Caring for the spirit: lessons from working with the dying

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ABSTRACT

- Spiritual care is integral to palliative care, and palliative care experience in offering spiritual care can be a resource for the emerging healthcare interest in spirituality.
- Spirituality is best understood in terms of the web of relationships that gives coherence to our lives, uniquely identifying each person.
- In palliative care, responsibility for spiritual care is shared by the whole team, with leadership given by specialist practitioners such as pastoral care workers. The palliative care approach to spiritual care may, however, be transferred to other contexts and to individual practice.
- Spiritual care encourages and supports people in a quest for meaning and personal autonomy. It is offered, not imposed.

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IN THE 1970S, the hospice movement, from which contemporary palliative care has emerged, established a model of care for dying people that encompassed physical, psychological, social and spiritual dimensions of need. Over the past 30 years, hospice and palliative care services have generated a rich store of accounts about the ways in which people face death.[1] These make it plain that the imminence of death, together with the changed circumstances associated with illness, cause many people to reflect on questions such as: Who do I belong to? What's the purpose of my life? What can I hope for?

Traditionally, questions like these received religious answers, and hospice care practitioners regarded attending to these questions as spiritual care. To do so, they drew at first upon religious resources, but soon began to develop a broader perspective in which spirituality was understood as "ultimate meaning". Concepts enunciated by Cicely Saunders — "openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her own journey towards their ultimate goals"[2] — were considered fundamental to hospice practice. The role of practitioners was to be companions on this journey, responding to the dying person's spiritual quest rather than imposing their own views. They observed that people became aware of spiritual need in various ways: through trying to cope with their changed physical, emotional or

social environment; through seeking to redefine their personal identity in changed circumstances; or as a result of their religious beliefs and practices.

Kellehear rightly points out that a multidimensional model incorporating all three of these aspects (situational, moral/biographical and religious) is essential.[3] Spirituality is inseparable from everyday life and experience. It denotes perceptions, insights and beliefs that reconnect facets of personal experience fragmented first by life in modern materialist society, then by a healthcare system that delivers multiple services through a variety of practitioners, with little attention to the overall impact on the recipient. Spirituality, as palliative care practitioners understand it, is often expressed in everyday language that may not be recognised as "spiritual" by people whose ears are attuned principally to religious language or who regard spirituality as something separate from ordinary experience.[4-6]

Describing spirituality

Spirituality may be described as the web of relationships that gives coherence to our lives. Religious belief may or may not be part of that web. Often we only become aware of strands in the web when they are stretched or broken, as happens with a life-changing event like a diagnosis of serious illness in ourselves or in someone we love.

Lartey describes this web of relationships as "levels of a system".[7] Spirituality, he says, involves relationships with places and things, with ourselves, with significant others, with groups and communities, with transcendence. For each of us, these relationships form a unique pattern, and each of us needs that pattern to be largely intact in order to feel secure, or whole. Some of us feel most whole in particular places or when surrounded by particular things or by people we love; some of us feel whole when, through prayer, ritual or silent waiting, we find ourselves close to God. Our web of key relationships defines who we are, and when those relationships are disrupted, we feel vulnerable. Klass has suggested that "a good way to begin thinking about spiritual life . . . is to look for those moments when we feel most deeply connected to our world, when we feel least isolated inside our usual ego boundaries. We feel a part of something larger than ourselves, and the rest of the world makes sense."[8]

Spirituality and religion: a continuing debate

In the palliative care context, spiritual care supports people in searching for meaning in their dying. Survivors of life-threatening illness also indicate the need to attend to spiritual issues in order to resume everyday life. Connections between health, religion, and spirituality have received increasing attention in recent years, although comparison between studies is complicated by conceptual and terminological differences. A succinct review is given in recent paper by Peach.[9] (The subsequent exchanges between Peach and Koenig demonstrate these complications and the potential for misunderstanding that can occur when the terms "religion" and "spirituality" are used more or less interchangeably.[10-12])

Many people today describe themselves as spiritual but not religious: they seek spiritual experiences, but neither interpret nor express these through conventional religion. Conceptually, the relationship between religion and spirituality is complex. Religious beliefs and practices focus more upon the sacred; contemporary spirituality attends more to the self. Religion points to Spirit, of which the human spirit is a reflection; contemporary spirituality attends to and expresses the human spirit. Some contemporary spiritualities draw upon the resources of several religions;[13] some religious spiritualities today adopt the form of other contemporary spiritualities in the authority given to subjective experience.

A religion-based understanding of spirituality — spirituality as beliefs about the sacred — tends to be more acceptable in healthcare contexts because it provides definitional clarity that assists the division of professional responsibilities. However, many patients do not observe this conceptual neatness, applying the term "spiritual" to core values, meanings and practices that integrate their experience, often with only tenuous connection to ideas of transcendence. This popular usage makes defining spirituality in terms of the content of belief virtually impossible; but behind the variety of content is a common process. Spirituality involves a quest for meaning — a meaning that is personal.[14,15] Individuals embrace spirituality to affirm themselves in the face of the "expert" knowledge they experience as taking over their lives. Contemporary spirituality resists the expert authority of both tradition (religion) and modernity (medicine).

Of course, many of today's older patients are religious in a traditional sense, while others will not countenance any talk about spirituality. But the proportion of those who understand spirituality as a personal quest is growing. An important implication is that, to offer spiritual care, healthcare practitioners must engage with patients as companions on a quest. An "expert" stance will not be effective — practitioners should begin not with formal definitions but with the lived experience of the patient.[16]

Spiritual care

In palliative care, providing spiritual care is a whole-team responsibility. All are involved in attending to the connections and disconnections in each patient's web of relationships. Some of these become apparent in an admission interview; others emerge as patients develop trust in team members and share stories of their lives, their current concerns, their hopes and fears concerning the future. Over time, a picture of the web emerges. It is essential that spirituality be monitored over the course of the illness, as issues arise at different points for different people. Some already have answers to existential questions before illness disrupts their lives; some only begin to reflect after diagnosis; some defer them permanently.

For some patients it is enough to have their spiritual needs and resources acknowledged, implicitly or explicitly, by the

team. Others will want to examine the significance of what has emerged. Working with an individual to explore the meaning of these connections and disconnections — as compared with observing them — is best done by team members with expertise in processes of self-understanding, changing perceptions, and spiritual development: psychologists, social workers, and pastoral care workers. Referral may also be appropriate, particularly for those who would appreciate care from an authorised religious practitioner. The overall spiritual care strategy will involve the whole team.

The strength of a team approach is that the variety of relationships available to the patient more readily elicits the diverse strands of the web. However, spiritual care offered by individual practitioners follows a similar approach. It begins with attention, offers companionship in exploring issues that arise, encourages a quest for meaning, and continues to support the relationships that give life. Strategies for care will address physical, psychological, social and spiritual aspects of a person's life, and may involve intervention to change his or her circumstances, assistance in revising a sense of self, or support to re-examine fundamental beliefs.

Finally, spiritual care is to be offered, not imposed. Clinical practitioners are often in an ideal position to offer spiritual care, precisely because they are involved in the experiences that disrupt patients' lives. Practitioners' attention to spiritual concerns, and their capacity to legitimate spiritual quest, can be enormously powerful. But there is an associated danger that the prescriptive approaches of clinical treatment can be extended to spiritual interventions. If so, it is more likely that these will be experienced not as care but as an intrusion. It is a fundamental requirement of spiritual care that we respect the way people go about looking for answers, for at this point what matters is not the content so much as the quest itself.

Competing interests

None identified.

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