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The interface between psychology and spirituality in palliative care

Francisca Rego and Rui Nunes

Abstract

In palliative care, a biopsychosocial-spiritual model is essential to address the patient in totality. Spirituality is often a relevant issue in such settings, yet there is a need to differentiate spirituality from religion. Spirituality in palliative care focuses on the psychological and spiritual aspects of care, helping to relieve the physical, emotional, social and spiritual distresses of the patient, family members and healthcare professionals, produced in such conditions. Psychologists, according to their ethical responsibilities, may include the assessment of their patients' spiritual needs in therapy, as it will help to identify the patients' values, belief systems, spiritual history, distress and needs. All patients have different needs, some may need religious/spiritual guidance, in collaboration with spiritual care workers, and others may not demonstrate needs regarding these issues. The essential is that each patient is treated as a 'whole', addressing his physical, psychological, social and spiritual needs.

Keywords

biopsychosocial-spiritual model, holistic care, palliative care, psychology, spirituality

Introduction

Palliative care focuses on a holistic, transcultural, comprehensive and patient-centred approach, thus supporting the biopsychosocial-spiritual model which was presented as a reaction to address the totality of the patients' relational existence – physical, psychological, social and spiritual (Beng, 2004; Sulmasy, 2002). According to Sulmasy (2002), the expansion of the biopsychosocial model to include the spiritual concerns of patients would make healthcare professionals aware that they should attend the needs of patients as whole persons. Persons can be considered beings-in-relationship; however, illness can be considered a disruption in biological relationships, which consequently affects all the other relational aspects of a person. Thus, a genuinely holistic health care must address the totality of the patient, that is, his or her relation with the physical, psychological, social and spiritual.

Spirituality is one of the fundamental dimensions of quality of life and culture care. As such, spiritual well-being is an essential component on palliative and end-of-life care (Long, 2011). However, most research in palliative care addresses spirituality and religion together, yet spirituality is a broader belief system and not the same as religion (Richardson, 2014).

University of Porto, Portugal

Corresponding author:
Francisca Rego, Faculty of Medicine, University of Porto, Alameda Prof. Hernâni Monteiro, 4200-319 Porto, Portugal.
Email: mfrego@med.up.pt

Overall, spirituality can be defined as a journey of self-discovery, which allows a person to experience the transcendent meaning in life, expressed as a search for the sacred (God, nature, family, etc.), whatever gives a person a sense of meaning and purpose of life (Puchalski et al., 2004; Richardson, 2014). Spirituality is personal, but also connected with others and with the world around, moved through the search of the meaning of life (Puchalski et al., 2004).

On the other hand, religion is considered an outward expression/practice of a particular spiritual understanding or organised system of beliefs, values, codes of conduct and rituals (Koenig et al., 2001). And beliefs, in health and religion, can be reconceptualised as structure of feeling contingently associated with discursive practices and narratives (Cromby, 2012). Religion is considered a covenant faith community that can enhance the search for the sacred and promotes morality (Dollahite, 1998; Emmons and Paloutzian, 2003). It casually influences health by means of social support and improved health behaviours, enhances positive psychological states (e.g. faith, hope, inner peace), offers psychological strength for acquiring/maintaining positive health behaviours and influences health by distant healing or intercessory prayer (Oman and Thoresen, 2002).

These concepts must not be viewed as incompatible, as they include the search for the sacred; however, religion may include search for social identity or health, as well as recommend rituals to assist in this search for the sacred that are valid for that faith community (Emmons and Paloutzian, 2003; Hill et al., 2000; Zinnbauer et al., 1999). A person can be spiritual without assigning to a specific faith belief or religion, as spirituality is unique, described as the 'inner self', embedded in everyday and inner life, used in daily interactions and as daily support, associated with higher rates of social support and lower levels of depression, possessing different meanings to different people and changing through phases of life (Bailey et al., 2009; Bennett and Shepherd, 2012; Bush and Bruni, 2008;

Edwards et al., 2010; Long, 2011; Sinclair et al., 2006).

Individuals may consider themselves neither religious nor spiritual; however, existential beliefs play an important role in every person's life, as they relate to what means to be a human being and provide a person with a purpose or ultimate meaning, such as connection with loved ones or creative expression (Selman et al., 2007). The human person is intrinsically spiritual, as a being in relationship, and sickness is understood as a disruption of right relationships. So, the appropriate care of a dying person requires attention to the restoration of all the interpersonal and extra personal relationships that can still be addressed (Sulmasy, 2002).

