

## ***Reading in Recent Literature on the Practice of Spiritual Care with Palliative Care Patients***

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### ***Introduction and Context***

An integral part of my work as minister at Lansdowne Presbyterian Church Masterton is to respond to the news that a person has received a diagnosis of terminal illness. The practice of pastoral care brings me alongside them and their family during their experience of dying. I create, as requested, a ceremony that enables all who loved and respected them to celebrate their life and reverently farewell their body, and I offer pastoral care for those who remain in their absence. This practice usually involves a church member or a person with religious background, and I am asked to be involved in my capacity as a Christian minister. This often means visiting at home or in hospital, bringing prayers and readings from Scripture, providing a listening ear and sometimes practical support, responding to ideas, questions or protests about death with compassion, hope and faith.

In a person's final days I may meet different generations of family members who are gathering to farewell their loved one. It is sometimes the case that family members are not aware of the significance of a dying person's faith affiliation as this was seen as a 'private' part of their lives, and may not be shared by others in their own lives. I may also be meeting with a dying person whose younger family members express conflicted emotions about death, or who hold differing expectations as to how a funeral will be conducted. In these situations I need to be able to understand what is of importance to the dying person, whilst relating well to those who are gathering to grieve and farewell them. I need, in effect, to speak the grief languages of different generations, and of people who do not hold Christian faith. Allied to this, I am also asked to take funerals for people where it is expected that a minister takes the funeral, but religious faith does not feature strongly either for the person who has died or their mourners. For such a ceremony to have integrity it needs to come close to their world and reflect what is important in their lives.

In 2008 I was asked to become a *spiritual advisor* to the newly formed Kahukura, Palliative Care Service of Wairarapa District Health Board. I was honoured to be included in a diverse and richly skilled team of medical, nursing, pharmaceutical, therapist, and social work professionals dedicated to providing best practice for palliative care patients in the Wairarapa. Access to spiritual care is mandated by Wairarapa Hospital's patient care policies, and is seen as integral to Kahukura's assessment and ongoing care of patients who are terminally ill. However, over the course of several training events in palliative care with health care providers it has become clear that spiritual care is not well understood by many people involved in caring for a dying person, and opportunities for its practice are correspondingly lost. I make this comment with reference to the non-Maori provision of care, the area in which I am involved. I believe that as diverse professionals caring for terminally ill people we need to find a more common language for their spiritual care and well-being.

### ***Methodology***

Over a period of four weeks in June 2009 I undertook reading in recent literature relating to spirituality in palliative care, and met for discussion with Rev Paul Ranby, Chaplain at Arohanui Hospice, Palmerston North. In September 2009 I attended the 11<sup>th</sup> *International Death, Dying and Disposal Conference* at Durham University England, and *Reversed Thunder: The Art of the Psalms Conference* at St Andrew's University, Scotland.

I wish to acknowledge conversations with Dr Mary Murray, lecturer in Death Studies at Massey University, and with Anne Savage, clinical nurse educator at Kahukura, Wairarapa Palliative Care Service. My thanks are also due to Ronnie Parton, librarian at Te Omanga Hospice Lower Hutt for her generous welcome to the resources under her care. In this necessarily brief time I read or attended a breadth of papers in the field, and alighted upon two books in particular that have influenced my action-reflection in the ensuing months.

**Palliative Care** is understood as the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care also supports the bereaved family or whanau. (*NZ Palliative Care Strategy, Ministry of Health 2003*)

In preparing a working definition in a New Zealand context the Palliative Care Subcommittee, NZ Cancer Treatment Working Party (2007) used as a starting point the 2002 World Health Organisation palliative care definitions:

*“Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.*

*Palliative care:*

- *Provides relief from pain and other distressing symptoms*
- *Affirms life and regards dying as a normal process*
- *Intends neither to hasten nor postpone death*
- *Integrates the psychological and spiritual aspects of patients’ care*
- *Offers a support system to help patients live as actively as possible until death*
- *Offers a support system to help the family cope during the patient’s illness and in their own bereavement*
- *Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *Will enhance quality of life, and may also positively influence the course of illness”* (www.moh.govt.nz)

### **Spirituality and Religion**

It is helpful in the first instance to consider contemporary understandings of spirituality. Resistance to the practice of spiritual care may arise from the position that sees spirituality and religion as synonymous terms. Neglect of spiritual care may arise from difficulty with the concept, little attention to it from care-givers in their own experience, or lack of formal introduction in palliative care education (*McBrien 2006, Hickey et al 2008, Bush et al 2008*).

Understanding spirituality is the starting point for most of the articles listed. The majority of researchers and practitioners cited concur with the view that traditionally spirituality has been associated with personal beliefs about relationship with God, derived from a religious framework, and expressed in worship and prayer, often in company with others. For many people within our

New Zealand population, particularly those of mature years, this understanding continues.

