

## CHAPLAINS WORKING IN A HOSPICE PALLIATIVE CARE TEAM RE-COUNT THE SPIRITUAL CHALLENGES AT THE END-OF-LIFE

*Caroline McAfee, Barbara Cochrane, Mary Waldron, Felicity Hasson, W. George Kernohan*

*Abstract: As part of an on-going review of service provision for Hospice adult patients, six chaplains were interviewed to elicit their views and experiences of meeting spiritual needs within a multidisciplinary palliative care team. Interviews were taped: transcribed and common themes were identified. The chaplains highlighted many positive aspects of their work, recognising their role as one of service to the patients. They emphasised the importance of teamwork, both within the chaplaincy service and throughout the wider palliative care team. Negative aspects of working in palliative care were also identified, such as compassion fatigue. Chaplains need special coping skills and ongoing support in their work. They must recognise and obtain resources for patients from other world faith communities.*

*Key Words: Chaplaincy, Hospice, Spiritual Care, Standards, Support, Team working*

### Introduction

A fundamental spiritual dimension emerges within those who provide and receive palliative care. It has long been recognised that spiritual care is a core part of a comprehensive programme delivered to patients and carers, in addition to the management of physical and psychological symptoms. The inclusion of “spirituality” in palliative care practice has become increasingly commonplace in recent years and is reflected in recent policy statements. The National Institute for Clinical Excellence (NICE, 2004) guidance on cancer services recommends that patients and carers have access to staff who are sensitive to their spiritual needs and that multidisciplinary teams have access to suitably qualified, authorised and appointed spiritual care givers to act as a resource for patients, carers and staff.

The main objective of the review of chaplaincy services at the Northern Ireland Hospice was to assess how well the service is attending to the spiritual and religious needs and to ensure that the service meets the Association of Hospice and Palliative Care Chaplains’ Standards of Hospice and Palliative Care Chaplaincy (AHPCC, 2003). These standards are based on the work of the Marie Curie Cancer Care

chaplains and the Clinical Standards Board for Scotland (CSBS 2002). The standards seek to define the role of chaplaincy within the multidisciplinary palliative care setting. Although the standards are mandatory in Scotland they are not enforced elsewhere in the United Kingdom. There are seven standards identifying the core elements of a chaplaincy service. However for the purposes of this study the chaplaincy service was audited against the following three standards set out in the AHPCC (2003):

- Access to chaplaincy services;
- Spiritual and Religious care;
- Resources.

### Chaplaincy in healthcare settings

While many health professionals have substantial gifts to offer to patients’ spiritual care, the clergy member’s role on the palliative care team in providing spiritual care cannot be overstated (Meador, 2004). The chaplain can be called, depending upon the situation, to accept the role of comforter, mediator, ethicist, educator, or counsellor (Mellon, 2003). Knowles (2003) describes each encounter with a

dying patient as a unique honour that pastoral and clinical carers are especially privileged to share. Mellon (2003) also suggests that chaplains must establish relationships of trust and acceptance with patients of different faiths. As prayer is a common denominator among almost all major religions, he stresses that often this relationship can be developed through the ministry of prayer.

Schneider-Harpprecht (2003) argued that a contemporary model of pastoral care and counselling should accept religious pluralism and recognise that alienation from their denominational roots is a fact of life for many people. Both Elliott (2002) and Ellershaw et al (2003) recommend that chaplains become familiar with many of the cultural expectations of patients of world faiths other than Christianity. Indeed, Wright's (2001) study of chaplaincy in hospitals and hospices in England and Wales found that the chaplain's role had changed, in that while spiritual care was largely operationalised within a Christian context and tradition, patients had a wide range of non-religious requirements which included wanting someone to listen and some one to 'be there for them' suggesting patients frequently wish to address non-religious issues – concern for relatives, dealing with suffering, death and dying. Moadel et al (1999) identified specific patient needs (in decreasing order of importance) with overcoming fear, finding hope or someone to talk to about, finding peace of mind, the meaning of God and dying and death. This is similar to Walter (1999)'s contemporary hospice version of the "good death" which typically entails a socio-psychological finishing of the person's business as well as pain management. Caterall et al (1998) concluded that companionship, showing support, commitment, integrity, and respect is fundamental to spiritual care.