This article attempts to address how an articulated psychological and spiritual support promotes a better quality of life in palliative care, namely, how a psychologist may incorporate appropriate spiritual support into psychological care.

Spirituality in palliative care

A definition of health includes not only physical, cultural, psychosocial and economic needs but also spiritual needs and not simply the absence of illness (Marks et al., 2015). Existential well-being has been considered a strong predictor of health-related quality of life (Lawler-Row and Elliott, 2009), and for many people, spiritual experiences are a source of great meaning to their lives, thus encouraging engagement in health-promoting behaviours and avoiding health-risking behaviour (Marks, 2016; Piko and Brassai, 2016). However, spiritual beliefs and experiences are far from universal (Marks, 2016). According to the Meaning-Making Model (Park, 2013), the degree of discrepancy between the perception of one's illness from one's global beliefs, such as identity, health and global goals, determines the extent to which the illness is distressing. In some cases, those beliefs are spiritual in nature (Park, 2013). Qualitative studies about spiritual aspects at the end of life point to three main themes: spiritual despair – alienation, loss of self, dissonance; spiritual work – forgiveness,

self-exploration, search for balance; and spiritual well-being – connection, self-actualisation, consonance (Marks et al., 2015; Williams, 2006).

In palliative care, it is not uncommon to experience spiritual distress, defined as the disruption of one's beliefs of value system (Richardson, 2014). Anandarajah and Hight (2001) suggested that spiritual distress happens when a person is unable to find sources of meaning, love, comfort and so on or when conflict occurs between beliefs and life's events. Saunders (1978) introduced the concept of 'total pain', which includes physical, social, emotional and spiritual distress. In palliative care, pain is one of the most distressing symptoms patients may experience and unaddressed spiritual issues may frustrate one's attempts to treat other symptoms and have an adverse effect on quality of life; however, if each dimension is addressed, distressing symptoms may be alleviated (Puchalski et al., 2004; Richardson, 2014; Sulmasy, 2006).

Although limited, research points to the importance of spiritual and existential issues in patients with life-threatening illness and to the close relationship between spiritual, social and psychological well-being. It has been found that spiritual issues/beliefs contributed for patients and carers to find meaning and were considered the main source of hope (Scott et al., 2003, 2004; Westlake and Dracup, 2001); spiritual well-being/striving was associated with less depressive symptoms and less negative affects (Bekelman et al., 2007; Perez et al., 2009) and greater spirituality buffered the impact of stigma on self-esteem (Noor et al., 2016). Feelings of spiritual support seem to be particularly valuable to people searching for a sense of connectedness and control in life (Zinnbauer et al., 1999), and evoking spirituality and accepting the disease, adopting a positive attitude and engaging in self-talk were considered as emotion-focused coping strategies to reframe the way patients thought about their illness (Roomaney and Kagee, 2016). It is important to note the relevance of resilience when attending palliative care patients' emotional needs, as in palliative care resilience is referred to the ability of patients to cope with incurable illness and

the derived problems (Radbruch and Payne, 2009). Interactions between spirituality, resilience, social support network and physical symptoms have been observed, namely, resilience was found to have a high predictive value for spirituality, social support network to have a direct positive effect on the interpersonal dimension of spirituality and spiritual elements to enhance the effectiveness of mindfulness for pain, suggesting that spiritual engagement may itself be a resource in managing pain (Feuille and Pargament, 2015; Fombuena et al., 2016).

Spirituality and psychology in palliative care

The view of death varies according to a person's values, beliefs, culture and meaning of life. The important issue is that each individual may react to his or her beliefs in a unique way, and so, the health professional must address each case individually (Koenig et al., 2001; Shannon and Tatum, 2002).

