"Diagnosing" and "Managing" spiritual distress in palliative care: Creating an intellectual framework for spirituality useable in clinical practice.

Geoffrey Mitchell1
Judith Murray2
Patricia Wilson3
Richard Hutch4
Pamela Meredith5

1. School of Medicine, University of Queensland, Ipswich
2. School of Psychology, University of Queensland, Brisbane
3. Mater Health Services, South Brisbane
4. School of Religion, University of Queensland, Brisbane
5. School of Health and Rehabilitation Sciences, University of Queensland, Brisbane

REVIEW

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Corresponding Author:
Geoffrey K Mitchell
School of Medicine Ipswich Campus
Salisbury Rd
Ipswich, 4305, Australia

Abstract

Definitions of Palliative Care emphasise the holistic nature of care and specifically name spiritual care as an essential element of that care. However, many health professionals are reluctant to engage in spiritual care, often for fear of imposing their own beliefs on a patient at a particularly vulnerable time. We sought to develop a framework for the identification and management of spiritual issues in health care. We found that religion and spirituality were considered as interchangeable concepts, where religion is more properly considered as organising spiritual expression through a formal set of beliefs. Spirituality is best considered as a search for greater meaning, purpose, and direction in living. The key to addressing spirituality is to recognise its role in a person's attempt to make sense of what they are experiencing. The health practitioner's best response is to create an environment in which the patient can express their distress in a secure setting, and identify what, within their belief systems, could provide comfort. Translating this framework into "diagnosing" and "managing" the person's spiritual state helps health practitioners to understand the observations and actions that are inherent in achieving this. The critical importance of the health practitioner acknowledging their own spiritual and religious state, and being willing to offer empathy to the sufferer, is emphasised in this framework.

Key Words
Spirituality; palliative care; clinical care

One of the most important areas of health is caring for people in the last days of their lives. The discipline boundaries that serve health well when diseases can be cured or controlled are challenged when cure is not possible- and the task becomes to support the process of dying. It is in this context we see how vital each realm of the Biopsychosocial-Spiritual model of care (1) becomes. Physical symptom control is exacerbated by psychological stressors, the social demands of dying and by the spiritual challenges of ascertaining meaning from the situation and facing the unknown. Consequently, guidelines for palliative care have necessarily called for care across all dimensions. In 2004, the World Health Organisation defined palliative care as:

> *an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.(2)*

Hence, there is a recognition that spiritual issues must be accounted for in the care of those facing death. However, incorporating spiritual care into care of the dying has not always been easy to achieve. There have been many reasons for such unintentional neglect and/or intentional exclusion. Issues of definition, lack of a clear knowledge base and delineated disciplinary control, the intensely personal nature of spiritual experience, and issues of

accountability in terms of measurable quantifiable outcomes, have plagued the efforts to implement spiritual care into the realm of palliative care.

As western society increasingly adopted the scientific premise, where only knowledge that can be 'proved' is truly valid, and where reductionist and logical thought is of higher status, there ceased to be an unquestioning acceptance of religious and spiritual beliefs. In the 21st Century, although findings suggest a diminution of the role of religion in western society they also demonstrate that a majority of people still believe in a 'Higher Being' and consider themselves to be spiritual. Kaut (3) argues for greater attention to be paid to developing better understanding of the spiritual within the biomedical context. Formal research findings confirm the importance of spirituality in the realm of health care. The Gallup International Institute (4) found that people want to reclaim and reassert the spiritual dimensions of dying yet not many people saw clergy as providing broad spiritual support when they contemplated their own dying. Mytko & Knight (5) showed, by literature review, that cancer patients described their religious and spiritual beliefs as providing a profound method of coping with the disease and improving their quality of life. Kaczorowski (6) demonstrated a positive association between spiritual well-being and reduced anxiety in adults diagnosed with cancer. McClain, Jacobson et al. (7) found that belief in an afterlife was associated with lower levels of end-of-life despair, but was not associated with levels of depression and anxiety. However, when levels of spirituality were controlled, the effect of afterlife beliefs disappeared. This suggested to these researchers that spirituality had a much more powerful effect on psychological functioning than actual beliefs held about an afterlife. Spiritual beliefs affect outcomes associated with bereavement. (8) In contrast to these studies that have found positive effects of spirituality on health outcomes, King, Speck & Thomas (9) found that, for 250 patients discharged from hospital, those with stronger spiritual beliefs were more likely to stay the same or deteriorate clinically after nine months.

