



1st International Conference, *Spirituality in a Changing World*, 4 - 6 May 2010

Report on the Roundtable, *Spiritual Care at the End of Life*

The session, chaired by Professor Margaret Holloway, Vice-chair of BASS and Social Care Lead on the National End of Life Care Programme, had been organised partly in acknowledgement of the support for the conference from the DH, but also to take forward a developing series of events in the UK. Three speakers gave brief introductions to the discussion. There were around 25 participants across a range of disciplines and a mix of academics and clinicians/ practitioners. A few participants were from outside the UK. Not all participants were from end of life care work contexts/perspectives. There was a shared understanding that spiritual care at the end of life is everyone's business – one speaker used the phrase 'too important to be left to the professionals'.

Simon Chapman, NCPC.

Simon reported on the NCPC conference held in March 2010 on spiritual care (*The Missing Piece* - deliberate pun on piece) and the issues arising in delegate discussions. He summarised the background to the conference and the reasons for NCPC focusing on spiritual care:

- Palliative care is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as follows:

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

- Palliative care aims to:
 - Affirm life and regard dying as a normal process
 - Provide relief from pain and other distressing symptoms
 - Integrate the psychological and spiritual aspects of patient care
 - Offer a support system to help patients live as actively as possible until death

- Offer a support system to help the family cope during the patient's illness and in their own bereavement
- Similarly in End of Life Care, the advantage of a comprehensive end of life care strategy is that it enables you to consider everything.
- Spiritual care at the end of life is vital for many reasons:
 - Dignity
 - Personal
 - Issues of identity.
- People find it difficult to discuss. Professionals find it difficult to discuss. *Dying Matters* is a coalition set up to raise awareness about death, dying and bereavement. To enable people to become better informed and more confident about discussing these issues.
- There is a need to distinguish between spiritual support and religious support.

Issues arising from the Missing Piece

- a. Recognition of the importance of spiritual care
- b. Need for professional confidence and training; build competencies.
- c. How to produce an evidence base to persuade commissioners to fund spiritual care services? What are the benefits of providing spiritual care?
- d. Language: is "chaplaincy" helpful? Spiritual care or support?
- e. Definition
- f. Often in the end comes to "needs" – what needs can be assessed and identified by professionals? When is it so complex they need help?
- g. Spiritual beliefs often tied up with understanding of ethical issues; religious people might have spiritual needs which can't be answered by their religion.
- h. The coming situation: demographic change and budget deficit/debt mean more people will be dying in the community. Who can provide spiritual care in the community? What training are religious leaders in the community getting in end of life care? Can volunteers be used for spiritual support/ companionship?

Anne Cullen, Manager of Psychosocial and Spiritual Care, Princess Alice Hospice

Anne spoke about the experience of offering spiritual care through multidisciplinary team (MDT) working. The team consists of social workers, bereavement service coordinator and chaplain, plus the manager (who is a registered social worker) and team secretary. The team works with hospice patients and their families as inpatients, on day care and in their own homes. Two of the social workers work in NHS hospitals, funded by the hospital trust as part of a service level agreement. The extended team includes around 30 bereavement and chaplaincy volunteers.

The present team was brought together nearly two years ago and has evolved an increasingly integrated model of service delivery. In contrast to many social workers in NHS and statutory social care services the social workers are able to operate from a holistic focus. They talk sometimes about two distinct aspects of their work. Firstly, the practical side: welfare benefits, applying for grants, negotiating care arrangements and funding for these, advocacy and safeguarding. Secondly, social/psychological/spiritual care: this area of work is about supporting and enabling patients and their families in relation to the impact and implications of terminal illness, progressive disability, the prospect and reality of death, emotionally, psychologically and spiritually – how this affects their relationships and how they try to find ways of making sense and finding purpose in their lives. Language blurs the boundaries.

The team's remit is holistic further in the sense of working with patients, families and significant others in some cases from the point of referral to palliative through to bereavement support and counselling. Conceptually and in practice the team (more or less explicitly) recognises a substantial area of common concern across the disciplines of social work, counselling and chaplaincy in terms of social, psychological and spiritual care. There is a lot of co-working and joint projects. This includes some co-counselling and joint facilitation of groups. Members of the team also provide clinical supervision to colleagues, as well as teaching within the service and externally. Advise on integrating spiritual care within total care plan. Contributions to ethics committees are one example of offering consultancy on spiritual issues.

Anne felt that the team's particular contribution to MDT discussions and continuing professional development of colleagues is to try to promote a more holistic appreciation of the individual as an experiencing subject, and of how this is shaped by their network of personal experiences, family and wider social networks, current and previous roles and identities.

