

## Article

# Spiritual Care in Palliative Care

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**Abstract:** Palliative care has always included spiritual care, but the provision and inclusion of spiritual care within and across palliative care services internationally is sub-optimal. In this summary overview, we address understandings and meanings of spirituality and related terms, both generally and in the context of healthcare, and outline the importance of spiritual well-being and spiritual care at the end of life. We summarise what spiritual care involves, its benefits for palliative care patients and their families, and consider how its provision might be helped or hindered. There is currently a limited evidence base for the efficacy of interventions including spiritual and/or religious care, and large-scale studies in particular are lacking. However, those mostly small-scale and/or qualitative studies which have been conducted to date show that addressing the spiritual needs of patients in palliative care is associated with many positive outcomes for both patients and their relatives. More research in this area is necessary to develop and enhance the evidence base, and optimal provision of spiritual care requires that providers explicitly recognise the need for such care, including through providing training and support for staff.

**Keywords:** spirituality; spiritual well-being; spiritual care; palliative care; terminal care; end of life; religion; well-being



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## 1. Introduction

Palliative care has always included spiritual care (Saunders et al. 1981; Saunders 1967; Mount 1976). The World Health Organisation (WHO) recently reaffirmed that ‘palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual’ (World Health Organization 2020). However, the provision of spiritual care in palliative care is still patchy, for reasons including inadequate understanding and training of staff (Best et al. 2016a; Selman et al. 2018). This paper provides a summary overview of the place of spiritual care in end-of-life care.

## 2. What Is Spirituality?

Many definitions of spirituality have been suggested, and health care discussions on this topic have been dominated by debates over the meaning of the term (Reinert and Koenig 2013; Tanyi 2002; Vivat 2012). Those attempting to find a workable definition acknowledge the need to embrace the richness of spiritual diversity while at the same time finding common ground (Nolan et al. 2011). Cultural diversity in understandings of spirituality should also be considered (Hanssen and Pedersen 2013), and can particularly affect how the place of religion is understood in relation to human spirituality.

The Spiritual Care Task Force of the European Association of Palliative Care (EAPC) has defined spirituality as ‘the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature,

to the significant and/or the sacred' (Nolan et al. 2011). Similarly, spirituality has been described as the way people engage with the purpose and meaning of human existence, and the way this informs their personal values (Cobb et al. 2012a).

Weathers and colleagues (Weathers et al. 2016) conducted a conceptual analysis of spirituality, and, resonating with previous definitions, identified three defining attributes: connectedness, transcendence, and meaning in life. In their analysis, transcendence refers to the individual's ability to see beyond the limitations of the present situation and any suffering it might entail. Sulmasy (2002) conceptualises human spirituality as beings in a relationship, employing a biopsychosocial–spiritual model of human beings, who identify relationships with themselves, others, the environment, and/or the significant/sacred as the source of their spiritual strength (Sulmasy 2002). Personal spirituality is shaped by a person's worldview and can be heightened by challenging experiences such as serious illness. Weathers et al. (2016) also highlight the multidimensionality of spirituality, the particularity of each person's spirituality, and that it is broader than religious beliefs or affiliations. The nature of any person's spiritual beliefs can therefore only be known by asking them.

It is salient here to clarify the contribution of religion to spirituality. It has been argued that religion also has no universally accepted definition, and that it is not clear that it means the same thing to all people (Koenig et al. 2012). However, it is usually understood as explicit beliefs and formal, organized practices for people who share common beliefs in a spiritual cognitive and behavioural context (Gijssberts et al. 2011). Hill and colleagues (Hill et al. 2000) offered an operational definition of both religion and spirituality as: 'a search for the sacred', but added that religion is also constituted by the means and methods (e.g., rituals or prescribed behaviours) of the search that receive validation and support from within an identifiable group of people. As a formal system of belief, religion can contribute to a person's spirituality, and should be considered as such for those with religious faiths, and for some agnostics, who may move towards or away from religion across their lives (Lim et al. 2010).