However, in Western European societies from the mid 20<sup>th</sup> century onwards spirituality has been increasingly understood apart from formal religious affiliation and practice (Rumbold 2002). This has taken place in the context of secularising trends especially marked in generations currently aged 65 years and under, and growing diversity of ethnic groups through immigration and settlement. In *Last Words: Approaches to Death in New Zealand's Cultures and Faiths* (Schwass 2005), compiler Margot Schwass includes contributions from 32 cultural and faith groups, including non-religious, and in addition to Tikanga Maori.<sup>1</sup> In his Introduction, Race Relations Commissioner Joris de Bres comments

*“... death always has a particular meaning for individuals. For many of us, that meaning is shaped by our culture, spirituality or religion. ... As this book makes clear, the line between culture and religion is blurred and sometimes contested.”* (Schwass 2005)

Recent understandings of spirituality in nursing theory are well expressed by this summary:

*“that element within the individual from which originates: meaning, purpose and fulfilment in life; a will to live; belief and faith in self, others and God; and which is essential to the attainment of an optimum state of health, well-being or quality of life.”* (Ross 1997)

In considering the attributes that characterise spirituality McBrien (2006) includes reference to inner strength and peace achieved by an individual's acceptance of their situation, and the connectedness that arises from significant relationships with self, others, God or a higher power, and the environment. He suggests that two consequences of spirituality in the context of palliative care are hope and self-transcendence; the latter enables the individual not only to accept their illness, but also move beyond loss of hope to aspire to a meaningful life, (as Jones 2005). Addressing the experience of loss of hope, McClain writes in *The Lancet*:

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<sup>1</sup> Last Words(2005) was commissioned by the Funeral Directors Association of New Zealand to recognise the ways in which different groups in New Zealand approach death at the start of the 21<sup>st</sup> century

*“There is some evidence that spiritual well-being offers some protection against end of life despair in those for whom death is imminent.” (McClain 2003)*

There are, however, alternative voices that consider too much elasticity has been applied to understandings of spirituality,

*“... stretching it out so that it includes virtually everything that might be of importance to somebody.” (Paley 2008)*

Paley calls for a more rigorous assessment of the role of spiritual care, separate from psycho-social support, making it clear that he starts from the assumption that religious and spiritual beliefs may be classed as ‘positive illusions’, a special case of falsehood. In response to existential distress, Paley recommends:

*“While caring for patients who have religious beliefs, it is legitimate to discuss God, the ‘afterlife’, and other forms of ‘transcendence’, if it helps to alleviate existential distress, ... but the theoretical account will refer to the psychology of positive illusions.” (Paley 2008)*

In his medical review of the relationship between religion and health, Garrison (2005) uses the terms ‘religion’ and ‘spirituality’ interchangeably. Of greater concern to him is the facile treatment of a patient’s religious faith, that is, whether a patient is religious or not, without due attention to the content of that belief.

*“It is this sort of understanding that is implicated when researchers recommend that physicians encourage their patients to make use of health-promoting resources from the patient’s own religious tradition, insofar as the physician is unconcerned with the exact beliefs and rituals of that particular tradition.” (Garrison: 2005)*

Not all religious resources or experiences will lead a palliative care patient to acceptance, inner peace or hopefulness in the face of death. A patient may be grappling with feelings of guilt, failure and unresolved conflicts in relation to their beliefs or primary relationships. They may need a skilled practitioner in spiritual care to identify such needs and to guide them towards resolution.

Writing with broad reference to Christian theology and pastoral care in dialogue with sociology and philosophy in his book *The Theology of Death*, Davies reflects on how the ideas, values, beliefs and behaviours that

constitute our life-style also relate to our death-style. The summary phrase 'death-style' becomes a touch-stone in relation to Davies' proposal that:

*"The key focus of our reflections lies with the body, this matrix and medium of our beliefs and values. This is not simply the temple that enshrines our prime values, but is the very basis for them, a view that warns against the overly abstract nature of theology or philosophy."* (Davies 2008)

### ***Spiritual Needs and Spiritual Care***

In a rare article addressing *Spirituality and Dementia*, Doherty (2006) describes the spiritual needs of patients as being connected; being respected and appreciated; being loving and being loved; being known and accepted; giving and sharing; being productive; to still become and to have hope. She promotes the use of a 'Senses Framework' for carers to engage the following needs in patients:

- A sense of security, free from threat, harm pain and discomfort
- A sense of continuity, linking past biography to present and future
- A sense of belonging, recognition of meaningful relationships
- A sense of purpose, opportunity for purposeful activity
- A sense of fulfilment, meeting valued goals
- A sense of significance, of being valued as a person of worth.

Living with terminal illness, nonetheless, can mean that a person experiences existential distress or spiritual pain. This may be variously expressed as

- loss of meaning or purpose
- grief at reduced abilities and increased dependency
- loss of control over one's life and lack of choices
- sense of absurdity or unfairness
- worry about family and their future
- loss of peace of mind
- sense of regret, sin or shame
- loneliness and anxiety over the process of dying.

