

**THE UNIVERSITY OF SHEFFIELD**

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Academic Palliative Medicine Unit  
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**SPIRITUAL HEALTH CARE: AN ENQUIRY INTO THE  
SPIRITUAL CARE OF PATIENTS WITH CANCER WITHIN  
THE ACUTE HOSPITAL AND THE SPECIALIST INPATIENT  
PALLIATIVE CARE UNIT IN ENGLAND AND WALES**

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## SUMMARY

**Question:** What are the features of the spiritual care of patients with cancer within hospice and the acute hospital?

**Objectives:** To identify:

- guidelines relating to spiritual care
- the means whereby spiritual needs are assessed
- key features of spiritual care
- perceptions of spiritual care stakeholders
- perceptions of health professionals, patients and relatives

**Methods:** A mixed method design incorporating three phases. Phase I - a survey of the views of chaplains in 151 hospices and 195 trusts. Phase II - a phenomenological enquiry into the perceptions of spiritual care amongst 16 stakeholders. Phase III - a multiple case study in 4 health settings.

**Data handling:** Phase I data: collected by postal questionnaire; analysed using SPSS. Phase II data: collected by recorded interviews; analysed using NUD\*IST software. Phase III data: collected from case studies involving observation, documentation and recorded interviews; analysed using NUD\*IST software and biographical and documentary techniques.

**Conclusions:** Spiritual care is founded on the assumption that all people are spiritual beings. It affirms the value of each person and acknowledges the search for meaning in the big questions of life and death. Institutions determine the spiritual needs of patients using both formal and informal means. Such needs are met through the provision of physical resources and human resources. Chaplains figure prominently, although a broad view of spirituality is currently attracting a wider ownership. Within both settings, chaplaincy is almost exclusively Christian. Hospices with funded chaplaincy provide a higher level of service than hospices with voluntary chaplaincy. There is a greater demand for religious care in hospitals rather than hospices. Illness may prompt a patient's spiritual (re-)

awakening, articulated through religious imagery possibly stretching back to childhood. Patients' non-religious needs include someone to listen and to 'be there'. Religious (Christian) needs centre around holy communion, prayer and worship.

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## PUBLICATIONS IN PEER REVIEWED JOURNALS

The investigation presented in this thesis was comprised of three empirical studies: a survey, a phenomenology and a multiple case study. Shortly after the project began, I took the decision to publish a paper related to each of these studies in *Palliative Medicine*, thus producing a cohesive body of work. At the time of writing, the first paper has been published, the second paper is in press – scheduled for the next edition – and the third paper is ready for submission. In addition, the conceptual model of spirituality that informed the project has been published in a peer reviewed edition of *Progress in Palliative Care*. Details are as follows:

Wright MC (2001) Chaplaincy in hospice and hospital: findings from a survey in England and Wales. *Palliative Medicine* 15: 229-242

Wright MC (2002) The essence of spiritual care: a phenomenological approach. *Palliative Medicine* 16 (scheduled for January 2002)

Wright MC (2001) Spirituality: a developing concept within palliative care. *Progress in Palliative Care* 9 (4): 143-148

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## PREFACE

### AN AUTOBIOGRAPHICAL NOTE

*Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are disclosed... Virginia Woolf (1967:14)*

In this preface I outline the study's origins and give an indication of its personal significance. I show the debt it owes to diverse experiences and life-long reflections that have crystallised around the spiritual dimension of health care. Consequently, I acknowledge the recent influence of hospital chaplaincy, but also outline the perspectives gained in other arenas, such as education and fostering. In addition, I have regard to the subjective experience of illness, its impact upon personal spirituality, and its formative influence upon the study.

In practical terms, this study found its origin in a decision taken by Ms Jackie Daniel, Director of Nursing Services at Doncaster Royal Infirmary, to turn a paper I had written on the spiritual dimension of health care into a funded research project, supported by the trust. Nurtured by Professor David Clark and the Reverend Canon Dr Martyn Percy of the University of Sheffield, it subsequently developed into the multi-method, three-phase enquiry into the spiritual care of patients with cancer, presented in this thesis. Yet its roots go back much further, for in a sense it is the result of a life's work. That is not to say that it *is* a life's work, or even a *magnum opus* – clearly, it is not – but rather that the study is underpinned by a kaleidoscope of experiences, reflections and concepts that have a personal significance and which, over time, have become invested with meaning. In view of this close relationship between myself and the study, this autobiographical note is offered as a preface to the thesis. Hopefully it will



give the reader an insight into the shape and ingredients of the study and an idea, perhaps, of what it means for the writer.

Significant events fall into two time frames: pre and post 1994 - in other words, before and after an illness.

As an undergraduate in the 1960s with an interest in the Old Testament and a sense of vocation to the priesthood, a degree in Theology followed by training for the ministry seemed entirely appropriate. Events were to take a different turn, however. An experience of teaching in a local primary school - arranged as part of the Theological College curriculum - turned out to be a defining moment. A sympathetic Principal persuaded the Church Commissioners to fund a full-time course in teacher training which, after ordination, led to a joint position as curate of the parish of All Saints, Dormanstown (Redcar) and teacher of religious education at the local secondary modern school. It was a formative time. Dormanstown was originally built for Dorman Long's steelworkers and the down-to-earth life and warm hospitality suited this miner's son from West Yorkshire. Within the boundaries of a small community and a school population of around 250 it was possible to know all of the children and most of their families. There was a seamless relationship between the boundaries of the school and the boundaries of the parish, as there was between the education of the pupils and the pastoral care of them and their families around baptism or matrimony or bereavement. Yet change became inevitable, and after leaving Dormanstown, it would be 26 years before I next sought a post within the stipendiary ministry.

If nothing else, the 1960s were a time of ferment and innovation and there was no exemption for the Church. Writings like *Honest to God* (Robinson, 1963) and the secular – to – sacred meditations of Michel Quoist (1963) resonated with Dietrich Bonhoeffer's (1971) notion of secular holiness and

his call for religion-less Christianity. It signalled a time of reflection and re-alignment: a new form of engagement with the world. This new engagement was fuelled by notions of freedom and responsibility, based on the existentialist views of writers like Albert Camus (1947) and Jean-Paul Sartre (1943); and of a new form of courage that equipped a person to stand alone in the face of anxiety (Tillich, 1962). Also influential were the perceptions of Martin Buber (1970) put forward in *I and Thou*: of a relationship with God that permeated every aspect of daily life. These ideas combined with new concepts of specialist ministries and worker-priests to produce a seductive mix of opportunity and expectancy.

It was within this context that I felt called to serve at that point of the interface where received notions of being 'in the world' butt up to the realities of being 'of the world'. Such a ministry, outside of the traditional structures of the Church, seemed particularly energising and in a phrase of the day - 'avant garde'. Education beckoned, and the opportunity to become involved in the growth and development of young people during formative stages of their lives. Mary Warnock's (1978) report encapsulated the vision: of an education service that enlarged knowledge, experience and imaginative understanding; that developed an awareness of moral values; that included a capacity for enjoyment and encouraged independence. It was apparent, however, that although the aims of education may be the same for all, the starting points of individuals were very different. Social disadvantage, crises of life, discrimination and disability all exert pressure on the potential for achievement. For a teenage girl whose mother is dying of cancer, quadrilateral equations may not be the top priority; nor, at a time of great physical and emotional changes, may she be able to articulate why she feels such isolating sadness. For a faith whose leader had something to say about those on the margins, these issues present particular challenges: of reconciling an incarnational theology with personal practice. In this instance it meant retaining a focus on young people but coming more

closely alongside those on the margins. Consequently, in addition to the 'day job' seven years were spent working part-time in what was then called a Borstal Institution. A family commitment was also taken to foster adolescents who, in the opinion of social workers, had become hard to place. This continued for ten years, and ended when the last two foster children were adopted into our own family.

In a strange way, both the Borstal trainees and the foster children had much in common. Neither group had a physical wall around them, but both felt a loss of freedom and a sense of misfortune. Both groups were familiar with institutional life and the behaviour of individuals swung from displays of bravado to acute vulnerability. Feelings of rejection were intense. Amongst the foster children, 'Sharon' had been placed with a family on nine previous occasions. Each placement had broken down. 'Peter' had been adopted since the age of seven along with his twin sister, 'Fiona'. Shortly before his 13<sup>th</sup> birthday his adoptive father contacted social services while Peter was still in school to say he could not return home that day or ever again. Peter never did return home – nor did he ever understand the grounds on which he was rejected but his sister was accepted. 'Emily' was abandoned by her mother when she was four years old: left in a market place to fend for herself, a small bag of clothes nearby - and 'Gareth' had been so frequently hospitalised by his stepfather's beatings that he was taken into care for his own safety.

