

Spiritual care at the end of life: whose job is it?

*Jacqueline H Watts, Open University, UK
Claudia Psaila, University of Malta*

Interest in and recognition of the function of religious and spiritual coping in adjustment to serious illness has been growing. In particular, there has been increasing interest in the importance of understanding and valuing patients' individual spirituality as a function of providing appropriate support, particularly as part of nursing practice. This stems partly from the influence and application of palliative care principles in a range of care settings and not just hospices. Four decades of professional rhetoric have emphasised the importance of care for the 'whole' person in terms of spiritual as well as psychological, physical and social needs, without evaluating its impacts on patients or considering whether this approach is realistic in every case. Professional ideology within palliative care has been dominant in influencing a culture of openness between professional health workers and dying patients in their care, with attention to spiritual needs an increasing part of professionals' remit.

New ways to both assess and address spiritual concerns as part of overall quality of life are being developed by health care practitioners as part of a package of support for people with critical and terminal illness (Randall and Downie, 2006; Watts, 2008). For this support to be meaningful, however, it is necessary to determine which dimensions of spirituality are relevant and the ways in which the human spirit can be celebrated in the face of life-threatening illness (Cobb and Legood, 2008). The ultimate value of such exploration is to make it possible for us to die the way we live (Hockey, 2002).

Understanding Spirituality

Palliative care philosophy acknowledges the importance of spiritual values and beliefs in contributing to making us who we are. Beliefs provide a dependable framework of meaning, within which people are able to make sense of their lives (Cobb, 2008). Beliefs also inform meanings of 'spirituality', a concept that is now being contested. However, there does seem to be some understanding as to the elements and attributes that make up spirituality, with some arguing that spirituality is a multidimensional concept (Crossley, 2005; McSherry, 2006; Tanyi, 2002).

Attempts to define spirituality have frequently been made through differentiating between the concepts of 'religion' and 'spirituality' – and often through polarizing them. Religion is often described as a system of beliefs, having norms and representing the institutional and public domain. At the other end, spirituality is characterised by transcendence, individual meaning and personal development and expression. In rich Western, post-industrial nations, this differentiation may be understood in the context of sociocultural changes that reflect the shift from sacralisation to secularization (Heelas et al., 2005; Norris and Inglehart, 2004). These changes have led to an emphasis on the personal and the subjective, as opposed to authority, norms and an understanding of the transcendent as being external to the person. They have also had an impact on other areas where spirituality has been

applied, such as nursing, where the institutional and dogmatic discourses of religion are challenged by discourses of spirituality, with its emphasis on personal development and individual meaning.

However, while religion and spirituality are separate, they are also overlapping constructs, since both deal with answering ultimate or existential questions (Moore et al., 2001; Swinton, 2001). Swinton clarifies this by saying that what distinguishes religion from spirituality is that the former has to do with a system of beliefs, and that this system usually centres on 'some conception of God' that is shared in a community (Swinton, 2001).

Moreover, he explains that, although 'spirit', which is the root of the term 'spirituality', derives from the Latin *spiritus* (meaning 'breath'), spirituality and spirit are distinct terms. Spirituality is the expression or manifestation of spirit that is the essential lifeforce in the individual that 'motivates and vitalises human existence' (Swinton, 2001). Consequently, while spirit imbues the person with meaning, motivation and purpose, and is indescribable and invisible, the effects of spirit (spirituality) are tangible and understood. Each person's spirit may find expression in what Swinton terms religious or non-religious spirituality. While the former is an expression of a person's religious beliefs, the latter, he says, 'incorporates humanistic, existential and philosophical perspectives as well as religious ones'.

Spiritual care at the end of life

With the assumption that spirituality is a fundamental dimension of the human person and of human experience, a number of health and social care professions are now emphasising spiritual care as an essential element in their practice, with the nursing profession leading discussion of 'best practice' in this area (Dyson et al, 1997; McSherry, 2006; Tanyi, 2002). The application of theory to practice, however, appears to be fragmented, not least because meanings of spirituality and how these might inform the delivery of spiritual care remain a contested area (Peberdy, 2000). This notwithstanding, all components of care have increasingly become associated with the discourse of 'patient-centredness', aimed at respecting autonomy and individual choice (Wright, 2004), acknowledging that 'one size does not fit all'. In pursuit of high quality personalised spiritual care, Stoll (1979) documents the way in which nurses have in the past been advised to construct a spiritual history of their patients by questioning them about their understanding of 'god', hope and the significance to them of faith practices. The idea that spiritual values can be neatly and conveniently identified, categorised and responded to in ways similar to those of disease diagnosis and treatment, is now acknowledged as problematic, although vestiges of this can still be traced within the 'audit culture' that now dominates UK health care delivery.