*(Marata 2003; McKinlay 2006)*

Taking this further Marata (2003) identifies three issues in spiritual pain: over temporality (loss of future), concerning relationships, and identifying

autonomy. With respect to a person's loss of future, Marata proposes carers assist in a life review to help find meaning in the present. This significance is extended where a person's religious faith anticipates life after death. Where spiritual pain in a person concerns their relationships, Marata suggests they talk about or write to people in the life review. While decreasing autonomy remains a primary experience of palliative care, Marata encourages the person to recognise their control of perceiving, thinking, speaking and doing.

### ***Components of Spiritual Care***

In response to this reading I reflected on my practice of spiritual care with seriously ill and palliative care patients. I identified five components of spiritual care that are shaping my interaction with patients and families, and guiding my conversation and listening:

- Respecting the story
- Bridging relationships
- Relieving the pain of dying
- Making meaning
- Using ritual, both formal e.g. communion or appropriate ritual from a person's religious affiliation, or informal e.g. using readings, prayers, symbols that relate to the person's life.

By respecting the story I refer to a position in which the spiritual care practitioner comes alongside a person, and hears the person's life stories in their own terms. Through attentive listening and reflective questioning the carer will identify what has meaning and significance for the person, and be able to affirm the values or experiences that have shaped their life (*life-style as per Davies*) and continue to do so as they are dying (*death-style*). In my experience, this can take place over time in repeated visits, or may be focused in a short space of time as a person nears death and has family members present. In the latter case, remembering 'the good times' or 'saying the important words' has capacity to bridge the grief of separation as a person dies. I use the word 'bridge' intentionally in the sense of providing supports and linking connections between the dying person and those they are leaving.

From a nursing perspective Byrne, community palliative care nursing in Glasgow, values the use of metaphor in the language of spiritual care:

*“In palliative care the metaphor of journey is often used to describe the experience of illness. Cicely Saunders<sup>2</sup> described it as a spiritual journey, demonstrating opportunities for growth and development, hope and discovery. As professionals we share that journey. Stories often include metaphoric images and give an understanding of the uniqueness of individual fear and inner need.” (Byrne 2008)*

Byrne advocates the use of metaphor to increase shared understanding of a clinical situation, or to assist in cross-cultural communication. Where words are not primary tools for a person, art therapy or ‘mindfulness groups’ may also help them to express their experience and needs.(Chadwick 2008) Somerville notes the paradox for nurses in caring for patients of different cultures in that;

*“In endeavouring to treat everyone equally, nurses treated everyone as individuals. They made intense efforts to transcend both cultural and language barriers.” (Somerville 2007)*

Might not this also be our practice in providing spiritual care?

### **Who does Spiritual Care?**

The provision of spiritual care is integral to palliative care, since the latter is shaped by what is important to the patient:

*“Whether or not our religious patients are ‘delusional’, as Dawkins suggests ... and you agree with the statement is, of course, immaterial. Professional palliative care is defined and determined by our response to the patient and their family’s needs and not our personal preference or prejudices.” (Smyth 2008)*

The nursing papers cited started from the viewpoint that medical and nursing staff have a role to play in the assessment and provision of spiritual care, in order that there might be

*“balance of mind, body and spirit for the maintenance of health in a person” (McBrien 2006)*

However, the articles I researched suggested that formulating a commonly understood and interpreted framework for spiritual care by nursing and

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<sup>2</sup> Cicely Saunders: Founder of the Hospice Movement in Britain

medical staff continues to be a work in progress. (*Hickey et al 2008, Touhy et al 2005, Slater 2007, McCabe 2009*)

The caring, listening and assessing roles of nursing staff are seen to be particularly useful both in conveying support to a patient and their families, and in recognising when the issues raised require more specialised attention. The Palliative Care Subcommittee, NZ Cancer Treatment Working Party of 26 February 2007 states:

*“Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.” (www.moh.govt.nz)*

At this stage a spiritual advisor or chaplain may be called by staff, or requested by a patient or their families. (*Cornette 2005, Edmeads 2007*) One area of research eliciting further attention and thoughtful practice is that described as ‘end-of-life’ experiences. (*Brayne and Fenwick 2008*)

Where a patient has been resident in nursing care, their loss becomes a matter of grieving for the care-giving staff in addition to their families and friends. (*Touhy et al 2005*) At this point spiritual care of the nursing staff has significance, for e.g. through a memorial ritual, or recognising the way in which individual staff place flowers by or on the recently deceased person. In the focus of spiritual care for patients, we should not omit to nurture the spiritual well-being of the primary health carers.

Finally, we ought not to forget that a dying person’s spiritual carers may include their own family members. They too are on a spiritual journey of releasing their loved one and experiencing the transitions of identity and purpose which accompany such loss. Through such times they may hold the meanings and rituals that sustain spirit and keep faith for those who die and for those who remain.

I offer this report in the hope that it will engender further discussion and better understanding of spiritual care for patients, families and palliative care providers.

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