Alongside the loss of freedom ran other, deep losses: of son-ship or daughterhood, of belonging and of being loved. Adults with the closest of ties to the children had demonstrated that they could not be trusted. Primal notions of fatherhood and motherhood had become invested with fear. God as father figure brought terror. Issues of forgiveness or reconciliation assumed massive proportions - due frequently to an inability or unwillingness to communicate at deeper levels. Embedded feelings of

isolation and a misplaced reliance on self-sufficiency presented a 'couldn't-care-less' attitude towards others. The truth, however, was very different: it was safer to shut people out than to run the risk of being hurt again.

Issues that relate to individuals may also apply to groups; questions similarly arise about difference and the resolution of conflict. In particular, how to accommodate the challenging individual whilst preserving the good of all? After being appointed head teacher of first an inner city, then a suburban high school, consideration was given – amongst other things - to the spiritual nature of the institution. Was it a loving institution? Did it encourage responsibility, decision-making and ownership? Was it a forgiving, reconciling institution? Was it just? And were these values incorporated into its structures and policies, its practices and procedures: into the concept and application of its code of conduct, its rewards and sanctions and its acknowledgement of success? A cross-curriculum audit sought to determine the opportunities that existed for education within the spiritual domain – from the nurturing of spiritual expression in the arts to the wonder of creation in the field, the exploration of stillness during worship to the possibilities for fulfilment within human relationships; from acceptance of oneself to acceptance of others.

The public articulation of a spiritually inclusive (though not religiously denominational) form of education proved to be popular. It struck a chord with the local community and in days when change followed change, was interpreted in some quarters as a commitment to higher values and a source of some stability. As attainment rose and exclusions fell, requests for transfers increased, not least on behalf of youngsters experiencing difficulties. Any success, however, was due to the body of staff – teaching and non-teaching - which shared a vision of inclusiveness that was fundamentally based on gospel values. As for me - someone who regarded himself as a priest immersed in other roles - the whole nature of

professional life during this time owed much to a robust type of practical theology, brought into sharper focus by the opportunities afforded by an annual budget of around £1.5 million.

On the 25<sup>th</sup> of July 1994 everything changed. The experience of an excruciating chest pain during my daily run caused an admission to the coronary care unit of the local hospital. As a lifelong non-smoker and fitness devotee, a heart condition seemed unlikely. Test results confirmed that view. Just four months later however, walking short distances induced breathlessness, climbing a flight of stairs necessitated rest periods, and activities such as washing the car were impossible - such were the effects of ischaemic heart disease. Unimagined changes accompanied the condition, symbolised by a dramatic shift from strength and activity to weakness and quiescence.

Finding a meaningful context within which to ground these changes proved elusive, not least because of difficulties in identifying with the changed person – a person that had become unrecognisable. Both a landscape and a lifestyle had disappeared. The familiar independence and pro-activity were colonised by an unfamiliar passivity and dependence upon others. Giving was replaced by receiving. Learning to receive - constantly and with good grace - became emblematic of a shift in power, from within to without. Past practices of running through pain and traditional metaphors of battle were of no value: the greater the physical effort the greater the evidence of incapacity.

In the hospital setting, chaplains offered a ministry of healing, supported by holy communion, anointing and the laying on of hands. What healing meant in the context of a chronic condition, however, had become uncertain. The notion of woundedness became significant in the light of Nouwen's (1994:8) paradoxical suggestion that the source of healing was to be found

therein. As boundaries narrowed, new perspectives were required on personhood and identity. William Vanstone's (1982) book - *The stature of waiting* – became important in this respect, offering an insight into the value of the weak and their inclusion in the Kingdom of God. Such insights – coupled with the prayers of others at a time when one had lost the capacity to pray for oneself – became personally significant. Strangely, out of all the wreckage emerged a desire to become vegetarian. Though never fully articulated, there seemed to be a symbolic appropriateness about it: the beginnings of acceptance and a new – if faltering - relationship with self, with others, with the world and with God.

Twelve months and three angioplasties later, it was a restored but different person who stepped out of headship to become chaplaincy manager of the Doncaster Royal and Montagu Hospitals Health Care Trust. Many things were familiar: the large institution, the focus on people in transition, special rituals surrounding admission and discharge, the clients' assumption of a special role and the personal relationships at the point of service delivery. Other things were different: a newly found humility in the face of suffering and a reverence for both the resilience and fragility of life. In that illness has a capacity to challenge beliefs and values and raise fundamental questions surrounding the concepts of health, wholeness and brokenness, it has become closely associated with spirituality - for according to Robert Twycross et al. (1991:8) that which is 'spiritual' embraces the very essence of what it means to be human.

The last decade has seen a growing interest in the spiritual domain and health care is not excepted. A variety of groups have expressed an interest. These include the Department of Health (1992), the National Association of Health Authorities and Trusts (1996), and the Chaplains and Pastoral Care Committee of the Northern and Yorkshire NHS Executive (1995). Other disciplines are represented by the physician (Whipp, 1998), the nurse (Ross,

1994), the psychologist (Johnston, 1998) and the counsellor (Bellamy, 1998).

This study has been prompted by a life-long interest in the spiritual domain that since 1994 has crystallised around the delivery of health care. From the personal perspective of a hospital chaplain, spiritual care most frequently relates to individual clients. Operationally, however, a commonality of issues becomes apparent: uncertainty and loss, pain and suffering, mortality, bereavement and grief. Amongst other caring responses, religious support has a part to play - but experience has demonstrated that some patients who describe themselves as non-religious also require the support of prayer or ritual. The question arises as to whether spiritual care provision takes account of the breadth of spiritual diversity in contemporary Britain and encompasses the popular, innate folk spirituality that becomes apparent during times of crisis, illness or stress. Opinions are plentiful on these matters, but data are in short supply. This project is a response to that situation - designed specifically to collect data and to shed light upon the complex nature of the spiritual dimension of health care.

The concept of crystallisation is apt. Laurel Richardson (2000) notes that crystals change and grow, reflecting and refracting as they create different colours and patterns. Viewed from a variety of perspectives, this study is informed by the personal, professional, historical and biographical experiences of the researcher. It casts its gaze upon the patients and their significant others, allowing them to tell their stories and to articulate the impact of illness upon their beliefs, their losses and their hopes. It considers the nature of spirituality and seeks to identify the spiritual essence of palliative care. It explores the role of the chaplain, the ingredients of religious and non-religious care, and the management of a spiritual care service. By placing the findings within the broader theoretical frameworks of health care, practical theology and sociology, the study attempts to give a

multifaceted insight into the nature of spiritual care prevalent within the acute hospital and the specialist inpatient palliative care unit at the beginning of the new millennium.



## CHAPTER 1

### THE SPIRITUAL CONTEXT OF ILLNESS

This chapter is in three parts. In the first part, I address the theoretical content of concepts that are closely associated with illness: loss, suffering, pain, hope and woundedness. These concepts underpin the whole study and come to feature in different ways during the research process. The second part relates to chaplaincy. In this section I acknowledge the influence of Norman Autton's formative concept of the chaplain-hero and trace the emergence of alternative perceptions of chaplaincy. A theoretical model is proposed that combines ways of relating (to the institution) with ways of ministering (to patients). The resultant quadrants represent four paradigmatic chaplaincy styles. In the third section I detail some of the wider influences that have a bearing on the nature of contemporary spirituality - such as perspectives on postmodernity and secularity - and set them against the back-drop of philosophical and practical developments in palliative care. I present an inclusive theoretical model that acknowledges multiple articulations of spirituality and suggest that amongst patients drawn from pluralistic societies, there is no single world view or spiritual source. It is this model and its related definition of spirituality that have informed the study.

## Concepts

*Loss.* When Ruth Picardie (1998), writer and journalist, was diagnosed with breast cancer in 1996 she placed her feelings in the public domain and laid them open to scrutiny. Until shortly before her death in 1997, she wrote a series of articles for *Observer Life* that gave readers an insight into her deteriorating condition. What hurt most, she said, was ‘losing the future’(1998:58): not being there to clap when her babies learnt to write their names or to kiss their knees when they fell off their bikes. In a similar way, Hellen Rollason (1998) - presenter of BBC’s *Grandstand* – spoke of the impact her impending death from liver cancer would have upon her daughter. ‘I don’t fear death’, she famously declared. But she did fear ‘the carnage’ she was leaving behind – embodied in the person of an emotionally stunned child. She also admitted to a ‘sneaking hope’ that a cure was just round the corner.

By ‘going public’ with their feelings of loss and hope, Ruth Picardie and Hellen Rollason effectively cast light on their unique experience of illness. The concept of illness figures prominently in this study and differs significantly from notions of sickness and disease. Sickness is regarded here as either a disorder in its generic state, distributed across a population, or as a phenomenon that attributes special status – as in the sick role; disease is understood in the narrow terms of the biomedical model. Illness, however, is to do with ‘the innately human experience of symptoms and suffering’ (Kleinman, 1988:3), the impact it makes upon human relationships with self and others, and the meanings that are constructed around it by the individual.