In general, the religious/spiritual coping is associated with positive mental and physical health outcomes. However, if patients attempt to rely solely on their higher power for mental and physical health without any form of collaborative problem solving or if patients use negative religious/spiritual coping styles, they are more likely to have poorer long-term health outcomes (Wachholtz and Pearce, 2009). A positive religious coping is associated with a constructive reliance on faith that promotes health adaptation and psychological adjustment to stressors, as serious illness, predicting a positive spiritual support (Ai et al., 2012; Ano and Vasconcelles, 2005; Pargament et al., 2000; Phelps et al., 2009). A negative religious coping, on the other hand, tends to view illness as a divine punishment and can indicate an existential crises, therefore predicting a negative spiritual support (Ai et al., 2012; Ano and Vasconcelles, 2005; Pargament et al., 2001; Phelps, et al., 2009). So healthcare professionals' awareness on how their patients are using their faith to cope with pain and to influence quality of life will help to identify whether specialised mental health

practice would be an added benefit for pain management (Bekke-Hansen et al., 2014; Wachholtz and Pearce, 2009). Nevertheless, it is important to maintain a distinction between 'spirituality' and 'religion', as spirituality was considered part of most patients' total existence, encompassed more than religion, does not necessarily relate to religion and patients prefer not to be judged or forced into religion (Edwards et al., 2010; Hermann, 2001; McGrath, 2003; Stephenson et al., 2003; Tan et al., 2005).

Psychologists in palliative care play a key role with respect to providing support and counsel for end-of-life patients and their family member, and other healthcare providers. Although psychologists tend to be reluctant to address spiritual issues with their patients, the ability to question patients about their spirituality is an important element in therapy, as this information frequently reveals significant data in the overcoming of difficulties (Lomax et al., 2002), allowing the use of their skills and knowledge towards the patient's spiritual needs and to work effectively with other spiritual care workers on the palliative team (Kaut, 2002; Moss and Dobson, 2006). Spiritual issues (e.g. severe meaningless, guilt) lead to distress that causes psychological and physical suffering, such as depression, anxiety or acute pain (Puchalski et al., 2009). One leading explanation based on the mediating role of psychological well-being in the link of spirituality and health outcomes is the stress-buffering effect of goals, beliefs and meaning (Park and Folkman, 1997; Piko and Brassai, 2016).

Psychological support allows to assemble the meanings and the psychological representations and values of the spiritual and/or religious beliefs and symbols (Alleti, 2008). Narratives help make life meaningful for patients and can be understood and addressed from different clinical perspectives, therefore being fundamental for a holistic care (Mundle, 2015). 'Narrative care' has demonstrated therapeutic benefits of empathic listening and, when focused on spiritual care, helps clinicians understand more fully the meaning of a patient's 'total pain' (Moore et al., 2015; Mundle, 2015). Hence, the personal life history is understood as how it was felt and perceived by the subject and how it fitted in his or her internal life experiences, allowing a personal understanding at many complex levels (emotional, social, motivational, cultural, etc.) and so promoting a better self-knowledge and better relational skills and allowing the search for solutions appropriate to the individual's needs and psychological processes (Alleti, 2008), thus being more comprehensive on these matters than pastoral care that focuses on finding answers related to complex philosophical and theological questions (Hermsen and ten Have, 2004; Smyth and Bellemare, 1988).

The incorporation of spirituality into psychology care is consistent with the biopsychosocial-spiritual model from which psychologists operate – recognising their patients' problems as multifaceted (Sulmasy, 2002), therefore addressing the patient's unique life experiences, values and beliefs in order to maintain a sense of personal dignity (Chochinov et al., 2002).

Tan (1996) described two main models of integrating religion/spirituality into the therapeutic process: implicit and explicit integration. A clinician who adopts an implicit approach tends to hardly/indirectly initiate a conversation about spiritual matters. The spiritual issues are dealt only if identified by the patient, supporting the patient's autonomy to mention spiritual issues in therapy or not. It focuses on the words patients use to describe their beliefs and practices in order to comprehend how that patient experiences spirituality (Griffith and Griffith, 1992). However, research indicates that many patients wish their medical practitioners addressed spiritual/religious matters (Post et al., 2000).

The explicit approach incorporates spiritual/religious issues into therapy. The clinician must be careful when conducting the assessment of the patient's spiritual needs, as it may include the use of prayer or referral to religious groups or texts (Tan, 1996). On the other hand, there is the inclusion of forgiveness, which is common in therapy and not directly related to spirituality/religion (Richards and Bergin, 2005). It is

common for palliative care patients to have access to institutionally based chaplains or spiritual care workers, who are in a position to address the more explicit techniques (e.g. rituals) that are outside the ethical bounds of a psychologist's competence and training (Chappelle, 2000; Moss and Dobson, 2006).

