THE PROVISION OF SPIRITUAL CARE IN A HOSPICE: MOVING TOWARDS A MULTI-DISCIPLINARY PERSPECTIVE.

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Abstract: Hospices are spiritual places. The need to be sensitive to the spiritual is embraced by a wide spectrum of professionals. This article is an attempt to map the territory of the provision of spiritual care. It introduces two spiritual care frameworks then offers a brief over view of some of the key issues within medicine, nursing, occupational therapy and social work as they embrace spiritual care in their caring role. This invites readers to consider the interface between chaplains and the rest the multidisciplinary team as the team collectively care for the spirit and make a compassionate response. This article is based on a paper originally submitted to the SJHC 10th anniversary conference in Crieff, March 2007.

Keywords: chaplaincy, hospice, medicine, multidisciplinary, nursing, occupational therapy, social work, spirituality, spiritual care.

The hospice: a spiritual place.

*Palliative care is "an approach to care which improves quality of life of patients and their families facing 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."(*WHO 2004)

Spiritual care is integral to palliative care because death and dying is a spiritual place (COBB 2001, RUMBOLD 2002) describes dying as a 'spiritual quest'. It is evident that spiritual issues, such as making sense of it all, fostering hope, conserving one's dignity, feeling connected to one's self, one's family, one's God, all become more important as one faces the existential crisis of one's mortality (KEUBLER, DAVIS, MOORE 2005).

'Many individuals do not seriously search for the meaning and purpose of life but live as if they will go on for ever. Often it is not until crisis, illness or suffering occurs that the illusion of security is shattered. Therefore illness, suffering and death by their very nature become spiritual encounters'.(Granstrom cited by ROSS 1995)

What this means is that hospices are unique, liminal places, somewhere between the living and the dying and for the patients and for the staff, the spiritual is very close to the surface (LAWTON 2000). Spirituality matters. Implicit or explicit it is there. It makes demands on both patients and healthcare professionals. It is the particular hospice context of living in the face of death that sets the tone, the honesty, the depth and the character of the spiritual care provided.

So the need to be sensitive to the spiritual and to offer spiritual care is embraced by a wide spectrum of professionals and is widely reflected in the palliative care literature (DOYLE, HANKS, MACDONALD 1998; 2004; TWYCROSS, 1999; COBB, 2001; RUMBOLD, 2002). The spiritual dimension has recently written into professional and political standards (AHPCC, 2003; NHS QIS, 2002).

The fact that spiritual care may be provided by all disciplines in one way or another (NICE, 2004; NHS QIS 2005) is both a strength and a challenge. The challenge is that not only does the perception of what exactly constitutes spiritual care vary from person to person and profession to profession, but at an institutional level there is often a blurring of boundaries, roles and expectations within the team (WALTER, 1997). Recent philosophical debate –

'It is not morally acceptable to assume that patients want and consent to care for emotional, social and spiritual distress'

- invites caution and a reconsideration of the way, if at all, psychosocio-spiritual care is provided (RANDALL, DOWNIE 2006). In summary, there is a need to clarify roles, boundaries, expectations, practice and educational needs.

Spiritual care: mapping the territory.

Within healthcare three diverse but connected concepts describe the spiritual experience of illness, dying and death: spiritual distress, spiritual needs and spiritual wellbeing (STOLL 1989; MCSHERRY 2006).

"distress of the human spirit . . . a disruption in the life principle which pervades a person's entire being and which integrates and transcends one's biological and psychosocial nature". (KIM in STOLL 1989)

Serious illness disrupts and challenges inner wellbeing. Cassell, Kearney and Mount (CASSELL 1991, KEARNEY, MOUNT 2000) describe spiritual pain as alienation from the depth of one's being. The NCCN (2003) describe spiritual distress as the struggle for meaning whenever there has been a disruption of the life principle. Frankl (FRANKL 1962) says there is a spiritual dimension to suffering. Death is perhaps the permanent existential challenge (HEIDEGGER 1962, HOLLOWAY 2004).

Spiritual well-being is perhaps the other side of the distress coin. In a positive sense a person's spirituality may help them cope with the crisis of illness and in the face of death (COBB 2003; MCLAIN, ROSENFELD, BREITBART 2003). The provision of spiritual care is the response to the specific and unique spiritual needs expressed by the patient. The crucial issue is that all of the members of the palliative care team are involved to some extent or other – personally / professionally; implicitly or explicitly in the provision of spiritual care. This is because physical, social, psychological and spiritual interventions can all alleviate spiritual distress and sustain spiritual well being. They are woven together.

Spiritual care: frameworks.