Loss is a fact of life and during a life-time human beings experience many losses. These may relate to the transitions of life: moving home, leaving a

job, passing the childbearing years; or to possessions, to relationships or self image. Within illness, the dimension of loss is a central and inescapable feature (Ainsworth-Smith and Speck, 1982; Kleinman, 1988), and the act of admission to a health care institution bears witness to a loss of lifestyle and social status. Admission procedures provide a ritual for entry into a different space which, according to Katherine Froggatt (1997), is a sacred space. Drawing on the work of Arnold Van Gennep (1960) and Victor Turner (1977), Froggatt suggests that concepts associated with rites of passage apply also to hospice. Consequently, an incoming patient undergoes a change in status and becomes separated into a new state known as liminality. This transitional space is inhabited by those in the process of crossing boundaries between one status and another. It is also the vehicle for entry into 'communitas' and the new pattern of relationships contained therein.

By the time of entry into a health care institution, a patient's losses may be many and varied, frequently including the loss of a career, of family life, of motivation, independence and self esteem. Eventually, these losses may include continence and use of the senses. William Vanstone (1982) highlights the effects of a debilitating illness: the transition from activity to passivity, the change in outlook and increasing isolation. Such losses impact significantly upon the dying patient (Nuland, 1997), each loss bearing witness to the incremental dismantling of personhood; the disintegration of that unique human dimension which is 'coherent, bounded, individualised, intentional, the locus of thought, action and belief, the origin of its own actions, the beneficiary of a unique biography' (Rose, 1996:3). Since these losses are irretrievable, they have the capacity to induce a considerable amount of suffering.

*Suffering* is a complex phenomenon combined physically and linguistically with patienthood through its latin stem of *pati* (to suffer). Generically, suffering is thought to confront the whole person, threatening destruction and causing strong feelings of disintegration (Cassell, 1991). It has many facets. In an ethnographic study of suffering in a hospital setting, no fewer than 24 different types were found amongst patients. These ranged from meaningful suffering to hopeless suffering. Some patients held on to their suffering in an attempt to manipulate or control their circumstances (Flaming, 1995). This finding resonates with the idea of suffering as battle. Arthur Kleinman (1994) places suffering within the context of resistance – to either the lived flow of experience or to political power - a view embodied in the experiences of Victor Frankl. For Frankl (1984) resisting and suffering during his incarceration in a concentration camp during World War II, his condition was encapsulated in a search for meaning and a re-affirmation of the potential to be human. That search and re-affirmation was actualised through a continuing capacity to give and receive love - prompting notions that would subsequently become influential contributors to the philosophy of modern hospice.

*Pain* is regarded as a major contributor to suffering. As a universal part of the human condition, its origins and significance have been persistently problematic. Notions of punishment imposed by an angry God are still to be found, wrapped within folk religion and submerged under the surface of everyday life. Those with a biblical perspective may point to Old Testament ideas of disobedient sin (see Genesis chapter 3) or to New Testament ideas of a judging God (see Luke chapter 10 verse 15). Theological commentary takes up these points, considering the impact of pain upon human perceptions of God (Schultz, 1993; Lewis, 1977). Although answers to the problems posed by pain are not readily forthcoming, acknowledgement of the questions is widespread. Publications asking why bad things happen to

good people (Kushner, 2000), and where God may be found by those who are suffering (Becton, 1989), have a popular demand.

On a human level, the experience of pain has come to be regarded as a complex phenomenon. In her study of acute pain experienced by the victims of torture, Elaine Scarry (1985) argues that in many cases, such pain is beyond language and indescribable. Chronic pain has now come to be regarded as a different phenomenon and is imbued with mystery. Unlike acute pain, it is not a universal experience, and in the absence of any clear physiological determinants, attention has come to focus on the role played by psychosocial factors. For those living with chronic pain, the effects have been described as an 'ontological assault' (Pellegrino, 1979:44) that ultimately strikes at the very concept of self. To study the pain of patients, therefore, requires an entry into the patient's world, thereby setting the pain within the wider context of family, the workplace and the community (Kleinmann, 1994).

It was an understanding of pain in its wider context that contributed to the concept of 'total pain' put forward by Cicely Saunders (1964); a concept that incorporated John Bonica's (1953) view of chronic pain being qualitatively different from acute pain, not merely the same thing prolonged (Clark, 1999). Total pain, therefore, became a theoretical response to patient experiences and to perceptions that 'it was all pain' (Saunders, 1966:139). Whilst acknowledging physical symptoms, total pain also gave credence to other factors that were located in the social, psychological and spiritual domains – 'even in the soul itself' (Clark, 1999:734). It was a view that quickly gained ground. In 1986, Norman Autton published a book on pain – with a preface by Cicely Saunders – that indicates how far this concept had become accepted. He writes:

Pain is a great puzzle...Such diverse disciplines as philosophy, medicine, psychiatry and social anthropology will each have its distinct theories and approaches to the study of the complex problem of pain. The philosopher will be concerned with the sensations: feeling, suffering and meaning; the anaesthetist and surgeon with the physical manifestations; the psychologist with the emotional qualities; the psychiatrist with the mental reactions to stress; and the theologian with aspects of guilt or retribution (Autton, 1986:2).

As pain has come to be regarded as more than a physiological sensation, responses to it have shifted in emphasis from pain relief to pain management (Quint Beniol, 1995). Interest has developed in special fields such as cancer pain, terminal pain, neuropathic pain and post-operative pain. Alongside these interests, spiritual pain is coming into sharper focus. Significantly, distress of the human spirit is considered to be more than a localised phenomenon, but rather 'a disruption in the life principle which pervades a person's entire being' (Kim et al, 1987:314). This is graphically seen in the testimony of holocaust survivors who use 'a lexicon of disruption, absence, and irreversible loss' (Langer, 1991:ix): 'We are left with loneliness. As long as we live we are lonely' (Langer, 1991:x).

*Hope* is considered to have a crucial role to play in countering the losses that seem 'so definitive, so irrevocable and so utterly forever' (Roy 1998:3). Indeed, hope has been thought to be so important, so vital to life that its loss is equated to the loss of life itself (Fromm, 1968). Questions arise as to the nature of hope, and why it enables some patients to rise above the adversity of a progressive, life-threatening illness, while other patients spiral downwards to the depths of despair. Cheryl Nekolaichuk and Eduardo Bruera (1998) suggest that hope is challenged by three popular myths: the myth of immortality, the myth that every illness is curable with a magic bullet; and the myth of truth telling – that patients want and need to be told the truth about their condition, particularly at the end of life. Questions of

hope at the end of life are of particular relevance to this study. After the hopes invested by patients in curative treatments have begun to fade, what kind of hope follows after? Indeed, what is the experience of hope when hopes for a cure have past?

*Narrative.* Integrally related to hope is the patient's understanding of his or her illness and the meanings constructed around it. Questions such as why me? feature alongside metaphors of journey, battle, death and re-birth – considered to be archetypal, transcultural myths (Hawkins, 1999). In this scenario, patients articulate their experience of illness as personal narrative, communicating individual meanings and constructing a coherent self in the face of threatened disintegration (Reissman, 1990). Narrative is considered to be part and parcel of human experience: a feature of life that is present in every age and in every society (Barthes, 1974). A recent development has been the emergence of what Anne Hawkins (1999:339) terms pathography – an 'autobiographical or biographical narrative about an experience of illness' – that is uncommon before 1950 and almost exclusively a feature of the 20th Century. In essence, a pathography is thought to articulate the patient's testimony as s/he bears witness to her own illness - and is exemplified in the work of Susan Sontag (1979) and Arthur Frank (1991, 1995).

The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability. (Frank, 1995:xi).

*Woundedness.* Underpinning these pathographies is a common experience of what may be termed woundedness, a concept currently alluded to in a variety of contexts that impacts upon images of both the patient and the carer. Frank (1995) notes that it was the wounds of Tiresias – his blindedness – that gave him the power to reveal to Oedipus the story of

whose son he really was; in the bible, it is the wounded hip of Jacob that authenticates the story of his wrestle with an angel. Consequently, the view emerges of a wounded storyteller, a raconteur whose wounds become emblematic of the story's potency. In these days when the population of the Western world is ageing and the incidence of chronic conditions is increasing, the application of the term woundedness to those living with serious illness is apt. For the wounded, storytelling becomes a vehicle for recovering the voice that illness has silenced: a means of re-claiming power after diagnosis through the knowledge that an individual story is both worth the telling and worthy of being heard.

Woundedness is also thought to have a special relationship with healing. Holders of this view (Hall, 1997; Kearney 1996) point to shamanic times when woundedness was seen as a direct preparation for healing. Consequently, a link was established between the power to heal and the journey by healers into their own wounded selves. Michael Kearney (2000) suggests these ideas find an echo in Greek mythology in the story of Chiron, whose unhealable leg wound led him to discover the healing power of herbs – but only for others. They are also to be found in the wounding and healing powers of religious leaders such as Jesus and the Buddha. An appreciation of the power of wounds and of their importance to healers may also be found in the writing of Carl Jung (1983), Henri Nouwen (1994) and Jane Hall (1997). Sheila Mitchie (1996), a nurse, describes what being a wounded healer means to her:

...through our wounding and continual healing we become aware of our connectedness to all life. There is no separation, there are no them and us, there is only all of us irrevocably bound together, searching for love. As we express God's love more deeply and openly, those who are touched by our presence discover a safe sacred place where they are accepted with respect and understanding, a place filled with love where they can reveal their



vulnerability and wounding and where healing can begin' (In Hall, 1997:39).