The ethical appropriateness of pure explicit integration in psychology may be damaging to the therapeutic process, as this approach is likely to work best when both the psychologist and patient have similar belief systems, and in case of misinterpretation, as the palliative individual is already in a very vulnerable position, this can potentially be construed as disrespectful and paternalistic (Chappelle, 2000; Moss and Dobson, 2006). A pluralistic culture would be best served with an implicit integration, but with an added degree of directivity to provide a responsible degree of attention to the patient's spiritual health. If a more explicit approach is needed, which may or may not fall out of the ethical and competence bounds of the psychologist, the patient can be referred to an institutionally based chaplain/spiritual care worker in the palliative care team or a religious leader within the patient's community for counselling directly the religious concerns, which may result in a collaboration with these leaders (Chappelle, 2000; Moss and Dobson, 2006). The primary roles of the psychologist in this regard are to listen nonjudgmentally and to assist the patients in determining what actions are needed to fulfil these needs (Richards and Bergin, 2005). Ethical principles, such as respect for patient's rights and dignity (American Psychological Association (APA) Ethics Code, 2002); responsibility to be aware of how spiritual matters impact the patient's life (McMinn and Dominquez, 2005); to seek appropriate consultation to religious/spiritual professionals, if needed; honesty about skills and limitations as professionals; competence awareness; and concern for others' well-being, can greatly help the professional to approach spiritual issues (Plante, 2007). Also, appropriate education on spiritual issues evoked by patients and families faced with life-threatening illness and regular assessment of spiritual and existential needs, goals and concerns

such as life review, hopes and fears, meaning purpose, beliefs, forgiveness and life completion tasks should be taken into account (American Academy of Hospice and Palliative Medicine et al., 2004; Puchalski et al., 2009). Self-knowledge is an important component of competence and spiritual awareness (Wasner et al., 2005). Psychologists need to explore their own beliefs and attitudes to different spiritual values associated with death and dying, especially psychologists working with palliative patients, as the frequent confrontation with death involves continually being faced with one's own mortality (Moss and Dobson, 2006). In case patients do not require spiritual or religious care, psychological support should still be crucial to counsel end-of-life patients (Lomax et al., 2002).

Conclusion

Spirituality has been identified as an important factor in the overall health and well-being in palliative care. It is understood at an individual level and can be viewed as a sense of internal peace and search of a purpose and connectedness to the sacred (Drutchas and Anandarajah, 2014).

Psychological and spiritual distress are common in end-of-life patients, and they often trigger thoughts of an accelerated death when pain and physical symptoms have been treated, as patients may become demoralised and hopeless (Moss and Dobson, 2006). This is a wide challenge for the patient, family members and healthcare team, who try to find meaning for this journey and where spirituality appears to be one of the ways to cope with this distressing experience (Scott et al., 2003, 2004; Westlake and Dracup, 2001).

In palliative care, the incorporation of spirituality into psychological care is consistent with the biopsychosocial-spiritual model (Sulmasy, 2002). According to Tan (1996), there can be an implicit or explicit integration of spirituality in psychological care. In the implicit integration, the spiritual issues are dealt only if identified by the patient (Griffith and Griffith, 1992). On the other hand, the explicit

approach incorporates spiritual/religious issues into therapy; however, this may fall outside the ethical bounds of a psychologist's ability and training (Chappelle, 2000).

A multicultural population would be best served with an implicit integration, but with an added initiative from the psychologist to address the patient's spiritual health. In case the patient needs a more explicit religious/spiritual guidance, the collaboration of institutionally based chaplains or spiritual care workers is required (Chappelle, 2000).

In this sense, spirituality should be incorporated into psychological end-of-life care as it demonstrates cultural inclusiveness (Shafranske and Malony, 1996) and comprises the patient as a whole, promoting an appropriate response to the patient's needs and to the dying process (Moss and Dobson, 2006). In palliative care, psychologists are essential in providing support and counsel for end-of-life patients, their family member and other healthcare providers. By incorporating a spiritual component, the psychologist gains value insight about the patient and helps to fulfil the duty of responsibly caring for the 'whole' person, and by allowing the person to indicate his or her spiritual issues and needs, their dignity, right for self-determination and autonomy are being respected (Moss and Dobson, 2006).

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