The delineation between the terms and concepts of religion and spirituality is blurred, which leads to variation in the measures used to describe these concepts, and consequent confusion within evidence-based care guidelines for spiritual care. For many people, spirituality and religion are interchangeable terms: hence those deemed the most spiritual people have been seen as those most involved in the organized activities of mainstream religious faiths. However, deeply spiritual people may not be affiliated with a particular religious group. The terms are not synonymous. There is much debate about how spirituality is defined. Being so personal to each individual, the experience of spirituality is different for everyone, and it is discussed and displayed differently between cultures. The issues that are confronted on a spiritual plane may also change for each person depending on the situation in which he or she is placed. Aldridge (10) examined the definitions of spirituality used within medical literature. All 13 definitions identified cited or alluded to the following elements: the need to transcend or rise above everyday material or sensory experience; one's relationship to God or some other higher universal power, force, or energy; the search for greater meaning, purpose, and direction in living; and healing by means of non-physical kinds of intervention (e.g., prayer, meditation, religious belief). Lapierre (1994) sought to describe spirituality in terms of six dimensions through which life as a spiritual person can be experienced: a journey as one searches for purpose, direction, and meaning in life; an encounter with transcendent being; a level of reality that exceeds the limits of ordinary human experience; a sense of community with fellow journeymen; religion in terms of a pattern of spiritual life; a sense of the mystery of creation and a connectedness with the natural world, and personal transformation.

The National Institute for Healthcare Research (11) argued that spirituality represents a person's unique search for what is sacred in life, answers to life's ultimate questions as well as a feeling of connectedness to others and the environment. This may or may not be as a member of a religion. Therefore, religious traditions may represent different manifestations of human spirituality. Worthington, Kurusu, McCullough & Sandage (12) made a distinction between the two concepts arguing that religion concerns beliefs (statements consistent with an espoused religious position) and religious values (statements consistent with what is considered by that tradition to be important in life). They considered spirituality to refer to believing in, valuing, or being devoted to some power higher than that which exists in the physical world.

Consequently, while it may be relatively easy to compare and contrast *religions* in a general manner in terms of beliefs, traditions, rituals, and organization of the faith, comparison of the *spirituality* of individuals is much more difficult. While religious traditions may change over time, there exist recognized ways of integrating these changes into the existing structures (e.g., Papal edicts, synodical decisions, and charting the history of these changes). In contrast, a person's individual spirituality can change abruptly or gradually, and often imperceptibly. Sometimes single events (a traumatic event, a dramatic conversion experience) can change a person's spiritual beliefs significantly, either toward or away from a spiritual path. In something as real and raw as facing one's own death or the death of a loved one, it is not surprising that the spiritual path for many can be altered and questioned, take on a new direction, or even feel directionless. It may even be the first time that this reaches a level of conscious thought. Hence, the care of those facing these issues deserves to be addressed.

As health professionals carries out their daily duties, they will be confronted with a diverse range of personal perceptions of spirituality that may, at times, be very different from that of their own. Woods and Ironson (13) tried to identify the way that ill patients describe their own spirituality by interviewing persons faced with life-threatening conditions of cancer, cardiac problems, and

HIV. They sought to find out what these people mean by being 'religious' or 'spiritual'. People identified themselves as religious or spiritual or both. There were many similarities between groups in terms of amount of time spent in prayer, beliefs setting tone for their life, a connection to God, and a sense they will live on in some form. However, there were also differences. Those identifying themselves as spiritual described recovery and healing as happening *through* them, and saw God as an active agent in their lives; whereas, those identifying themselves as religious were more likely to say that healing happens *to* them, and see themselves as a part of God, a part of the unity of life.