These concepts are important features of the enquiry. They emerge in various ways during the research process in relation to both patients and caregivers, for they lie at the heart of the illness experience. Significantly, it is these concepts - and in particular, the ways they would be explored with patients - that came to attract the interest of local ethics committees, described later in the thesis.

## **Chaplaincy**

This study is set in the context of the acute hospital and the specialist inpatient palliative care unit (subsequently included in the shorter term 'hospice'). It is concerned therefore, with the delivery of spiritual care within an institution. Although the two types of institution differ in purpose and size, they both present a similar challenge: how to blend spiritual care with other forms of care within the context of a largely secular organisation.

*Hospital chaplaincy.* At the inception of the National Health Service (1948), a communication from the Ministry of Health advised hospital authorities to provide spiritual care by appointing paid chaplains from different traditions (NHS, 1948). This was a key innovation. It was the first time that hospital chaplains were employed by a secular organisation rather than by the Church. Amongst the first to appreciate the possibilities of a new form of ministry within the health service was Norman Autton. Ordained in 1945, Autton soon developed an interest in the Church's ministry to the sick, becoming the first full time chaplain to the Deva Psychiatric Hospital (Chester) in 1956, before moving to St George's Hospital (London) in 1961. A life-long writer, Autton produced around thirty publications. These ranged from the pastoral care of the mentally ill

(1963) to a handbook on sick visiting (1981) and the use of touch in palliative care (1996). Autton's collaborators included the prominent figures of his day. His monograph on suffering and wholeness (1971) drew contributions from John Hinton (on the psychology of dying), Colin Murray Parkes (on the psychology of bereavement), Archbishop Anthony Bloom (on the theology of suffering) and Bishop Ian Ramsey (on the theology of wholeness). His thinking was associated, therefore, with some of the ground-breaking leaders of his generation.

Autton also made significant contributions to policy by serving on working parties and committees. These included the Spiritual Care Work Group of the International Workgroup on Death, Dying and Bereavement (1990), the 'Mud and Stars' (Twycross et al, 1991) work group that looked at the impact of hospice experience on the Church's ministry of healing, and the King Edward's Hospital Fund working party (1965), that enquired into the role of the hospital chaplain. The King's Fund report was of particular significance, since it lists no fewer than 39 recommendations *a propos* the training of chaplains, the collecting of denominational information and the size of hospital chapels; it also recommends the provision of a room for interviewing and secretarial support for chaplaincy departments. Crucially, the report concludes that the newly formed District General Hospitals should employ a whole time chaplain irrespective of the number of patients, that chaplains should have their expenses re-imbursed, and that chaplains should assume responsibility for the mortuary chapel to ensure that it is reverently maintained. These recommendations not only give an insight into the prevailing attitudes of the day, (regarding the appropriate seating capacity for chapels, for example) but continue to impact upon chaplaincy provision in relation to accommodation for confidential discussions and the allocation of secretarial support.

It was in his role as Director of Training for the Hospital Chaplaincies Council, however, that Autton was to have a major influence on the shape and direction of hospital chaplaincy. His training courses were attended by a generation of new, aspiring chaplains. Handbooks and anthologies provided a range of new material for chaplains and lay visitors (1976a; 1976b; 1980). Strong links were forged between parochial clergy and local hospitals, and Autton's perception of chaplaincy became the orthodoxy of the day. Significantly, his ministry spanned six decades and being of an energetic disposition, he remained actively involved in health care until his death in 1998. Sue Beven (1996), Project Secretary for the Essex-based Friends of St Petersburg Health Care Trust, reports on his visit to Russia as part of the team to support the development of palliative care at Kolpino Hospice in 1995. Autton was in his mid 70s at the time but clearly retained the power to impress. Beven notes that:

Tremendous interest was aroused in the lectures on spiritual and ethical issues. Rev Canon Norman Autton talked on spiritual pain and its causes, symptoms and treatment. He emphasised the importance of the patient understanding that they were not alone and that someone was trying to understand their fears and unique feelings. In his second lecture, he spoke on touch: 'holding a hand or placing an arm around a shoulder conveys a positive message to the dying – no matter what happens, I shall be with you, I won't let you down (Beven, 1996:29).

For Autton, the quintessential nature of the chaplain resides exclusively in ordination to the priesthood. While others may assist, there is a uniqueness about the priestly function that only the chaplain can perform: about the eucharistic sacrifice that only the chaplain can offer (1968:2). Consequently, the chaplain is separate and unique, involved in 'a ministry that is truly incarnational, bearing the unbearable, sharing the unshareable and entering into the heart of shattering pain...' (1968:2) Such uniqueness makes strong demands upon chaplains and in order for the role to be

effectively fulfilled, Autton provides lists of what the chaplain should know - spirituality, theology and psychology; what the chaplain should do - care, comfort, challenge and respond; what the chaplain should have - confidence, compassion, gentleness and love; and what the chaplain should be - available, acceptable, sincere and a servant. In essence, the chaplain's role is to focus upon the spiritual life of the hospital community - giving it meaning, interpreting what God is about and explaining the temporal in terms of the eternal. It is also to bind up the brokenness of human existence and to reconcile the patient to his or her neighbour, to self and to God.

Autton's contribution to the development of health care chaplaincy is immense. He brought innovation and imagination to a new situation, formulated a chaplaincy role that could stand alongside other professional roles and established a bridge of communication between health care institutions and the parochial ministry. However, in a landmark paper that argues for an incarnational model of chaplaincy, Stephen Pattison (1980) expresses reservations about Autton's chaplaincy model - particularly the notion that the role of the chaplain must be as meaningful as medicine itself. In essence, Pattison detects a sacramental, one-dimensional model of chaplaincy that focusses so sharply on the number of communicants that it runs the risk of dislocating the chaplain from other human beings. To Pattison, Autton's chaplain is:

...a man of iron, professional to his fingertips, self contained and *arrived!* He is not insecure, he is the one who has got there and so has the grace to help others along the way. This man is confident and superhuman (Pattison, 1980:6).

Not alone in his criticism, Pattison suspects that Heiji Faber's (1971) model of chaplaincy was put forward 'to counteract the arrogance and idiocy of 'sacramental' chaplains who blunder into hospitals and think they have all the answers' (Patterson, 1980:9). Unlike Autton's model of the chaplain-

hero, Faber's radical concept likens the chaplain to a clown. S/he appears to be unskilled, an amateur through and through, yet is capable of producing a spontaneous, creative act when the need arises. It is a ministry of being rather than doing - alongside and with the suffering. Faber's chaplain is one who recognises the structures of hospital life but chooses to adopt an element of detachment, becoming positioned between the patient and the staff. It is a difficult position to hold, belonging to the team yet not quite part of it – a guest in familiar surrounding.