There are an abundance of models and frameworks of spiritual care (WALTER 1997; KELLEHEAR 2000; COBB 2001; RUMBOLD 2002; WRIGHT 2004). Each model offers an insight into the nature and dimension of spiritual care.

Rumbold (RUMBOLD 2002) describes four strands which inform spiritual assessment, intervention and evaluation.

> Strand 1: questions of 'identity' brought on by the onset of illness and expressed as existential insecurity are repaired within supportive relationships.
>
> Strand 2: A person's loss of meaning and purpose in life is addressed by helping people review their lives and fashion fresh meaning.
>
> Strand 3: Where illness threatens religious convictions, spiritual care encourages people to revive connections with faith communities.
>
> Strand 4: Similar to 3, but people rely on new spiritualities to inform their spiritual quests.

The four strands complement each other and are woven together. Spiritual assessment is discerning which strand takes priority at any one time.

The Principal Component Model of Spiritual Care (MCSHERRY 2006)

McSherry (MCSHERRY 2006) distributed a recruitment questionnaire to staff and patients in three areas – two acute hospitals and one hospice. He recruited 53 participants (29 women, 24 men; nurses (24), chaplains (7), Social worker (1), Occupational therapist(1), physiotherapists (2), patients (14), and the public (4)) by purposeful sampling so that the diversity of belief, professional experience, religious affiliation and spiritual awareness was maximized. In semi-structured interviews participants shared their perceptions of spirituality, and the extent to which they expected either to provide or receive spiritual care. Following the principles of grounded theory there was concurrent collection and analysis

of the data by three levels of coding. The findings generated a Principal Components Model - an aid to integrate spiritual care into a healthcare context. The six principal components are individuality, inclusivity, integrated, inter/ intra disciplinary, innate and institution. While the sample size of several of the healthcare professionals was small, threatening validity, the findings do identify key issues which influence the provision of spiritual care.

Whichever model or framework one prefers the crucial aspect of care is that is begins with the patient.

'to provide spiritual care that is relevant, meaningful and supportive to the patient necessitates a process of discernment of what the person's needs might be, exploration of the options appropriate to meeting those needs and then engaging together in the relevant ritual or activity.' SPECK 2003a)

The compassionate response: the multidisciplinary team.

'with careful attention being paid to each individual patient, and with knowledge of what each member of the team can and cannot offer, it may be possible to find someone who can accompany each patient at least a little of the way'. (WALTER 2002)

Many professions – chaplaincy, (SPECK 2005; MOWAT, SWINTON 2005); nursing (HOLLINS 2005); occupational therapy (HOLYLAND, MAYERS 2005); medicine (PUCHALSKI 2006); psychiatry (CHOCHINOV, BREITBART 2000) - now argue strongly for being in some way responsible for and certainly clinically involved in the provision of spiritual care. But what is the interface within the team. How are roles, boundaries and expectations delineated?

The rest of this article offers a brief overview of some of the key issues within medicine, nursing, occupational therapy and social work. It is hoped that this will prompt some reflection about where chaplaincy fits into the healthcare team. How can chaplains use their spiritual wisdom and experience to support and encourage their team to be sensitive to the spiritual and competent in the provision of spiritual care?

Medicine

*The time is ripening for doctors to recall, reinterpret, and reclaim our professions sacred dimension'. (*Culliford, 2002, 1435)

While over history there has been a significant distancing from religion/spirituality in branches of psychiatry, psychology and medicine there has been a recent shift towards a holistic and implicitly spiritual approach (SWINTON 2001; Duke Institute on Care at the End of Life
http://www.iceol.duke.edu/index.htm;
George Washington Institute for Spirituality and Health http://www.gwish.org). This shift towards holism is embedded in palliative care. The benefits of physicians addressing the spiritual dimension of their dying patients are illustrated by Sulmasy (SULMASY 2006) who with reference to a particular case study delineates the role of the physician as:

> To take a spiritual history such as FICA (PUCHALSKI 2006) or SPIRIT (MAUGANS 1996) or SPIR (PETERMAN et al 2002; FRICK, REIDNER, FEGG, HAUF, BORASIO 2005) which provides 'a backdrop' against which to understand the current spiritual questions that dying people face.
>
> To conduct a spiritual assessment such as the FACIT-Sp to gauge the patient's present spiritual state and present spiritual needs (KELLY, MCCLEMENT, CHOCHINOV 2006).
>
> To facilitate spiritual care interventions.
>
> To recognize limitations and have an "exit strategy."

Underlying all is the ability of physicians to show respect, be present, show a genuine interest and listen carefully to what the patient as they come to terms with death and dying.

Nursing.