In considering how health professionals could utilise this work, we visualised the religiosity and spirituality as distinct variables. Religiosity could be considered the degree to which adherence to a formal belief system was important to a person. Spirituality could be considered the degree to which the search for meaning was important to the person (Figure 1). While the figure represents these two elements as dichotomous, they are more properly thought of as continuous variables.

Figure 1. The relationship between spirituality and religiosity

Religiosity
Is adherence to a formal belief system important to the person?
Yes
No
Spirituality
Is the search for, or sense of meaning important to the person?
Yes
No

Moving toward spiritual care in palliative care

From the preceding discussion, the importance of spiritual care for those facing their own death or that of their loved ones is obvious. However, the difficulty of determining the most appropriate manner in which this can be accomplished is also clear. The disciplinary rigour of practice guidelines is compromised by the nebulous nature of the care that can be offered.

Rumbold (14) asserts that spiritual care is integral to palliative care, and that the responsibility for this care lies with the whole palliative care team. He offers some explanation as to how spiritual needs may differ between those facing a life-threatening illness. For example, some patients will require only that their spiritual needs and resources are acknowledged, implicitly or explicitly, by the team; others, he suggests, will want closer examination of the significance of the meaning of these connections and disconnections, rather than just observation of them, and, as such, will require health professionals with specialised skills in this area. However, Rumbold cautioned that spiritual care is to be offered, and never imposed, and warned of the dangers inherent in imposing a prescriptive approach of clinical treatment to spiritual care.

The health professional's best response is to create an environment in which the patient can express their feelings about their situation, and identify what, in their belief systems, could provide comfort. Translating this framework into "diagnosing" and "managing" the person's spiritual state helps health practitioners to understand the observations and actions that are inherent in achieving this. The critical importance of the health practitioner acknowledging their own humanity and being willing to offer empathy to the sufferer is emphasised in this framework.

When considering spirituality in end of life care, Puchalski (15) believes that, as part of the obligation to respond to, and attempt to relieve, suffering, physicians and other care givers need to communicate with their patients regarding their spirituality, and how they cope with suffering. She encouraged health systems to enable people to die in peace in the way in which they desire. Effective health systems should facilitate activities that bring peace to people, such as prayer, meditation, listening to music, art, journal writing, sacred ritual, and relationships with others. She further recommended that spiritual care systems must be multi-disciplinary, with all team members working together to include spiritual care as part of holistic patient care.

A recent Australian study (16) of 36 patients supports the importance of not imposing prescriptive care or assuming that all patients will want to discuss deeply personal or existential matters. Health professionals need to recognise the importance of "emotional privacy". These patients described their need for staff to be especially sensitive in understanding that their feelings and concerns were deeply personal and, in some cases, attempts to elicit information by others, either staff or family members, were experienced as intrusive.

Translating spiritual care to the workplace

Encouraging spiritual care requires a translation of the theoretical perspectives discussed above, to a paradigm that is understood by health professionals. We have attempted to frame consideration of spirituality around the traditional medical model of diagnosis and management of a disease or problem. This requires conferring upon spirituality the status of a "problem", which is clearly not the case. However, converting "spirituality" to "spiritual distress" does allow superimposition of the medical model more readily.

1. Creating a holding environment

The first issue is to create an environment in the care setting that encourages exploration and disclosure of sensitive issues. We term this a ***Holding environment.*** The purpose of this is to have the patient sense sufficient security and confidence to explore issues for which the direction of the enquiry is uncertain, and the answers

unclear. Such situations can create considerable anxiety. The holding environment reduces the likelihood of fear. Patients are encouraged to find within themselves, through their relationships with others, and through their spiritual resources, whatever they need to make this journey in a way that is meaningful for them.