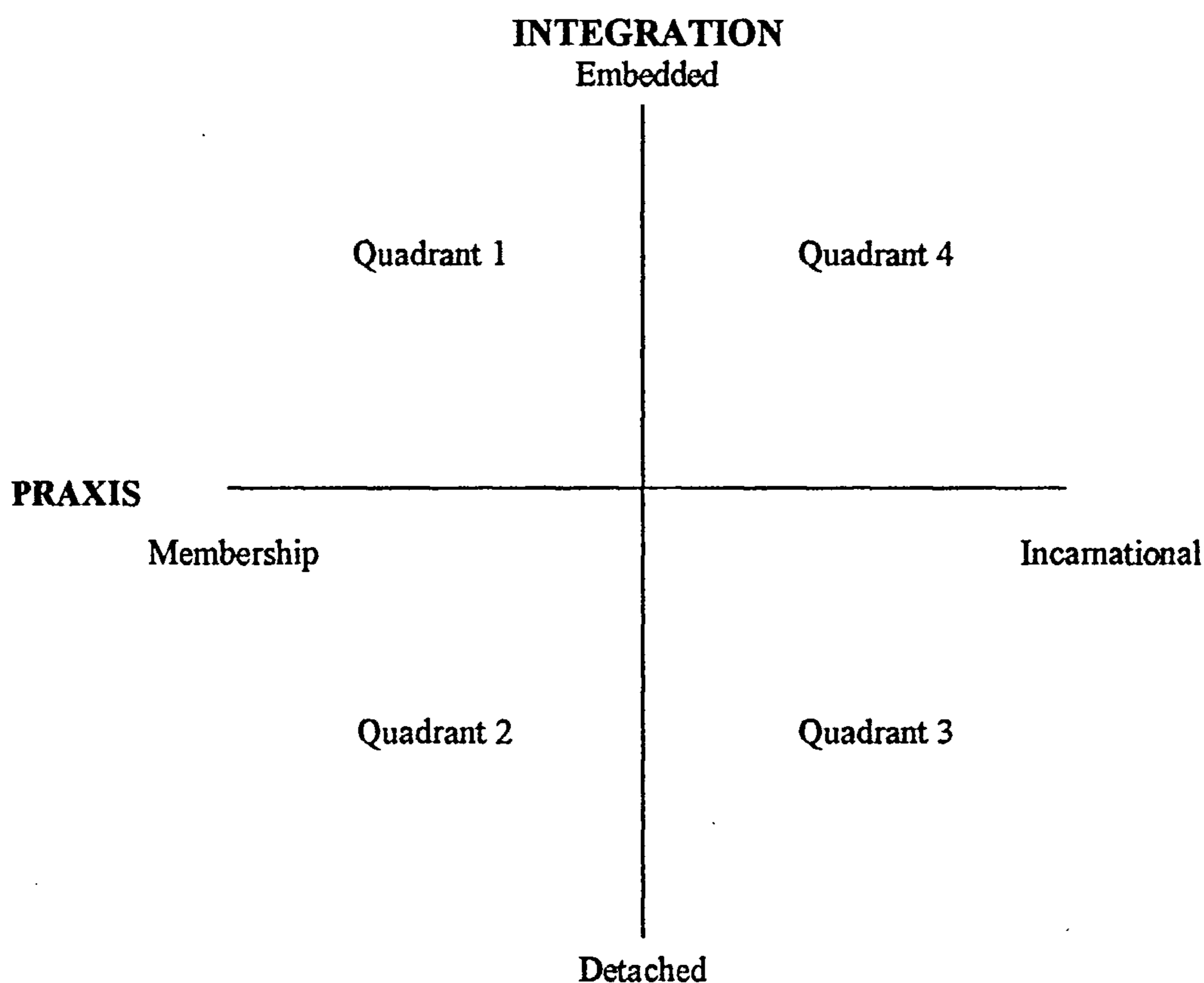
Helen Orchard's (2000) landmark study into the nature of hospital chaplaincy in the City of London provides evidence of diverse approaches to chaplaincy and spiritual care provision. To analyse her data, Orchard devised a framework that utilised a continuum linking two polarities. These represent what she describes as the 'sponsor defined' and 'employer defined' chaplaincy typologies. Chaplaincy practice in relation to the trust, the community, members of staff, patients and carers are mapped within this framework. Effectiveness is explored using three dimensions of practice: equity, integration and utilisation.

Significantly, Orchard discovered that only half of the departments ranked patients as the prime focus of their care. Evidence of uncertainty existed around the grounds for practice and the aims and philosophy of the service. An absence of reflection, theological or otherwise, was detected. Consequently, Orchard concludes 'it was difficult to identify tangible ways in which the service was demonstrating added value to the process of patient care' (2000:151).

This literature is underpinned by two fundamental tensions that occur within chaplaincy – of being *in* the world without being *of* the world. In this case, being part of a secular institution - yet standing prophetically over

against it; and of holding the Church's commission to minister to its members, yet wishing to be inclusive, responding to the needs of all. These tensions impact on the personal, philosophical and theological dimensions of chaplaincy and may become exaggerated when chaplains work in single-member departments. They are summed up in the following model of chaplaincy styles (Figure 1).

**Figure 1** A multiparadigm model of chaplaincy styles



Vertical axis: Integration. This dimension indicates the chaplain's relationship with the institution.

- i The embedded style is characterised by a total immersion in the institution's structures and decision-making processes. It has the advantage of having a voice at the heart of the organisation,

influencing direction and practice. Its disadvantage is that it is closely associated with management rather than the workforce.

- ii The detached style is characterised by standing 'over against' the institution, acting as its conscience or prophetic voice. It has the advantage of having a strong association with the workforce. Its disadvantage is that the chaplain is absent from the major discussion and decision-making forums of the institution.

Horizontal axis: Praxis. This dimension indicates perceptions of the chaplain's *primary* focus: members of the Church that the chaplain represents, or all human beings.

- i The membership focus is characterised by the chaplain's primary ministry to Church members. It has the advantage that those within the Church are supported during their time of dislocation. Its disadvantage is that the chaplain is removed from the majority of human beings and their suffering.
- ii The incarnational focus is characterised by the chaplain's commitment to all human beings. It has the advantage of a ministry that is seen to be alongside those who suffer. Its disadvantage is the possibility of becoming detached from the Church's practice or rubrics due to a desire to respond pastorally to non-believers.

The four quadrants represent paradigmatic chaplaincy styles. As such they encompass beliefs about the purpose of the chaplain and chaplain's role in relation to the institution.

Quadrant 1 is bounded by a primary ministry to Church members and total immersion within the institution. Whilst aware of the suffering of non-members, the chaplain located within this quadrant seeks first and foremost to meet the needs of Church members. Communication with parochial clergy is likely to be uncontentious, with referrals being passed to the chaplain from the parish and non-confidential information being passed back in return. There is likely to be limited contact with those outside the Church. Within the institution, the chaplain is likely to sit on numerous committees, have easy access to senior managers and be asked both formally and informally to express opinions. In some circumstances, the chaplain may be seen as another member of the management team.

Quadrant 2 is bounded by a primary ministry to Church members and a detached stance in relation to the institution. The chaplain located within this quadrant will also seek to meet the needs of Church members and communication with parochial clergy is likely to be uncontentious. As with the chaplain within quadrant 1, contact with those outside the Church is likely to be limited. Within the institution, this chaplain is likely to maintain a distance between him/herself and the formal management-led committees, working groups, decision-making processes and forums. In these circumstances, the chaplain is unlikely to mix freely with senior managers and opinions will tend to be requested formally rather than informally.

Quadrant 3 is bounded by a primary ministry to all patients in need - irrespective of Church membership - and a detached stance in relation to the institution. The chaplain located within this quadrant is likely to respond compassionately to pastoral need, and may experience role conflict when reconciling pastoral need with the rubrics of the Church. Those outside of their local church will not have information passed back to parochial clergy - a fact that in some circumstances could become contentious. Within the



institution, this chaplain is likely to maintain a distance between him/herself and the formal management-led committees, working groups, decision-making processes and forums. In these circumstances, the chaplain is unlikely to mix freely with senior managers and opinions will tend to be requested formally rather than informally.

Quadrant 4 is bounded by a primary ministry to all patients in need - irrespective of Church membership - and a complete immersion in the structures of the institution. The chaplain located within this quadrant is likely to respond compassionately to pastoral need, and may experience role conflict when reconciling pastoral need with the rubrics of the Church. Those outside of their local church will not have information passed back to parochial clergy - a fact that in some circumstances could become contentious. Within the institution, the chaplain is likely to sit on numerous committees, have an easy access to senior managers and be asked both formally and informally to express opinions. In some circumstances, the chaplain may be seen as another member of the management team.

*Hospice chaplaincy.* Within hospice, the provision of spiritual care evolved along different lines. When Cicely Saunders founded the modern hospice movement, she followed in the tradition of the ancient Christian 'hospes', welcoming the sick and performing the works of mercy contained in Matthew chapter 25 verses 35 and 36 (Saunders, 1986). Reflecting the new, egalitarian ethos of hospice, spiritual care was not devolved exclusively to any role or group of people. Instead, it became a corporate responsibility of the whole team. In the pioneering days of the 1960s and 1970s, this team was made up of disparate but like-minded people (Bradshaw, 1996). Fired by a sense of vocation they responded locally to the needs of the dying. Many of the pioneers had a strong Christian faith and local churches and Christian groups made significant contributions to

the establishment and development of hospices. For Britain and Ireland, the hospice history time line (Clark and Humphreys, 2000) shows that around sixty hospices are dedicated to a saint; others are inscribed with Christian nomenclature - 'The Good Shepherd', 'Trinity' or 'Our Lady' - and some have close links with the religious orders. The Christian faith, therefore, provides a visible influence within modern hospice and in this context, the chaplain represents one group amongst many that deliver spiritual care.

These models highlight the different approaches to chaplaincy towards the end of twentieth Century. In Australia, Lindsay Carey's (1997) enquiry into the perceptions of health professionals about the role of the chaplain found that whatever the formal role of chaplains, health professionals considered it important that a chaplain was available to patients at all times of the day and night. Respondents also considered that chaplains contributed to teamwork, to religious and psychosocial support and to bereavement support. They were also thought to provide the hospital with an ethical dimension, a community link, and a non-diagnostic communication role within the hospital.

In the United Kingdom, evidence is emerging of structural changes in chaplaincy provision following the continuing implementation of health care reforms. These changes were designed to show that, along with other staff, chaplains were meeting the standards outlined in the Patient's Charter (1991) by ensuring that the religious and cultural beliefs of patients were being respected. Consequently, the role of the chaplain has adopted a higher profile during the 1990s, resulting from a greater premium being placed on the chaplain's managerial functions and professional status (Beckford and Gilliat, 1996). Nevertheless, the role is a complex one. Christopher Moody (1999) suggests that the generic nature of chaplaincy is that of a wilderness ministry: a ministry that makes demands and includes risks; a possible

source of confusion and uncertainty. Significantly, Helen Orchard's (2000) study of chaplaincy in the hospitals of London showed a contemporary lack of clarity about the chaplain's role.

