefore, conceptualizing a relevant spiritual care should take into account the historical, cultural traditions that shape meanings of life, death and the care of the dying.

Such deep-rooted cultural and historical meanings of "spirituality", "care" and "death" are often preserved and transmitted through tradition. Exploring them is critical to understanding spirituality at the end of life. Antony Giddens' [86] definition of "tradition" clearly articulates how it can be understood to inform deep meanings about the way the present connects to the past:

Tradition is routine. But it is routine which is intrinsically meaningful, rather than merely empty habit for habit's sake . . . The meanings of routine activities lie in the general respect or even reverence intrinsic to tradition and in the connection of tradition with ritual. Ritual often has a compulsive aspect to it, but it is also deeply comforting, for it infuses a given set of practices with a sacramental quality. Tradition, in sum, contributes in basic fashion to ontological security in so far as it sustains trust in the continuity of past, present, and future, and connects such trust to routinised social practices ([86], p. 105).

Emphasising this complex, culturally sensitive nature of spirituality, Swinton and Pattison [87] argue that spirituality is a social construction:

Spirituality is constructed in different ways by various religious traditions, spiritual movements, belief systems, cultures, and contexts, and not least by particular individuals in specific circumstances. All may use the term "spirituality", but each may well be using it in quite different ways ([87], p. 230).

This recognition of the importance of the context within which spirituality takes its meaning and definition, therefore, is a significant contribution to the study of spirituality. In a conceptual analysis of spirituality, Vachon *et al.* [12] identified that faith and beliefs, attitudes towards death and fundamental values of life were the most influential determinants of what defines spirituality at the

end of life. Several scholars have recognised that relationships, belief systems and other social, cultural and religious factors play a significant role in shaping the understanding, experiences and expressions of spirituality [19,20,88].

Cobb [89] suggests that there are four conceptual areas that contribute to the notion of spirituality, namely: theology, philosophy, sociology, and psychology. All these domains take particular contexts as important sources of reflection within their own disciplines. Recognising this, Cobb emphasises that an attempt to understanding spirituality needs to take into consideration the “cultural embeddedness” of spirituality ([89], p. 25). In the particular context of spirituality at the end of life, in addition to spirituality being a contextually rooted notion, several scholars have acknowledged that understandings of and attitudes to death are also deeply rooted in cultural, historical and contextual factors [36,43,79].

These examples clearly indicate the growing recognition of the need for a historical and cultural understanding of spirituality at the end of life. History, culture and traditions of particular contexts have considerable overlap and are mutually dependent on one another. They play a fundamental role in constructing values and meanings that are core to the understanding of spirituality and therefore offer a rich set of resources for a contextual understanding of spirituality. Utilization of these contextual resources should set the agenda and direction for further research on spirituality at the end of life.

6. Conclusions

If spirituality is to be defined as an inner essence that accounts for the meaning and purpose of life and transcendence, philosophical and cultural aspects of local contexts need to be at the core of the understanding of spirituality. An articulation of the role of traditions through which deep and intangible aspects of spirituality find practical expressions is also crucial. There is a growing recognition of the importance of exploring history, culture and traditions for comprehensive understandings of spirituality. All three concepts involved in the notion of spiritual care at the end of life, namely, spirituality, care and death, have deep historical, cultural meanings recognisable through tradition. The spaces for these contextual factors for the study of spirituality are gaining recognition. But they still remain rather silent and require studies with appropriate methodological approaches to give voice to and fill those spaces with insights that can enhance our understanding of spirituality at the end of life.

Further research is needed to understand how spirituality is shaped by history and culture and maintained through traditions in particular contexts. Understandings of spirituality that do not take these contextual factors into account remain partial and incomplete. The applicability of these for providing spiritual care in clinical practice also often proves challenging. Articulation of the cultural embeddedness, historical rootedness and value of traditions in particular contexts offer valuable insights that present the often regarded “elusive” concept of spirituality a more tangible perspective.

Most existing empirical studies on the subject do not articulate the historical, theological, philosophical and cultural nuances that provide rich meanings to the elements or features they identify as their findings. Features of spirituality and the cultural and contextual factors that make them part of the essence of the person, which gives meaning and purpose to life and that which provide opportunities for transcendence. This recognition needs to find practical expressions setting the approach to studying spirituality and adopting appropriate methodological stances that adequately explore the rich and nuanced facets of the concept of spirituality. Cross disciplinary approaches to the study of spirituality involving philosophy, theology and sociology seem to offer the theoretical landscape where such methodological stances can be developed. Understandings of spirituality that result from such investigations can inform effective and culturally appropriate means for providing spiritual support at the end of life.

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