Mitchell and Sneddon (1999) found that whole-time Scottish chaplains had a very clear understanding of their role; to provide spiritual and religious care. They noted that multidisciplinary team working is embraced by chaplains as the way forward and that chaplains' experience and expertise give them a distinctive role within this type of team. Indeed, Watson and Lucas (2003) have suggested that the chaplain expects to be part of the multi-disciplinary team in palliative care and join in multi-disciplinary meetings. Moore and Levison (2003) argue for im-

proved role-clarification of chaplains within the healthcare team.

However, Hunt et al (2003) noted that chaplaincy practitioners have not routinely contributed to patient records, suggesting that the autonomous nature of chaplaincy practice has to some extent contributed to difficulties in systematically ordering spiritual care and that chaplains have often guarded the confidentiality of their interventions with patients and families. Farvis (2005, p189) goes further and raises the motivation for documentation as an ethical issue, "*Is it to help multidisciplinary team working or in order to be seen to be providing spiritual care?*"

While chaplains have a broad and integral role in providing support to staff and patients they also have a need themselves to feel adequately supported and valued within palliative care (Lloyd Williams et al, 2004). Wasner et al (2005) have identified one key issue in this area: coping with the emotional effects of the patients' suffering. While the work can be rewarding, it can also be stressful. Constant confrontation with the deaths of others may result for caregivers in repeated re-evaluation of their own mortality and re-examination of the meaning of their lives. Moore and Levison (2003, p16) argue that "*chaplains cannot be immune from the personal effects of pastoral relationships with patients, carers and staff and that offering support and 'being there' for them will inevitably take its toll on the chaplain*". The aims of this paper are to report an investigation of the experiences and perceptions of a hospice chaplaincy team.

## Method

Using semi-structured interviews, the views, experiences and perceptions of the six members of the chaplaincy team were explored (see table 1). This method of data collection was selected as it uncovers an acceptable depth of information, provides good detail and insight from key informants, can be prearranged, and could be scheduled for a convenient time and location, thereby ensuring a high response rate (Denscombe, 1998). With the participants' consent, individual qualitative interviews were audio taped and transcribed. Assurances were given regarding the confidential nature of the interview and the data collected.

Table 1 Interview questions posed to six Hospice Chaplains to elicit their views and experiences of spiritual care

- How often do you come to Hospice in your capacity as Chaplain?
- How do you see your role as Chaplain in the Hospice?
- How do you feel working in an ecumenical team?
- What are the positive aspects of working in a palliative care setting?
- Are there any negative aspects around working in a palliative care setting?
- In what ways do you provide religious care for patients?
- What do you perceive to be the valuable aspects of the daily service?
- Do you feel you have adequate resources to provide religious care to patients?
- Do you always seek the patient's permission before contacting their clergy?
- How do you contact the patient's clergy?
- How do you record your visits to patients?
- Do you feel this method is adequate?
- What do you consider is the most satisfying aspect of your role as a Chaplain?
- What is the least satisfying aspect of your role?
- Do you feel there are any improvements that could be made to the Chaplaincy service?
- Have you any further comments?

Additional Question for the salaried Chaplains:

- In your role as a Hospice Chaplain you are required to provide spiritual care to patients of all faiths and none. How comfortable do you feel in providing this care?

### Participants

The chaplaincy team comprised six chaplains, three of whom were salaried chaplains, (full time, 24 and 8 hours per week respectively). Four chaplains were denominational; three of these were unpaid. The eight hours a week chaplain was also a denominational chaplain. Two chaplains were female. Each denominational chaplain visits the hospice once a week with a usual commitment of one scheduled daily service per week and a rota for weekend Holy Communion services. Chaplains also visit patients of their own denomination individually and as required.