In that chaplains undertake a formal role as spiritual caregiver within the institutional responses of the hospital and the hospice, the present study has a particular focus on the chaplain's role and responsibilities, including possible sources of tension. It also addresses chaplaincy provision, support, funding and training, particularly if the chaplain is also required to deliver a spiritual care service to all sections of the organisation. These and related issues figure in all three phases of the study, but receive particular emphasis during Phase 1 (the survey) and Phase 2 (a phenomenological enquiry into the essence of spiritual care).

### **Palliative care: from religion to spirituality**

In a mission statement published in 1997 Cicely Saunders re-iterated that St. Christopher's Hospice was established and grew as a Christian foundation - not simply in terms of its care, but from a belief that the God revealed in Christ shared the darkness of suffering and transformed the reality of death. That belief had its roots in her conversion experience - a significant moment that brought with it a new awareness: it was 'like suddenly finding the wind at your back' (Du Boulay, 1948:48).

Challenged and invigorated, she decided to read medicine in an attempt to translate her Christian commitment into better care for the dying. Though related to a revivalist fervour, her approach to hospice articulated a Christian spirituality that integrated scientific research with medical practice and theology with compassion. Significantly, her mind had been exercised along these lines prior to the establishment of St Christopher's, resulting in papers

on Christianity and healing (Saunders, 1960), suffering (Saunders, 1961), and near-death conversion (Saunders, 1965). Remarkably, her first paper, published while she was still a medical student, contained the salient features of what eventually became the key elements of palliative care – including the need to attend to physical, social, psychological and spiritual problems of patients (Saunders, 1958).

As the concept of St Christopher's gradually became a reality, Dr Saunders remained true to her beliefs, ensuring that its underlying principles included an openness to the Holy Spirit and faith in Christ's victory over death. Her conviction and singleness of purpose precipitated a groundswell of interest - particularly amongst nurses (Clark, 1997, 1998) - that resonated with contemporary concerns for the dying and contributed to the success of both St Christopher's and other early hospices (James and Field, 1992).

The Christian articulation of hospice continues to occupy a significant place in the movement. St Columba's Fellowship exemplifies the point. With around 700 members worldwide, its aims are to sustain and promote the Christian foundation of hospice through courses, retreats and the ecumenical sharing of faith. Meetings of the Fellowship's trustees include time for prayer, for reflection upon biblical texts, and to seek the guidance of the Holy Spirit (St Columba's Fellowship, 1999). A founding member - interviewed during Phase 2 of the present study - highlights the Fellowship's character when she says:

I came into hospice work myself, very much because I felt that that was what God was calling me to do...to make my faith and the things real for me integrated with what I was doing as a professional and as a nurse.

*Routinisation.* As the hospice movement developed and spread, some aspects of Cicely Saunders' founding vision became the focus of challenge. Nicky James and David Field (1992) point to Max Weber's view (Bendix, 1966): that while charismatic leadership can act as a catalyst for social change, history alternates between charisma and routinisation through bureaucracy. According to Weber, leadership can remain charismatic only so long as the number of followers is small. When confronted by everyday demands, charismatic movements become confronted by the need to create an administrative machine and the process of routinisation begins.

With regard to hospice, James and Field suggest that as the movement advanced, processes of routinisation and bureaucratisation resulted in changes that impacted upon both the ethos of hospice and the perspective of carers. Consequently, in place of a service that operated outside of formal structures - staffed by volunteers, with few lines of demarcation - new initiatives developed that leaned towards re-professionalisation and the re-introduction of hierarchical models of management. This was thought to have a particular bearing upon staff recruitment. According to the thesis, a new generation of staff emerged that came to regard palliative care as a formative career experience, yet lacked the sense of calling found during earlier days of the volunteers.

This burgeoning professionalism seemed to be underlined when palliative medicine was acknowledged as a specialty in 1987, fuelling concerns about the possible re-medicalisation of hospices and the predominance of physical care over social, psychological and spiritual aspects of care. Such concerns appeared to have substance when Ian Maddocks (1997:196) commented that the introduction of palliative care had signalled a shift in emphasis away from the religious towards the secular. This shift had already aroused misgivings amongst those who had come to perceive a

dislocation from the sense of spiritual calling previously regarded as a fundamental characteristic of hospice. According to Ann Bradshaw (1996), this dislocation was emblematic of:

...a profound ideological rejection of the traditional understanding of the spiritual dimension of care exemplified by Cicely Saunders, accompanied by a re-defined concept of spirituality (1996:415).

It was in the context of an already widening fissure that a colloquium was held at Yale University in 1986 to examine the spiritual component of hospice care. During the proceedings, attention was drawn to what were considered to be the religious and secular features of spirituality. Factors influencing the recently-taken decision to reject a Christian foundation for the new Connecticut hospice were outlined. Jewish and Buddhist traditions were examined and Victor Frankl's (1959) belief - that love is the highest goal to which human beings can aspire - was put to delegates. Florence Wald expressed the view that in relation to hospice care, 'compassion is the professional tool for the intensive human care of hospice' (1986:32). Crucially, the findings of a survey were presented that had been undertaken by Cicely Saunders (1986) just prior to the Colloquium: 33 hospices in England considered they had a Christian foundation, 27 that they had not. In the context of such diversity, Dr Saunders felt the issue of spirituality was best highlighted by a response from the Sister-in-Charge of a National Health Service unit:

We feel as a team that 'spiritual' encompasses more than just religious, involving the meaning and purpose of life as defined by the patient and family which may or may not include God (1986:44).

As hospice philosophy developed internationally, further questions came to be asked about the status of its Christian foundations. Was the Christian

perspective - overt or implicit - an integral feature of hospice? Or did it serve mainly to provide a motivating/ sustaining force amongst like-minded innovators who were pioneering a new approach towards death and dying? Evidence suggests that human beings have a common desire to give and receive love, to be accepted or forgiven (Bellamy, 1998) and to achieve self-transcendence (Reed, 1992). It is also apparent that values central to hospice care: love, compassion and service - appear not to be bound by religion or culture, but are embraced equally by those who subscribe to the Christian faith, to other faiths, or to no faith at all.

In her study of the Koruna Hospice Service, Pam McGrath (1998) notes the commensurability of the Buddhist metaphysic with the ideology and practices of hospice. This is particularly apparent in the Buddhist concept of universal compassion, articulated by caring for the sick in loving service. Hospice is also to be found amongst other faiths: in Hong Kong - with its diversity of religious practices and differences in the approach to death (Chung, 1997); in Israel - where hospice and Judaism have discovered common values (Waller, 1997) and in Saudi Arabia - with its strong Islamic culture and the submission of its people to the will of God (Gray et al, 1997). This accessibility, whilst in keeping with the views of the International Spiritual Care Workgroup (1990), resonates poignantly with the prophetic nature of a statement made by David Tasma – a 40-year-old Polish Jew who was being cared for by Cicely Saunders during 1947. Believing he had achieved little for the world to remember him by, he left her a sum of £500 ‘to become a window in your home’. To Cicely Saunders, this was a defining act that effectively marked the beginning of the worldwide hospice movement (Saunders 1997:4).

Significantly, the religious climate is changing - a factor particularly evident in parts of Europe and in Britain (Davie, 2001). In an increasingly

multiethnic society, attention is being given to respect for religious and cultural beliefs (Department of Health, 1991, 1992) and to the needs of the dying from different faiths (Neuberger, 1987). A report from the Commission on the Future of Multiethnic Britain suggests that Britain has become 'a community of communities' (2000:3) and makes a plea for the recognition of a wider range of cultural identities. Challenges are made to the symbolic connections between Englishness and the Anglican Church, and public practices such as daily prayers at Westminster are regarded as unrepresentative of multiethnic Britain. Within this contemporary, pluralistic society, Anne Lister's (1997) suggestion seems particularly apt: that a health care setting which caters for the terminally ill of all faiths, minority groups, and those of no faith at all, should be an integral part of hospice philosophy.

There appears much to be gained from an inclusive approach. An English nurse manager (interviewed during Phase 2 of the present study) who grounds his spirituality within the Buddhist tradition, explained how his spiritual ethic has become operationalised within the context of hospice:

I think it's firstly about caring for the person - whether its going back after a while to ask whether the pain is less, or whether it's sitting with somebody whilst they cry or whilst they laugh. On top of that it's about being able to engage in the big questions with people, so enabling people to ask things like: why is this happening to me - enabling them to talk about their fears and anxieties as they get less well, about their worries about the process of dying...For some people, it's about supporting them in trying to leave things, or say things, or do things, which they feel are important to leave or say or do before they die. I think it's also about trying to listen to people properly, and that where possible, we try and let people tell us how they want things to be - and we try and make it be that way. I think a person's spirituality is about them as a person, as well as about what they express, so I also think it's terribly important that we accept the responsibility that when a person can't communicate with us any



more as themselves, that we continue to respect them - as themselves - up to the point at which they die.