### 3. Why Include Spiritual Care in Healthcare?

Medicine and religion have a long joint history (Koenig et al. 2012). Spirituality is a universal human characteristic and has always been an integral element of palliative care, whether understood as religion specifically, or more broadly. However, interest in incorporating spirituality into the role of healthcare professionals more generally has gone in cycles, even in palliative care, and has only recently become prominent across all health care. This recent increased interest is often attributed to scientific studies identifying links between spirituality and well-being, and high levels of patient interest in having their spiritual well-being addressed in the healthcare context (Best et al. 2015c; Koenig et al. 2012). However, even in the context of patient-centred care, patient wishes are not sufficient to justify including spiritual care in healthcare. Further, the beneficial outcomes for spiritual care identified in some studies, while encouraging, are not yet fully established empirically (Steinhauser et al. 2017). The major warrant for addressing the spiritual needs of patients lies in the nature of healing, and the complexity of human beings, who incorporate not only the physical, but also the psychological, the social and the spiritual, all of which are affected by illness (Sulmasy 2002).

However, Phelps and colleagues (Phelps et al. 2012) suggest that healthcare is enhanced when staff are aware of patients' strongly held religious and spiritual beliefs. Such beliefs are known to influence decision-making, so when staff are aware of them, they can arrange more appropriate and individualized care (Phelps et al. 2012; Pathy et al. 2011; Padela et al. 2012). It has been argued that by ignoring spirituality, staff may be separating the patient from what may be the most important part of a person's coping mechanism (Pargament et al. 1998).

Some discussions of the spiritual domain focus on attempts to distinguish the spiritual from the emotional/psychological and social domains. Relationships and connectedness at the end of life can be considered as elements of all these domains. A recent systematic

review considers how patients' social and spiritual needs may overlap (Lormans et al. 2021), and a recent survey of nursing home physicians in the Netherlands had similar findings (Gijsberts et al. 2020). Social workers, psychologists, and chaplains may all be involved in addressing these overlapping needs (IKNL 2018). Acknowledging the fuzzy boundaries between the dimensions of care other than physical care, the spiritual dimension can become increasingly important for a person with increased seriousness of disease (Koenig 1998).

Someone who receives a life-threatening diagnosis such as cancer is confronted with existential questions such as 'why is this happening to me?', 'what will happen after I die', or 'will my family cope after I am gone?'. This has been described as the 'existential slap' (Coyle 2004), or personal crisis, which accompanies the realization that death is a possible outcome, regardless of prognosis. Spiritual resources are required to cope with this crisis and if the questions that arise are not resolved, existential (or spiritual) suffering can ensue (Best et al. 2015a). Spiritual well-being can be valuable for coping with this event and can help to bring about transformation through personal suffering (Pargament 1996; Best et al. 2015a). The healthcare professional as healer therefore needs to address the whole person and will not practice exemplary medicine without attending to all patient needs, including spiritual needs. On these grounds, Sulmasy suggests that attention to the spiritual needs (that is, spiritual care) of patients is not only permissible, but a moral obligation for doctors (Sulmasy 2006).

#### 4. What Is Spiritual Well-Being?

Spirituality is a problematic concept as a health care outcome because levels of spirituality as a whole are challenging to assess, and particularly because a person's spirituality can have positive or negative effects on the person. Some spiritual and/or religious beliefs can cause distress for some, and may increase the burdens of illness, for example, by limiting treatment options (Conti et al. 2018; Pathy et al. 2011; Padela et al. 2012). Negative religious coping, such as interpreting disease as a punishment from God, is related to declines in spiritual, mental, and physical health and increased risk of mortality (Pargament et al. 2013). Thus, assessing levels of spirituality, as opposed to spiritual well-being, can have contradictory results. Health care outcome measures in this field therefore more often assess functions of a person's spirituality, such as spiritual well-being, or, conversely, spiritual needs.

Spiritual well-being has been identified as a core domain in the assessment of quality of life in the setting of serious illness (Brady et al. 1999; Peterman et al. 2002; Whitford et al. 2008). It has been shown to be as important as physical well-being when assessing quality of life in cancer patients (Brady et al. 1999). Quality of life measures identify a unique effect for the spiritual domain, distinct from psychosocial and emotional domains, and which enables some patients to enjoy life even in the midst of experiencing unpleasant physical symptoms (Brady et al. 1999; Peterman et al. 2002).