A good parallel is the loving nurture a mother provides for a toddler. This allows the child to feel secure enough to explore unfamiliar situations and emotions, even when the mother is not immediately present, confident that the mother will be available when needed.(17)

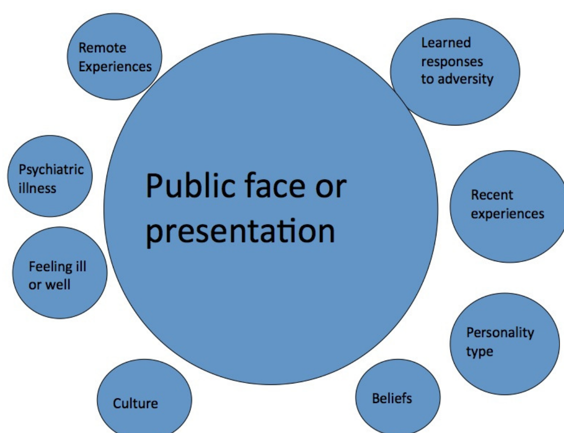
Thus the health professional's approach should make it clear to the patient that they are the centre of their attention, and that they are willing to explore beyond the immediate physical concerns that the patient may have.

2. Performing a spiritual assessment (a "diagnosis")

The phenomenon of the "public face"

The manner or persona presented to a health professional (the patient's "public face") is an amalgam of numerous influences, including the patients' physical and mental health, the presence and strength of close relationships, and the influence of beliefs and past experiences (Figure 2). It is tempting to interpret a patient's presenting manner – his or her public face – as the whole story: an assumption that may lead health professionals to react inappropriately. An angry person, for example, may have repressed fears or experiences that explain the anger when exposed to the light of day. However, if the health professional responds to this anger defensively, with returned anger or indignation, it is unlikely that the underlying cause may ever be found. The patient cannot be helped. It is better to absorb the anger, keep the relationship open, and wait until the underlying issues declare themselves.

Figure 2: Contributors to a person's "public face"



Making a formal spiritual "diagnosis": spirituality vs. religiosity

As discussed above, the terms spirituality and religion are frequently used interchangeably. The practitioner needs to seek clues as to what the person's belief system is, and how important it is to them. It is also useful that practitioners assess their own position with respect to spirituality and religiosity. An understanding of one's position in the quadrant model described in Figure 1 goes a long way to explaining why discussing these issues with other people can be difficult: the practitioner will often be in a different "quadrant" to the patient. This highlights the importance of the health professional attempting to understand the patient's point of view, and trying to find words that will help *them*, even if those words and thoughts will be foreign to *the professional.*

Gathering the information to make a formal diagnosis:

Observing the patient and his or her surrounds gives clues. If at home or in hospital, what are they reading? Are they wearing or using religious symbols? Do they have cards or photos that may reflect beliefs that may be important to them?

Using these as prompts might be a useful introduction into a conversation about the patient's beliefs. A simple non-threatening question, that does not reveal the belief system of the person asking it, can also allow the conversation to take place:

Do you have any religious or spiritual beliefs or practices that you would like me to know about? Astrow et al.(18)

This invites the patient to divulge more, or to refuse the advance and that is where the conversation stops.

Other clues to the person's spiritual beliefs come in the content of their talk. Vaughan (19) describes talk that contain any of the following concepts, then the person's spirituality is being addressed:

Authenticity
Letting go of the past
Facing our fears
Insight and forgiveness
Love and compassion
Community
Peace
Awareness
Liberation
Forgiveness

3. Recognising Fear – the reason for making a spiritual assessment.

Most people who suffer a life threatening illness will probably experience fear, or at the very least, uncertainty. Patients are being forced to grapple with a journey into the unknown, towards a reality one has not sought voluntarily. Health professionals firstly must recognize fear, legitimize the experience of it, and then provide support for the patient's efforts to rein it in.

Fear will occur with the arrival of unexpected bad news, or with escalation of symptoms. However, it may have no

particular trigger. It may relate to the presence of uncertainty: questions about what dying will be like, what lies on the other side of death, worries of how surviving loved ones will cope, and so on. It is essential to recognize the source of the fear, and to allow it to be expressed. Providing relevant information, for example, of what symptoms can be expected and what can be done to minimize their impact, can be very useful. It is clearly important to address physical symptoms that can be addressed.

Reactions to fear range from bewilderment, to denial, to stoicism, to tears, to anger, to expression of concern for the consequences for loved ones of their dying (Box 1). Can the patient articulate fear, or is fear an underlying contributor to that patient's "public face"?