*Postmodernity.* A major influence on contemporary ideas surrounding spirituality has been the issues around what has come to be known as postmodernity. Finding a base in the deconstructionist principles of literary theory - where the meaning of a text is dependent upon the perspective of the reader who engages with it - reality is thought to be experienced differently by each individual: an assumption that variously influenced the thinking of Jacques Derrida, Michel Foucault and Richard Rorty. Stanley Grenz (1996) comments significantly that the work of these thinkers reflects the central tenet of postmodern philosophy – that ‘all is different’ It is a view that:

...sweeps away the ‘uni’ of the ‘universe’...abandons the quest for a unified grasp of objective reality...asserts that the world has no centre, only differing viewpoints and perspectives’ (Grenz, 1996:7).

Alongside these changing perspectives, other views have emerged that challenge the assumptions of the Enlightenment - that knowledge is objective and inherently good; that the world is getting better; that progress and science will solve the problems of humankind. These challenges have been underscored by a 20<sup>th</sup> Century that witnessed two world wars, the use of atomic weapons, the genocide of religious groups and the plundering of the earth’s resources. The absence of an absolute criterion to evaluate a multiplicity of interpretations has resulted in truth becoming relational to the postmodern mind. Consequently, a new generation has arisen - frequently referred to as ‘Generation X’, after the book of the same name by Douglas Copeland (1991). Born between the years of 1960 and 1985, it is a generation familiar with uncertainty, fragmentation and the transient nature

of people and roles in the here and now: a generation distanced from that which has gone before, yet without a way to speak of what is to come:

Born into the threat of nuclear annihilation, growing up surrounded by environmental degradation, dominated by the breakdown of all sorts of once unassailable authoritative structures, from the Church to the family, it is easy to understand a certain pragmatism, even cynicism, in their attitude to life. So many of the once familiar cultural landmarks have now gone (Barnes 2000:8).

Viewed against the collapse of universal meta-narratives (Lyotard, 1984), activity within the realms of religion and spirituality take on added significance. Apologists for Christianity lament the lack of dialogue with those seeking spiritual reality and urge a re-discovery of transcendental mysteries (Drane, 2001). A new mindset is required; a different language, since the spiritual problems both of and for the Xers encapsulate the problems of the present and the future – and it is this generation that is now appearing as both health professionals and patients. Whilst acknowledging the transitory nature of postmodern values, however, soundings amongst Xers in America have found evidence of a discernible engagement with questions of meaning and authenticity - though located outside of previously held sources of authority:

Xers know that no-one is going to do it for them. They weren't given meaning, so they must construct it. Xers weren't given solid families, so they must create them. They didn't experience authenticity, so they must make sure that they are themselves authentic. Xers have no illusions about politicians giving a damn about them, any social security being around when they retire, or any saviour coming down from heaven to save them. Xers may as well be called 'the bootstrap generation' since the only way Xers will succeed is by self determination and hard work. Contrary to popular belief, Xers are hard workers if the job is meaningful and fair to them (Mabry, 2000:24).

These factors articulated by John Mabry - ambiguity, personal experience, authenticity, relationship and self-determination - are of some importance in the context of nascent perceptions of spirituality. Globalisation and the rise of new information systems have given instant access to a kaleidoscope of cultures and traditions, leading to the 'pick and mix' nature of postmodern spirituality - where the celebration of diversity promotes a new form of eclecticism. It is a spirituality wrestling in part with questions posed by the new world of cyberspace: how to live simultaneously within local and global frames of reference - in a networked world so wide that it challenges personal presence and the space of the body? John Staudenmaier (2000) suggests an answer can be found through a spirituality that re-discovers the nature of hospitality: a caring welcome where space and time are set aside to acknowledge the presence of others, to listen to their stories, and to demonstrate the uniqueness of each individual. Such a spirituality sits easily within modern hospice and palliative care.

*Secularisation.* Intertwined with postmodern perspectives are issues related to secularity. Although accurate data is difficult to collect - due partly to the way Church membership is defined - evidence suggests that fewer people are inclined to become religious. A survey of British social attitudes conducted in 1999 by the National Centre for Social Research (Sage, 2000) suggests that membership of the Church of England has fallen to 27% from a figure of 40% in 1983. Other data (Brierley, 1999) indicate that only 8% of the population worships on a weekly basis. Significantly, recent reports (Duggan, 1999) claim that the Diocese of London - the largest in England - has a deficit approaching £1.4 million and intends to reduce the number of its clergy to 35 by 2003. Such figures appear to support the view that in Britain, formal religion is on the decline and society is becoming increasingly secularised.

Secularisation is an issue inescapably linked to the present study. Perceptions of religiosity will inevitably influence both the type of spiritual needs required by individual patients and also the conclusions drawn from spiritual assessments undertaken by health professionals. Also influential is the widespread opinion, frequently perpetuated in the media, that Britain is becoming a godless society and that religion is an ever-increasing irrelevance. Against this background, Sharon Hanson's (1997) analysis of the theories of secularisation is illuminating. Based on Brian Wilson's (1966) understanding of secularisation – described as the loss of the social significance of religion - Hanson suggests that theorising about socialisation takes place through Broad or Narrow approaches. The Broad approach acknowledges the loss of religious significance at the level of the social system: the Narrow approach at the level of individual consciousness. The decline in numbers argument falls within the Narrow approach to socialisation. Related arguments suggest that fewer people go to church now than during the 19<sup>th</sup> Century; that fewer people now believe in God or a spiritual force; and that fewer people now believe in religion than in the middle ages. (Wilson, 1966; Bruce, 1995). Underpinning these views is the belief that there was a time of greater faith and a wider acceptance of a religious world view. This 'golden age' of greater faith is generally located within the middle ages.

It is a matter of debate, however, as to whether a golden age of faith ever existed (Stark R and Innaccone L R, 1994). Bruce (1995) suggests that during the middle ages lay people were neither expected nor encouraged to present themselves for worship – a point underlined by the fact that the size of medieval churches were so small that they could not have been designed to accommodate even a majority of the local population. Hanson's analysis also contains tables suggesting that more people go to church now than in the 19<sup>th</sup> Century and more believe in religion than in the middle ages.

Religious beliefs, therefore, have been thought to persist amongst individuals within society, irrespective of whether that society is in the process of becoming more or less secularised. Furthermore, if church-going has only a tenuous link to religion then secularisation cannot be primarily viewed in the light of church attendance. On a macro level, David Martin (1978) identifies conditions within the modern societies of Europe and North America that cause religious institutions to become less powerful and religious beliefs to be less easily accepted. These conditions vary according to whether individual countries have a religious monopoly – such as in the Catholic countries of Spain and Portugal; a duopoly - in which the Protestant Church is the major partner; a state Church counterbalanced by a substantial bloc of dissent – such as in England; or a condition of extreme pluralism, - such as in the United States of America – where the Church is completely unhinged from the state. Other variables relate to the level of anti-clericalism; the stability of democracy; the state of civil religion, and the condition of the Church-state nexus.

In Britain, Callum Brown (2001) is a recent exponent of the secularisation thesis. To support his argument he presents anecdotes and statistics drawn from the last 200 years, particularly emphasising influences from the 1960s onwards. What writers like Brown tend to overlook, however, is the religious resilience of modern times, seen in the processes of both resistance and accommodation: the ways in which religious perspectives persist in the formal structures of civil religion and also in the burgeoning philosophies of the New Age movement and other religious surges (Percy, 2001a; 2001b). Evidence suggests that beliefs have not been discarded: 7 out of 10 adults still claim to believe in God - endorsing Grace Davie's (1994) view of a population 'believing without belonging.' Paradoxically, as interest in religion has declined, interest in the spiritual appears to have increased. Yet this contemporary spirituality has emerged in a guise that is

dislocated from religion, especially in its institutionalised form. As a consequence, spirituality has been seen to break its religious boundaries (Sheldrake, 1999) and take on a multidisciplinary character that encompasses anthropology, psychology and the arts – attracting people who in other circumstances may have found a niche within religion and the Church (Drane 2001). Within such a scenario, official religion waxes and wanes against a backdrop of innate, intuitive spirituality (Percy 2000). This spirituality finds its expression in the 'common religion' identified by Wesley Carr (1997) and emerges intermittently in the symbolism and rituals of the 'folk spirituality' evident around catastrophic events or personal tragedies.

*Spirituality.* Etymologically, 'spirituality' has its modern roots in 17<sup>th</sup> Century France where it was used pejoratively to describe a form of contemplation expounded by Jeanne-Marie Guyon and the quietist movement. By the 19<sup>th</sup> Century, the term had come to be associated with mysticism and the practice of piety, before finally passing into today's common parlance (Wakefield, 1993). Dictionary definitions (Collins, 1995) outline current usage by relating 'spirituality' it to its root - 'spirit' - locating it thereby within the non-physical aspects of humankind: in profound thoughts and emotions; the part of a person thought to live on after death; a person's character, temperament and will to survive. These descriptions resonate with the notion of spirit as 'ruach' - 'breath' or 'life-force' - within the Judaeo-Christian tradition.