'Nurses need to be more reflective, critical and aware of the complexities of defining and using the concept of spirituality and more rigorous in the ways in which they use it and seek to develop 'spiri-

tual care' as a credible academic and practical field of enquiry'. (SWINTON, 2006)

The nurse has the most sustained contact with the patient and therefore may be best placed to provide spiritual care. The spiritual dimension of care is incorporated into the ethos of nursing (BRADSHAW 1994; CARSON 1989; ROSS 1995; MCSHERRY 2006). There are political and professional drivers (NMC 2002; UKCC, 2000) which lay a professional responsibility upon nurses to provide spiritual care. This can be seen as an opportunity or a burden (WALTER 2002).

Throughout the debate what is emerging is that nurses need to be spiritually aware (SAWATZKY, PESUT 2005) and nurses place value on establishing a caring relationship (TSCHUDIN 1986; MOK 2004). Within nursing the spiritual dimension infiltrates all dimensions of care (CARROLL 2001).

The qualities which make a good nurse in palliative care are to do with personal characteristics; relationships with patients; good communication skills; knowledge and the provision of comfort (JOHNSON 2002).

Several authors have found that although nurses regard the provision of spiritual care as belonging to them, they are unsure as to how to provide it. (MILLIGAN 2004; MCSHERRY 1998; NARAYANASAMY, OWENS 2001; KUUPELOMAKI 2001) This suggests that there is a theory-practice gap (OLDNALL 1996). Several studies (ROSS 1997; MILLIGAN 2004; TAYLOR AMENTA and HIGHFIELD 1995; WRIGHT 2002) have outlined some of the barriers as insufficient time; inadequate training; insufficient experience and insufficient support (MCSHERRY 2006).

Spiritual care giving is holistic and integrates the physical, psychological and social to the extent that the boundaries between spiritual care and nursing care are blurred (DRAPER, MCSHERRY 2002; MILLIGAN 2004).

Occupational Therapy

There has been considerable interest in the place that spirituality occupies within occupational therapy (WILDING 2002; HOLYLAND, MAYERS 2005; JOHNSTON, MAYERS 2005). The link derives from the belief that occupation influences spiritual well-being, and vice-versa. Is the relation between spirituality and occupation implicit or explicit? Beagan and Kumas-Tan (BEAGAN, KUMAS-TAN 2005) interviewed 20 therapists and 21 pastoral carers to see how the ways they describe their daily work indicate attention to the spiritual dimension of care. Therapists only referred to client spirituality six times suggesting that they do not think of their practice in the language of spirituality. However central themes such as respect, holistic practice, meaningfulness of occupation, fostering hope, helping patients to make sense of illness and the importance of connection all imply an implicit spiritual care. Subtle differences between professions were that whereas therapists identify meaning pastoral carers create meaning; and therapists drew on relationship as a tool for effective therapy pastoral carers saw the relationship in itself as healing.

The evidence suggests that spirituality is embedded implicitly rather than explicitly in occupational therapy. This means that occupational therapy is rightly concerned with occupational rather than spiritual goals (UNRUH, VERSNEL, KERR 2002).

Social work.

The social impact of illness is widely recognized and social work is at the heart of palliative care. (SHELDON 1999; HIGGINSON HEARN MYERS, NAYSMITH 2000; SAUNDERS 2001; SMALL 2001; MONROE 2004) Traditionally however social work has distanced itself from religion. In an attempt to re-establish the spiritual dimension as a legitimate dimension of social work practice recent papers (HENERY 2003; FAYER 2004, HODGE 2005) have reconsidered the relationship between spirituality and the social work role at a theoretical and conceptual basis. They have argued that it is essential to study the implications of spirituality as part of the whole person and developed different spiritual assessment methods (HODGE 2005).

Sheldon (SHELDON 2000) recruited an experienced social worker to convey the essence of social worker's role in palliative care. The social work role also enables the provision of spiritual care through establishing good values, managing anxiety and encouraging good team work.

Being aware of the rapid changes in social work practice, Clausen, Kendall, Murray, Worth, Boyd and Benton (2005) conducted a prospective serial qualitative interview study to explore whether palliative care patients would benefit from social workers' retaining the traditional 'casework' role rather than working as care managers. They found that social workers were 'conspicuous by their absence' in the community and highlighted areas – loss/dependency; family-centred issues; carers needs; practical tasks; emotional/spiritual and staff, in which social work intervention could have positively impacted on dying patients quality of life.

Summary.

Caring for the spirit belongs to the whole multidisciplinary team. It is too important to be left to the chaplain alone. Good palliative care requires the whole team to be competent, capable and compassionate.

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