### Findings

The transcripts were analysed using content analysis. A colleague independently read the responses and identified similar dominant themes.

#### Supporting Individual Patients and Families

All chaplains perceived their role as one of service, as a privilege to provide spiritual and religious care for patients and their families. They provide religious care in two domains: (1) the patient's individ-

ual support and (2) corporate worship consisting of a daily service and weekend services which offer Holy Communion. A religious service of 'Remembering Friends', which includes prayers for their families, is held in memory of deceased Day Hospice patients.

Chaplains cited the importance of being with and supporting patients at their vulnerable time, yet the knowledge that the great majority of patients, for whom they are caring, are going to die, was highlighted as a negative aspect of their work. They gain a sense of satisfaction from being present, and communicating with the patient in any way they can, 'drawing alongside people,' 'such as talking or holding the patient's hand.' They find themselves sharing in the patients' emotions such as 'laughter and tears' during their visits. One chaplain spoke of how humbling it was when patients invited the chaplain into their lives and put trust in them. Another felt that being a chaplain brought an awareness of personal growth and one's own spirituality, saying 'one received more from the people than one gave.'

All chaplains cited the individual patient's wishes as their starting point in the provision of religious care. They visit the patients; get to know them and build

relationships. They sit and talk to them, asking their permission to pray, or read from Scripture; doing so only if it is the patient's wish. The individual religious care for Roman Catholic (RC) patients was said to differ slightly from that for other denominations in that it was more structured on the Sacraments of the Eucharist, Anointing of the sick and Confession and other formal prayers.

### **Effect of Providing Spiritual Care**

Two chaplains spoke specifically of dealing with death, 'working in an environment of dying and death' and how negative that can be for them. One noted that he 'Needed to learn to cope with it (working around death)'. Feelings of helplessness were also expressed: such as 'wanting to be able to do more and the disappointment of not being able to do'. Three chaplains spoke specifically about the effect of tiredness on them physically and mentally: 'a large strain on you personally'; 'very telling on you as a person.' Similarly another chaplain suggested that it could be depressing while another spoke of it being negative. One chaplain spoke of having to remember that patients would be free of pain while another spoke of the 'good support' available from the team.

Lack of sufficient time to spend with patients was mentioned by two chaplains as a negative aspect of their work. One felt that wanting to respect the times for patients' meals and relatives which sometimes together with the daily service does not leave patients as much time as they might have had with voluntary or part time chaplains.

### **Multi-Faith Care**

The salaried chaplains were comfortable in providing spiritual care to patients of all faiths and none, describing it as a 'really challenging and interesting aspect of the work' and the essence of spiritual care was to meet people 'where they are at and let them set the agenda.' However chaplains were aware that, during the audit period, all patients admitted to Hospice or attended Day Hospice were Christian.

### **Procedure**

On their first visits to the patients, the chaplains offer the chaplaincy leaflet and an explanation of their role as well as letting patients know about services. They ensure that the patients have all they need for their religious practice such as icons, Scriptures or the rosary. Unless otherwise requested, the religious

care of RC patients was delivered entirely by the RC hospice chaplain, whereas the clergy of other faiths were contacted as necessary, by telephone. Five of the six chaplains stated that they always seek the patients' permission before contacting their clergy. If the patient is unable to give permission, the chaplains would respect the wishes of their relatives on this issue. The chaplains record the giving or withholding of permission to contact their clergy along with other pastoral details in the patients' pastoral care notes, which are part of the patients' nursing notes in the unit. There are two recording resources for the chaplains. There is the pastoral care sheet in each patient's nursing chart which records a summary of each visit and is signed and dated, and also the daily census form which is initialled for the patient administration system. This daily census form is kept in the chaplains' office and is available to the chaplains. Such paperwork was cited as one of the least satisfying aspects of the role of chaplain. One chaplain spoke of not recording as much as should be recorded, feeling that recording was one of the aspects of their work that is weak from a clergy perspective. The chaplain also stated that chaplains from a nursing background would be more familiar with and trained in record keeping. It was mentioned that the ward is very busy and it is not always practical to access patients' notes.