Box 1. Manifestations of fear

Anxiety
Panic attacks
Depression
Withdrawal from previous religious practices
Isolation and alienation from others
Preoccupation with being in control of matters and /or people
Obsessive behaviours
Anger
Increased physical pain, exacerbation of existing symptoms or new physical symptoms
Suicidal thoughts or attempts
Refusal of treatment previously accepted with signs of distress at the decision
Sense of hopelessness

Fear or uncertainty challenge preconceived norms. Yalom states that confronting a person's death will *...create a dramatic perspective-altering opportunity*(20). Faced with their own death, many will make radical changes to their outlook. Many find preconceptions about the strength of their beliefs are challenged. Some will find in their faith a source of strength; others will find their preconceived beliefs let them down under this stress.

It is essential that the spiritual distress arising from fear is distinguished from anxiety, depression or substance abuse – the management is quite different.

The key to managing fear (Box 2) is to understand that it may not be essential for answers to be provided:

Suffering is not a question that demands an answer; it is not a problem that demands a solution; it is a mystery that demands a presence. (anon)

Box 2. Dealing with fear

Acknowledge the fear, pain or confusion
Acknowledge that you can't fix it as such
Validate and encourage the patient that they have the answers or can gain them for themselves
Encourage and support their search

4. The Limbic system and emotions like fear

Lewis, Amini and Lannon (21) argue that while the cortex provides the sensory experience and logic to an event, the limbic system provides the emotional overlay to the experience. In the case of fear, it is the emotional response that is so unpleasant that it demands that the person avoids a repeat of the situation that caused it. It is a survival mechanism. However, this does not help when the situation is inevitable, such as impending death, or torture. Fear arises from the anticipation of severe adversity. Since the Limbic System has connections to all parts of the brain, fear thus impacts on the physiological reactions of all parts of the body. Thus to block fear – when fear ceases to confer survival value- is to block these all-encompassing responses.

5. Dealing with fear: *agape* love

A plethora of religious and secular writings describes love and fear as polar opposites: where one exists, the other cannot. For example:
There is no fear in love, but perfect love casts out fear. (The Bible - 1 John 4:18)

The notion therefore is that love can block the development of fear, and the experience of love can rein in fear.

Agape is a Greek word that captures the right notion. It has been described as
...a non-erotic pure love that seeks nothing in return...aligned with altruistic love, in which an individual can care for a complete stranger, as if that stranger were family. (22)

For the health professional, agape love involves offering compassion and humanity to the person: making them aware that their circumstances are understood, their visceral responses to the circumstances matter to the practitioner, and that the practitioner is willing to stand alongside them in their circumstances. As Pope Benedict XVI states:

…..while professional competence is a primary, fundamental requirement, it is not of itself sufficient. We are dealing with human beings, and human beings always need something more than technically proper care. They need humanity. They need heartfelt concern. (23)

Expressing limbic experiences

People communicate at the level of their emotions, without words having to be spoken. Lewis, Amini and Lannon (21) term this Limbic resonance. This is the basis of 'gut reactions' or non-verbal communications that identify dissonance between what is being said and what a person may actually feel is meant. While it is often neither logical nor explainable, there is little doubt to its validity.

Given that limbic experiences are non-verbal, it may be that the person may not find that words are adequate enough to express them – either to themselves or to others. Similar dilemmas may confront those attempting to meet the fear or uncertainty experienced by the dying patient. It may explain why it is often a struggle to allow

such a discussion to take place.

It may also be that both parties need to be encouraged to seek to express these experiences by other means – a favourite song, a picture, or simply the comfort experienced when sitting quietly with a person that is loved and respected. Health professionals should recognise this, and encourage the patient to seek out these non-verbal means of expression of their distress. Moreover, they should consider how they can practice this form of communication in a clinical setting. The use of silence – even the use of touch from time to time – can be very powerful.

Conclusion

This paper describes the central role of addressing spirituality. While this is focussed around the needs of palliative care patients, the principles relate to anyone suffering any sort of loss, which becomes all of us at some point. By understanding the dynamics of spirituality, and the essential role of developing a meaningful and trusting relationship with a patient, it is possible to assist them to use their deepest beliefs to make this most difficult part of life's journey tolerable, and perhaps even to derive profound benefits from it.

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