Steve Nolan, Chaplain, Princess Alice Hospice

Steve focused specifically on the role of the chaplain within the team and with patients/families as 'hopeful presence'. Although there may be a certain amount of conceptual uncertainty and, to some extent, ambivalence about spiritual care in a clinical context, chaplains intuitively understand that real spiritual care is not restricted to religious care; that spiritual care is delivered regardless of a patient's belief, and that it is delivered in and through relationships with patients. This is especially true with spiritual care at the end of life.

Like counsellors and psychotherapists, chaplains instinctively use themselves as the 'tool' by which they deliver spiritual care.

In building relationships with patients, the title 'chaplain' invariably evokes a reaction, positive and/or negative. By understanding a particular patient's reaction and by unconditionally accepting their response – which can often be rejection – chaplains demonstrate their willingness to stay with the patient (and their carers) as they face the often distressing reality of their dying. In doing this, chaplains journey with patients and provide an accompanying relationship of trust that allows dying patients to be and to say the things that they need to be and say. In this way, many patients report that the care

chaplains provide by their presence gives them spiritual strength, and that this enables them to remain hopeful. The chaplain 'gives permission' to open the door through:

- Accompanying
- Dwelling
- Strengthening
- Evoking a response
- Nurturing hope

The idea that spiritual care is relational, that it is about a quality of presence, may appear to reduce spiritual care to being little more than an enhanced version of the care provided everyday by all healthcare professionals. Steve agrees that it is certainly the case that many healthcare professionals understand that relationship, respect and compassion are spiritual qualities that raise the standard of healthcare above the routine. However, he argued that conceiving 'spiritual' care as relational, which many chaplains do, positions spiritual care in terms of care for the wellbeing of the 'inner' person. With End of Life care, this means care for the 'inner' wellbeing of a person facing the loss of everything that has ever mattered to them, including their own self.

As such spiritual care is a skilful care that requires to be informed by many factors – psychological, social, cultural, aesthetic, philosophical and religious. To this extent, spiritual care, particularly at the end of life, is highly personal and personalised.

Group discussion

The chair suggested that two themes ran across all 3 speakers' contributions and the group might like to start with these:

1. Issues of language
 2. The role of the chaplain and its relationship to other members of the team.
- Participants discussed building a team ethos around their common humanity and human exchange. Focusing on language as a barrier takes us away from our shared humanity. The inclusive approach puts spirituality back into everything.
 - Participants liked the notion of travelling/journeying with the patient - may not be able to articulate concepts but can practise spiritual care nonetheless; dwelling with people in vulnerable moments; touch, communicating at unconscious level. Point made that it may be important to explain to each other what we are doing – articulate spiritual care and make it explicit. There may be a number of conversations – some implicit and unconscious, others conscious and explicit.
 - Pastoral care is both simple and complex. Spiritual care should be offered at different levels, depending on the relationship with the patient and who/where we are in that relationship.

- Importance of education and training – NB spiritual care can be provided by domestic assistants. Takes time and money to provide good spiritual care.
- Contribution from Japan: no spiritual care provided officially. Terms such as spirituality, religion/ religiosity seen as belonging to the old world. Paradigm of coherence/cohesion has proved useful – demonstrating health outcomes for patients who feel their world view is OK compared with those who feel it is not OK. Greater coherence for staff leads to greater satisfaction. Over one third of the population is over 60 – need a tool to demonstrate the value of providing ‘spiritual’ support, though not using that language.
- Spiritual care is two-way – otherwise we risk burn-out in this field. Two-way compassion – how does that fit with a culture of measureable outcomes? Examples given from business cultures where ‘inner pain’ is seen as costly to the organisation in terms of absenteeism and sickness. In one care home which adopted a ‘whole ethos’ approach, the cleaners were found to be doing most of the healing work. The obstacles to the spiritual care environment being enhanced and impact maximised include ‘spiritual illiteracy’ – people do not know how to interpret/recognise what the other person is conveying; impact of secular society and lack of validation for the spiritual dimension. When this care home reversed this, it performed much better on all indices, including financial.
- Final comment: until we ourselves understand and can cope with our mortality how can we help others? Existential questions therefore paramount.

Evaluation

The session was not separately evaluated. However, several comments on the overall evaluation referred to the Roundtable as one of the highlights of the conference, providing time and space for in-depth reflection, although others would have liked longer. One delegate suggested that s/he will change her/his practice as a result. The suggestion has been made that there should be an ongoing network/ virtual discussion group and actions to take this forward have been initiated.

Margaret Holloway – July 2010.