### **Corporate Worship**

The chaplains stressed the importance of the corporate worship such as the daily service as a means of bringing people together and providing access to worship for those who cannot attend religious services in their own faith communities. Bringing patients and staff together for a short time produced 'a time of quiet fellowship and sharing together.'

The six chaplains had a rota for taking the daily service. This is perceived as offering patients a very positive ecumenical time of worship. 'Even if patients are initially wary of listening to a chaplain from a different tradition, they can become close and not feel threatened.' It is also regarded as an opportunity for them to meet with patients. One chaplain reflected that while on a personal level, the daily service can be a chore as it was difficult to be 'refreshing' for the same group of patients who would regularly attend on a specific day, patients did get a lot out of the service and wanted to be there. Similarly, another chaplain mentioned that 'the service makes patients feel that God has not abandoned

them.’ One chaplain felt that the daily service was particularly important for the Day Hospice patients so that the ‘spiritual dimension’ of their care was ‘catered for.’ However, there was an acknowledgement that patients from the inpatient unit are seldom present at the daily service.

### **Team work**

The chaplains are members of two teams, the chaplaincy team and the wider hospice care multidisciplinary team. All but one of the chaplains cited the latter as a positive aspect of their work. They spoke of their support for each other in their work and the benefits of being part of that team where there is good accountability and responsibility.

Being more involved in a multi professional team in the palliative care setting than one would as a chaplain in a hospital setting was also cited as a positive aspect, as was the sense of being included and supporting other staff. It also gave a better understanding of what was happening to the patient because of the involvement of the other professions and that sense of ‘looking at the whole person’ rather than disassociating the spiritual from the physical, emotional or social aspects of a patient. However one chaplain mentioned that while the team had developed very well over the past six years, it needed to develop more as it was difficult to find people willing to serve as chaplains. The setting of standards and clarity in their role was also said to help others to understand what the chaplaincy offers.

All chaplains spoke positively of their work within the chaplaincy team, each acknowledging their different backgrounds while citing the friendship within the team; learning from and helping one another. Chaplains referred to the team’s ‘spirit of unity’ and ‘greater flexibility’ and how it shows ‘the four main churches working together in an area where people are very vulnerable. Half the chaplaincy team stated that they had benefited individually from working within the chaplaincy team.

### **Perceptions of Adequacy of Resources**

All but one of the chaplaincy team members felt that they had adequate resources to provide religious care to patients. Two chaplains specifically mentioned the prayer card which they adapted as an ecumenical team and which they offer to patients. Chaplains also provide Scriptures as their patients are from a Christian tradition. One chaplain high-

lighted that that the Hospice religious care literature is geared towards those of the Christian tradition as there are few patients from other world faiths coming to Hospice. Half of the chaplaincy team highlighted the chapel as a resource in need of renovation to make it more ‘user-friendly’ for patients, their families and hospice staff, ‘providing an ambience that would encourage people, especially family members and give them time to reflect and be quiet’.

Two chaplains suggested paperwork as one of the least satisfying aspect of the role of chaplain.

### **Discussion**

This review of the chaplaincy service has provided the Northern Ireland Hospice with an insight into the current delivery and future development of the service. During the time of the review, 92% of patients indicated a belief in God or a higher being, stressing the need for and importance of the spiritual and religious care provided by the chaplains. Examining the first AHPCC (2003) standard, *access to chaplaincy services* revealed that chaplains provided patients with the chaplaincy leaflet on their first visit and this gave opportunity for the chaplains to explain their role and inform patients of services available. This usually occurs within 48 hours of admission; however, it is unclear at what stage this information is actually presented to the patient.

The second standard, *spiritual and religious care* is the most identifiable area of activity. Chaplains have a clear understanding of their role providing not only individual support based on patients wishes but also offering inclusive worship reflecting different faith groups. Chaplains valued the daily service and acknowledged the benefits of bringing patients and staff together to facilitate sharing and understanding.