A frequently used measure of spiritual well-being, the Functional Assessment of Chronic Illness Therapy—Spiritual well-being scale (FACIT-Sp) (Brady et al. 1999; Canada et al. 2008), is multidimensional, with two or three subscales (Faith and Meaning/Peace, or, separately as Faith, Meaning, and Peace). Faith refers to the perceived comfort derived from a sense of connection to something larger than the self. Peterman and colleagues found that the Faith subscale reflected measures of religious activity and intrinsic religiousness (Peterman et al. 2002). Meaning is a cognitive measure of spirituality, related to both physical and mental health, and correlating with one's sense of meaning and purpose in life (Canada et al. 2008). Whitford and colleagues found that Meaning correlated with social well-being, but was not related to religiosity (Whitford and Olver 2012). Peace refers to an affective dimension of SWB and harmony, for example that which is achieved by reconciling oneself to one's circumstances at the end of life, widely considered a feature of a 'good death' (Canada et al. 2008; Whitford and Olver 2012; Olver 2013; Steinhäuser et al. 2000a). This measure has been translated into 38 other languages. It was, however,

developed with non-palliative patients, and in a monocultural and monolingual context (the USA), and has been criticised for its cultural particularity (Vermandere et al. 2016).

The Quality of Life Group (QLG) of the European Organisation for Research and Treatment of Cancer (EORTC) employs a deliberate cross-cultural, multilingual approach to developing quality of life measures (Wheelwright et al. 2021). Following this approach, members of the QLG developed and validated a measure of spiritual well-being for people receiving palliative care for cancer, the EORTC QLQ-SWB32 (SWB32) (Vivat et al. 2017; Vivat et al. 2013). The measure was developed internationally from the outset, with collaborators in multiple countries and using a variety of languages, and the final validation study included 451 patient participants, in fourteen countries and ten languages (Vivat et al. 2017). The SWB32 has four scales: Relationship with Self, Relationships with Others, Relationship with Someone or Something Greater, and Existential, plus a global spiritual well-being item and a single-item scale for Relationship with God, for those with a religious faith including a personal God (op cit.). The measure has since been translated into another nine languages (including Swedish, Finnish, Greek, and Croatian), and validated in other countries and with people with illnesses other than cancer and with non-terminal diseases (Dabo et al. 2021).

### 5. How Does Spiritual Well-Being Affect Patient Outcomes?

Multiple studies have highlighted the importance of spiritual well-being for people living with advanced disease (Cobb et al. 2012b; Mesquita et al. 2017; Bandeali et al. 2020). Spiritual well-being is associated with social, mental and emotional health (Koenig et al. 2012). For example, high levels of spiritual well-being have been shown to be protective against depression and anxiety, and to promote adjustment to a cancer diagnosis and an increase in cancer-related personal growth (Yanez et al. 2009; McCoubrie and Davies 2006; McClain et al. 2003). Religion can be an important resource in coping with stress (Pargament and Abu Raiya 2007), and spiritual well-being has been found to be protective against distress for patients facing death, including that from pain, restlessness and symptoms of despair (Wasner et al. 2005; McClain et al. 2003).

Spiritual well-being has also been identified as beneficial for family caregivers of palliative care patients. Research suggests similar benefits for family members' quality of life as those seen for patients (Hebert et al. 2007; Best et al. 2015b; Delgado-Guay et al. 2013; O'Callaghan et al. 2020).

However, although the overall thrust of the literature suggests a positive impact for spiritual well-being, the underlying mechanisms for these associations have not been established and a cause-and-effect relationship has still not been confirmed. More research is needed, from all perspectives and using all methodologies: qualitative, quantitative, and mixed methods in prospective, longitudinal studies (Steinhauser et al. 2017; Selman et al. 2018).

### 6. What Are Patients' Spiritual Needs?

Qualitative research studies have explored patients' spiritual needs and found that these are numerous and broad in scope. Spiritual needs have been found to be common in patients with a life-threatening disease (Grant et al. 2005; Steinhauser et al. 2000a). Spiritual distress is prevalent amongst palliative care patients, ranging from 10–63% of inpatients, and family caregivers (Egan et al. 2017; Roze des Ordons et al. 2018). Kellehear developed a theoretical model of spiritual needs which characterized them as multi-dimensional, but all directed towards finding meaning in the illness experience in order to overcome suffering (Kellehear 2000). Hermann's study of dying patients identified 29 unique spiritual needs which were grouped into six categories: need for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature, and need for positive outlook (Hermann 2001). Steinhauser and colleagues found that being at peace with God was the second most important factor for quality of life at the end-of-life for cancer patients after freedom from pain (Steinhauser et al. 2006; Steinhauser et al. 2000b).

In their study with people with advanced cancer, Alcorn and colleagues (Alcorn et al. 2010) found that even those participants who claimed that religion and spirituality were ‘not important’ had at least one spiritual concern. Exline and colleagues found that half of those who identified as agnostic, atheist or non-affiliated religion in their study expressed anger towards God (Exline et al. 2011). These findings indicate that spiritual needs are not limited to those who profess religious affiliation, and that healthcare providers should not limit spiritual care to those who express or profess overtly religious beliefs.