Drawing on the broad understandings of spirituality outlined above, Twycross (2003) offers insight into what spiritual care at the end of life might mean, outlining a range of appropriate interventions and behaviours. He suggests that affirmation and acceptance of the person in a non-judgmental way together with achieving forgiveness and reconciliation, as a form of completion, are core components of spiritual care of the dying. Open communication and a sense of 'being there' are also important but it is the activities of giving time and listening that he suggests are

ultimately crucial. In his critique he identifies 'depersonalisation' rather than death as the ultimate tragedy of life. Key features of 'depersonalisation', he argues, are dying in an alien space, denial of appropriate spiritual nourishment and dying with no hope. Hockey (2002: 52) theorises the affirmation of self-identity in terms of acknowledging 'how we have become', as a key biographical spiritual resource that can counter institutional depersonalisation at the end of life.

Is spiritual care the job of professionals?

Issues of biography and inherited history challenge a culture of 'depersonalisation' within health care. They also bring to the fore questions about how realistic it is to expect professionals to enter the whole life discourse of the dying person, given the constraints of time and pressure on services that operate within a highly managed system of healthcare such as we have in the UK (Randall and Downie, 2006: 154). From the patient's perspective, how is it possible to convey the complexity, richness and diversity of a whole life in small snapshots of rushed time and are these highly personal disclosures, made to caring professional strangers, of benefit to dying people? Most palliative care literature on this topic assumes that they are. Woods (2007: 66) makes the important and related point that palliative care philosophy does not seem to discriminate between a need and a capacity to benefit, resulting in palliative care practitioners feeling obliged to address this element of care for all their patients. Even in hospices, where the patient/staff ratio is higher than in most other care settings, time is still often at a premium for staff, making communication a lower priority than many would wish it to be.

Against this backdrop, from the patients' perspective, the themes of achievement, joy, disappointment, guilt, loss and fear may be deeply held, interwoven and even unsayable, especially as part of the hurried professional encounter. The ideal that this mix of feelings which contribute to psychosocial distress that itself can be effectively 'treated' by professionals as they attend the spiritual care needs of the dying, Randall and Downie (2006: 153) suggest, is unrealistic and can lead to a form of 'harassment by questioning in the name of compassion'. The pressure on patients to 'disclose' rather than share concerns as part of the patient/professional relationship can result in patients making deeply personal revelations, feeling unable to dissent from this exchange often because it is part of a wider package of care that is wanted and appreciated.

Given that the time as death approaches may be one for reflection and life review, for this to be affirming it needs to be shared and mutually understood. How, though, can professionals understand or engage with mere fragments of past biography separate from contexts and personalities, in light of only recent association with the patient? The ability to fit the narrative pieces together to cohere as authentic reflection and reconnect people to stories of their past derives from knowing about one another's lives that functions as a form of mutual attachment. This is only truly possible in the context of longstanding valued relationships. This must lead us to question whether, without the features of choice and valued relationship, professional spiritual care work is empty, mechanical work bringing only limited benefit for the dying person. Randall and Downie (2006) make the related point that vulnerable, dying people may be at risk of manipulation from this kind of instrumental intervention because of the uneven power relationship inherent in the

patient/professional paradigm. Their contention that professionalisation which 'breeds' routinisation to produce attempts by professionals to address spiritual issues with dying patients, almost as part of a checklist, suggests the need to critically explore this area of health care.

Conclusion

Myers and Raspa (2007) argue that professional health care disciplines such as nursing focus on reconciling professional narratives of 'what is good for you', 'what is wrong with you' and 'what you need to do next' with patients' narratives of 'who I am', 'what I want to do' and 'what I believe is best for me'. Their critique draws attention to the schism often present within institutional health care practice between 'professional' and 'personal' that is central to the debate about professional delivery of spiritual care discussed herein.

These ideas may present challenges to health care professionals supporting dying people as their professional education and training incorporate a remit to include spiritual matters within patient care. The extent to which this remit also recognises the concomitant need on the part of clinicians to have their spiritual needs supported requires investigation and may have policy implications for managers responsible for staff health and safety.