The final standard, *resources*, provided a mixed response. For example, while chaplains had access to a chapel/prayer room, the need for physical improvements to be made on the chapel were identified. In addition, while chaplains had access to patient information systems and could record their interventions in the patient information records, some found this problematic and one chaplain identified the need for spiritual literature for non-Christian dominations.

The findings from the chaplains' interviews also highlight both the positive and negative aspects of their work in ministering to patients and their families. That all chaplains perceived their role as one of service and a privilege is reflected of Knowles (2003)'s view. Palliative care can be rewarding, but also stressful. While chaplains are strongly committed to their ministering role, it is evident that this work can be as challenging for chaplains as for all other disciplines working within a hospice setting. Feelings of tiredness, helplessness or strain indicate that chaplains can be affected by their work in palliative care. These findings concur with those of Wasner et al (2005) and Moore and Levison (2003). Fatigue is an accepted part of the nature of the work involved in palliative care and support within the team is cited as a valuable help in dealing with this issue. However consideration should be given towards the provision of a formal support mechanism for chaplains or the introduction of training which has been shown in other studies as a mechanism for minimising staff stress (Payne 2001).

Chaplains spend much time dealing with non religious matters. Patients frequently want someone to listen to them, be-there for them and address non-religious issues (Wright, 2001; Walter, 1999). This reflects Schneider-Harpprechet's (2003) contemporary model of pastoral care and counselling. The offering by chaplains of support and companionship to patients is also consistent with the Caterall et al (1998) view of a fundamental aspect to spiritual care. However some chaplains voiced concerns of the pressure that time constraints enforced upon them, leading them to have a lack of time to spend with patients.

The chaplaincy team's positive view of team work, both within chaplaincy and the wider multi disciplinary team was evident. As noted by, Lloyd Williams et al (2004), chaplains need to feel adequately supported and valued within palliative care.

Although Elliott (2002) and Ellershaw et al (2003) have argued that chaplains be familiar with many of the cultural expectations of patients of other faiths, the chaplains' prayer and Scripture resources were entirely Christian based. The lack of spiritual literature for different faith groups could have negative consequences for the patient and his/ her family. This is an area needs to be addressed to ensure that

the spiritual and religious needs of all hospice patients are addressed.

## Conclusions

The AHPCC (2003) standards were found to be relevant, measurable and practical quality indicators. Whilst the NI Chaplaincy Service is meeting most of the targets, there is room for improvement on the service for example the recording patient information, the availability of non-Christian literature and the need for resources to be made available to improve the delivery of the service. These results not only help to review the current service but will also act as a baseline comparison for future assessment of the service.

The findings have implication for chaplaincy teams. They affirm the value of the service being provided and the importance of including a spiritual dimension within a palliative care service. Chaplains have the benefit of this positive affirmation of their role which is important in facing the challenging task of providing spiritual and religious support to patients and their loved ones facing terminal illness. Teamwork was considered a very positive aspect of the chaplaincy role.

Equally, several negative aspects of the role were perceived to be important. Chaplains encounter feelings of helplessness in their role working with those close to death. If these essential chaplaincy services are to be sustainable in the long term, these negative aspects must be taken into account by ensuring that all members of the team have the necessary support and coping skills. Otherwise there may be a real danger of burnout and the subsequent loss of valued members of the team.

Chaplaincy resources were Christian based, and although it was commented that patients from other world faiths were 'rare,' resources for these patients should be made available. Arising from this, the chaplaincy service should consider the findings when reviewing the future chaplaincy complement while continuing to develop its wider role within the multi-disciplinary team. The team should also identify and obtain resources from other world faiths which could be made available to patients from these faiths, while working proactively to meet their needs by seeking advice and guidance from other hospices on this issue.