## 7. What Constitutes Spiritual Care?

Spiritual care generally refers to recognizing and supporting patients’ spiritual well-being in some way. Health literature often conflates the concepts of spiritual screening, spiritual history-taking, and spiritual care. This may be partly because spiritual discussion can itself develop into a therapeutic intervention, and some measures of spiritual well-being explicitly acknowledge that the discussion of the measure with the respondent should be recognised as a first step in an intervention (e.g., Vivat et al. 2017). It may therefore be difficult to distinguish between these terms (Cobb 2001).

Chaplains (also known as spiritual care or pastoral care providers) are often the staff members considered responsible for the spiritual care of patients, but the involvement of other members of the healthcare team in spiritual care is increasingly recommended in view of the benefits of a generalist-specialist spiritual care model (Puchalski et al. 2009). This is particularly the case in those settings where chaplain services are insufficient to meet patient need, or not available at all (Koenig 2014).

Engaging in spiritual care requires advanced communications skills and spiritual awareness in the clinician (Best et al. 2016b; Paal et al. 2017; Ross et al. 2015; Ford et al. 2014; Anandarajah and Hight 2001). Attention to the clinician’s own spirituality is often identified as the first step of spiritual care training (Best et al. 2020). Examining one’s own spirituality not only improves awareness of patients’ spiritual needs, but also encourages personal growth, and reduces the risk that clinicians’ own existential distractions impinge on patient care (Koenig 2014; Jones 1999).

Routine questioning about spirituality can be included in the social history when baseline information about a patient is collected. Some patients may not choose to share their spiritual concerns with clinicians until a therapeutic relationship has developed, but some research has found that patients are more likely to discuss spirituality in their first PC consultation when their doctor asks them about their concerns (Best et al. 2019), so routine questioning about spiritual concerns may be helpful. Regardless of the outcome of any spiritual discussion, details should be recorded in the patient record and care plan, as with any other relevant patient information.

Appropriate timing for spiritual inquiry requires careful interpretation of verbal and nonverbal cues, which may indicate patients are reflecting on questions of purpose and meaning. In the palliative care context, difficult to manage symptoms may indicate an underlying spiritual problem (Best et al. 2015b). Experienced clinicians report that initiating spiritual discussions is aided by observing patient characteristics such as choice of words (particularly religious terms), body language, or objects in the patient’s room (religious texts, family photos, etc.) (Best et al. 2020).

Skills in this sensitive area develop with experience, which newer professionals lack. Experienced clinicians often prefer to develop their own form of enquiry, which may often involve a single question prompting the patient to tell their story, such as ‘What is important to you at this time?’ or ‘What gives you strength?’ (Best et al. 2015b; Paal et al. 2017). It has been suggested that a prescribed set of questions may prevent clinicians from giving their full attention to building a relationship with the patient, and responding to what is said (Paal et al. 2017).

However, many tools are available to enable initiating discussion of spiritual well-being with patients, or support spiritual history taking, and these may be helpful for less experienced clinicians, who are uncertain of how to initiate such sensitive conversations

(Nissen et al. 2020). Some examples include SPIRITual History (Maugans 1996), FACIT-Sp (Brady et al. 1999), HOPE (Anandarajah and Hight 2001), FICA (Puchalski 2002), The Ars Moriendi (“Art of Dying”) (Leget 2007), FAITH (Neely and Minford 2009), EORTC QLQ-SWB32 (Vivat et al. 2017), and Q2-SAM (Ross and McSherry 2018). Tools may be suitable for specific clinical settings depending on their context of development and validation, a context which is particularly important for this area of care, where cultural variations are significant. The countries and languages in which tools are initially developed may affect their later transferability to other contexts (Vivat 2012).

It is known that patients’ spiritual needs fluctuate over time (Best et al. 2022), so it is necessary to check with patients at regular intervals in case any new spiritual needs have arisen. This ‘spiritual screening’ (Best et al. 2020) can be conducted regularly as part of initial intake and subsequent routine check-ups. Short screening tools have been validated in palliative care populations by Steihauser et al. (2006) and King et al. (2017), although conversational prompts can also be effective within an established relationship (Best et al. 2023).