## References

- AHPCC. (2003) *Standards for Hospice and Palliative Care Chaplaincy*, Association of Hospice and Palliative Care Chaplains, London
- CATERALL RA, COX M, GREER B, SANKEY J. AND GRIFFITHS G. (1998) *The assessment and audit of spiritual care*. International Journal of Palliative Medicine 4:4:162-168.
- CLINICAL STANDARDS BOARD FOR SCOTLAND (2002) Clinical standards for specialist palliative care. Clinical Standards Board for Scotland, Edinburgh.
- DENSCOMBE M. (1998) *The Good Research Guide for small-scale social research projects*, Open University Press, Buckingham
- ELLERSHAW J, WARD C. (2003) *Care of the dying patient: the last hours or days of life*, Clinical Review, British Medical Journal 326: 30-4.
- ELLIOTT A. (2002) *Putting Spiritual Care at the Centre of the NHS*, Scottish Journal of Healthcare Chaplaincy 5: 1: 15 -19.
- FARVIS RA. (2005) *Ethical Considerations in Spiritual Care*. International Journal of Palliative Nursing 11: 4: 189.
- HUNT, J., COBB, M., KEELEY, V. & AHMEDZAI, S. (2003) *The quality of spiritual care – developing a standard*. International Journal of Palliative Care 9:5: 208 -215.
- KNOWLES, S. 2003 *In Search of a Good Death*. Letter, British Medical Journal 327:224
- LLOYD WILLIAMS M, WRIGHT M, COBB M, AND SHIELDS C. (2004) *A prospective study of the roles, responsibilities and stresses of chaplains working within a hospice*. Palliative Medicine Issue 18: 638-645.
- MEADOR K G. (2004) *Spiritual Care at the End of Life*. North Carolina Medical Journal 65: 4: 226 -228.
- MELLON BF. (2003) *Faith to Faith at the Bedside: Theological and Ethical Issues in Ecumenical Clinical Chaplaincy*. Christian Bioethics 9:1: 57-67.
- MITCHELL D AND SNEDDON M. (1999) *Spiritual Care and Chaplaincy: A Research Project*, Scottish Journal of Healthcare Chaplaincy, 2: 2:2-6.
- MOADEL A, MORGAN C, FATONE A, GRENANAN J, CARTER, J, LARUFFA G, SKUMMY A, AND DUTCHER J. (1999) *Seeking meaning and hope: self reported spiritual and existential needs among an ethnically-diverse cancer patient population*, Psycho-Oncology 8:5:378-385.
- MOORE A AND LEVISON C (2003) *Chaplains Perceptions of Supervision*, Scottish Journal of Healthcare Chaplaincy, 6:2:16-20.
- NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer, Guidance on Cancer Services*, Executive Summary, National Institute for Clinical Excellence, London
- PAYNE N (2001) Occupational stressors and coping as determinants of burnout in female hospice nurses. Journal of Advanced Nursing 22, 396-405.
- SCHNEIDER-HARPPRECHT C, (2003) *Hospital Chaplaincy Across Denominational, Cultural and Religious Borders: Observations from the German Context*, Christian Bioethics, 9: 1: 91-107.
- WALTER T. (1999) *On Bereavement, The Culture of Grief*, Open University Press, Buckingham
- WASNER M, LONGAKER C, FEGG M. J. AND BORASIO JD,( 2005) *Effects of spiritual care training for palliative care professionals*. Palliative Medicine 19: 99-104.
- WATSON M AND LUCAS C. (2000) *Adult Palliative Care Guidelines*, The South West London and the Surrey, West Sussex and Hampshire (SWSH) Cancer Networks, 1<sup>st</sup> Edition
- WRIGHT MC. (2001) *Chaplaincy in hospice and hospital: findings from a survey in England and Wales*, Palliative Medicine 15: 229 -242.
- Caroline McAfee is Senior Chaplain, Northern Ireland Hospice, Barbara Cochrane is Director of Medical and Care Services, Northern Ireland Hospice, Mary Waldron is Research Assistant, Institute of Nursing Research, University of Ulster, Felicity Hasson is Research Fellow, Institute of Nursing Research, University of Ulster, George Kernohan is Professor of Health Research, School of Nursing and Institute of Nursing Research, University of Ulster, Newtownabbey*