Some palliative care patients have reported that they do not expect their clinicians to provide spiritual guidance (Best et al. 2014). If a spiritual need is identified, and/or the clinician feels unable to address the patient’s spiritual concerns, referral to a hospital chaplain or other spiritual care specialist is recommended. The individual selected should be appropriate to the spirituality of the patient and will be dependent on available resources. Chaplains are trained to conduct an in-depth assessment and the effectiveness of care does not depend on faith-concordance between provider and patient (Liefbroer and Nagel 2021).

Other patients may choose not to receive spiritual care from clinicians, or already have or arrange their own support networks. These choices should be respected. People who are living with terminal diseases wish for empathy, respect for their values, and legitimization of their spiritual concerns (Ellis and Campbell 2004) and spiritual enquiry and care should always be culturally appropriate (Best et al. 2020).

## 8. How Does Spiritual Care Help Patients?

Empirical studies have demonstrated that enquiry into a patient’s spiritual needs has a number of benefits. Such enquiry enables clinicians to get to know patients better through non-medical dialogue (Best et al. 2015b), and improves doctor-patient relationships by increasing trust (Taylor et al. 2011). When patients feel valued and affirmed by healthcare staff, it enhances their ability to cope and find a sense of meaning in their experience of illness (Grant et al. 2005).

Spiritual care provision is also associated with patients’ improved quality of life at the end of life (Balboni et al. 2010), increased satisfaction with care (Johnson et al. 2014), and has also been shown to reduce healthcare costs (Balboni et al. 2011).

Failure to address the spiritual needs of cancer patients is associated with suffering, which should be the primary target of care in medicine (Edwards et al. 2010; Boston et al. 2001).

Increasing numbers of randomised controlled trials are also being conducted to investigate the effects of religious and/or spiritual interventions on the well-being of people receiving palliative care (Vivat et al. 2022). A Cochrane review conducted for 1980 to 2011 (Candy et al. 2012), identified five RCTs, all conducted in the USA. The update of this review has identified 40 RCTs conducted from 2011 to 2022, and in far more diverse geographical locations (Vivat et al. 2022). The interventions most frequently used by included studies were reminiscence/life review (13 studies), and group or individual psychotherapy (14 studies), including Meaning-Centred Behavioural Therapy (Breitbart 2002) and Dignity Therapy (Chochinov et al. 2005). Small positive effects from these interventions were found, but meta-analysis was limited by the diversity of studies in the designs used and outcomes assessed, so it is impossible to make recommendations on the basis of these studies. More consistency between the designs of future RCTs and those of previous RCTs would facilitate comparisons and meta-analyses, and thereby enable the drawing of conclusions on the overall effects of such interventions (Vivat et al. 2022).

## 9. How Can the Provision of Spiritual Care Be Helped or Hindered?

Recent reviews of spiritual care have identified factors which influence the introduction of spiritual care in healthcare. In a review of the European palliative care literature, Gijsberts and colleagues found that spiritual competency and visibility of spiritual care are necessary for implementing spiritual care in palliative care (Gijsberts et al. 2019). Several studies have found that spiritual care training is the strongest predictor of spiritual care provision by clinicians (Balboni et al. 2013; Best et al. 2016a), and that spiritual care training and practice was more likely to occur when it received institutional support (Jones et al. 2021).

A review exploring the reasons why doctors do not engage in spiritual discussion found that the most frequent barriers to the provision of spiritual care identified were lack of training and time, although, interestingly, when more time was available, the frequency of spiritual discussion did not increase (Best et al. 2016b).

## 10. Benefits of Spiritual Care Training

Training in spiritual care provision benefits staff members as well as patients. High levels of competence in spiritual care provision and of personal spirituality are associated with reduced burnout in palliative care professionals (Paal et al. 2018; Wasner et al. 2005). Paal and colleagues (Paal et al. 2015), have argued that, when spiritual care is successfully integrated, it can ‘challenge the spiritual vacuum in healthcare institutions’, but point out that, for spiritual care to be successful, institutions need also to attend to the spirituality of their staff (op. cit.).

## 11. Conclusions

Studies to date have shown that addressing the spiritual needs of patients in palliative care is associated with many positive outcomes for both patients and their relatives. Although the evidence base for spiritual care interventions is currently limited, more studies are currently being conducted. More consistency in the design of RCTs, in particular, would enable meta-analysis and thereby the drawing of broader conclusions on the efficacy of these interventions. Provision of spiritual care requires that institutions recognise the need for such care, including through providing staff training and support, which benefits both patients and staff, who are thereby also enabled to provide better support to patients.

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