A word of caution is offered by Ian Markham (1998). 'Spirituality' has close associations with Christianity and is not a term that is recognised by every religious tradition. Even amongst religions that may ascribe it meaning, it looks very different: in Islam it is related to the extinction of self; in Judaism, it concerns the association between the divine and the

mundane; in Hinduism it relates to the link between the real self and the cosmic self; and in Buddhism it is associated with the cultivation of ethical dispositions.

Central to the debate is an acknowledgement that the non-physical, spiritual domain covers a wide range of articulations. Certain practices, such as prayer and meditation, appear to cross the religious boundaries and may properly be ascribed to what 'spirituality' has come to mean. In some cases, however, these articulations might not translate into English. 'Ikigai' is a case in point. Though used in everyday conversations amongst the Japanese and widely understood to relate to 'the positive aspect of quality of life' (Hisata et al, 2000), 'ikigai' has no direct equivalent in English. It is of such importance, however, that its determining factors have been the focus of a recent enquiry amongst post-operative cancer patients.

By claiming to be spiritually inclusive, palliative care is confronted by a number of challenges. These occur at the theoretical, managerial and operational levels of care. The overarching theoretical question relates to the essence of spirituality: what is it? In particular: what is its relevance to palliative care, and how might that relevance be articulated? Writers frequently point to difficulties posed by definitions and descriptions. These are not insignificant, particularly if spirituality is thought to be indefinable. Yet in that spiritual care is a widely publicised component of palliative care, assumptions may well be made about the existence of common understandings and operational definitions - particularly amongst those for whom the spiritual domain is important.

The delivery of spiritual care poses special challenges for managers. Within the context of the multidisciplinary team, questions arise as to the personnel best equipped to become spiritual caregivers. Chaplains have

traditionally played a leading role both in the delivery of spiritual care and, more recently, in the management of a spiritual care service. Tony Walter (1997), however, favours an alternative model. Outlining the benefits of shared responsibilities, he suggests that such an approach is advantageous because it can be offered by those both with and without a faith. Yet within such a broad spectrum, questions may be asked about staff recruitment and expertise. In particular: is spiritual care a responsibility that combines easily with other palliative care duties and if so, are trained staff readily available?

Operationally, some health care professions pay particular attention to spirituality. Nursing is a case in point. Florence Nightingale was a Unitarian with a strong faith that helped her to define nursing as a religious calling. Evidence of that tradition remains in the contemporary view that spirituality lies at the heart of nursing (Fry, 1997). Theorists like Joyce Travelbee (1971) regard illness as a spiritual encounter. Tracey Patten et al, (1998) note that Jean Watson advises nurses to create a supportive spiritual environment and Tamara Halterman and her colleagues (1998) note how Faye Abdella seeks to include progress towards the patient's spiritual goals within the nursing process.

In the United Kingdom, the UKCC (1986) directs that within Project 2000 student nurses should have the opportunities to identify the spiritual needs of patients and devise a plan of care. The findings from recent research however, indicate that the concept of spirituality is not very meaningful to nurses (Golberg, 1998) and that nurses are less than comfortable in the spiritual domain (Harrison, 1993). Significantly, Katrien Cornette (1997) suggests that before entering the spiritual domain of patients, care-givers should have begun to address their own spirituality.

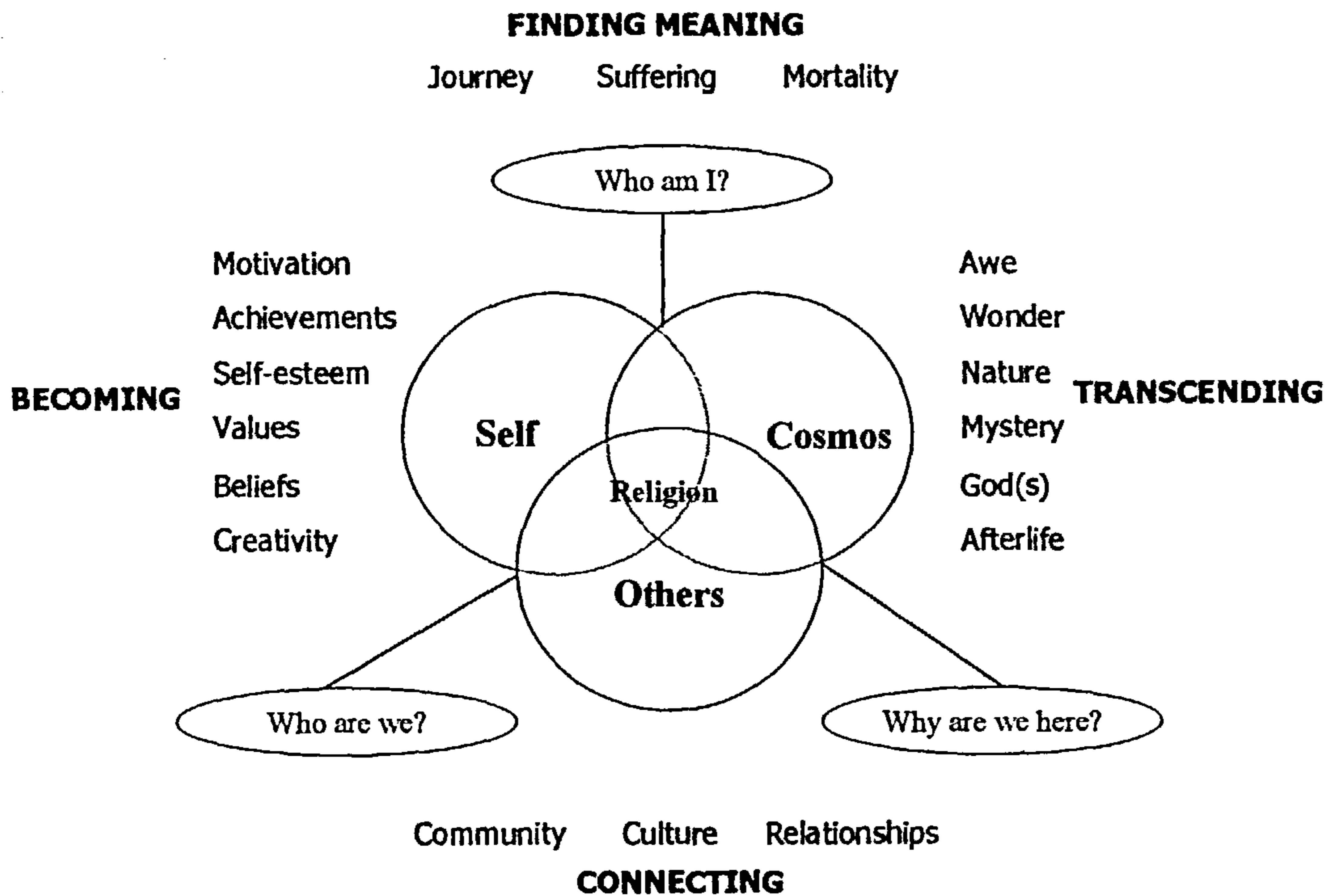


*Theoretical model.* One way forward is to acknowledge the limitations of language in the presence of mystery but at the same time attempt to tease out that which may be described in the form of a definition and conceptual model. The conceptual model and operational definition outlined here were devised to inform the research project and drawn from a synthesis of theoretical features found in both health care and other literature.

It should be stated, however, that the impetus which led me to construct this model is located firmly within health care - in the context of an acute hospital where, on any one day, inpatients associated themselves with more than 50 religious traditions. The model resonates, therefore, with the values of acceptance, beneficence and non-judgemental compassion, as individuals come to terms with the impact of their illness and locate it within meaningful parameters – some of them spiritual. Postmodern in character, it acknowledges diversity, relational truth, the loss of a sacred centre and the recognition that amongst patients drawn from pluralistic societies, there is no single world view or spiritual source - but rather multiple explorations, multiple interpretations and multiple articulations. It is a bricolage that resonates with health care concepts of holism, since it incorporates the possibility of spiritual encounters through multiple ways of becoming, connecting, transcending and finding meaning – including the creative, the emotive and the intuitive. Underpinning the model is the frequently stated view that every person is a spiritual being (Stoter, 1991), a view that has come to include atheists and agnostics as well as the followers of religion (Burnard 1988). The capacity to be spiritual, then, is considered to be a universal human attribute that crosses boundaries, peoples and cultures (Renault and Freake, 1996).

Key parameters of this model of spirituality are set out in Figure 2. At the core are located the dimensions of 'self', 'others' and the 'cosmos' and the dynamic relationship thought to exist between them (Whitfield, 1993). The

**Figure 2** A conceptual model of the spiritual domain



concept of the self has been described as 'a mental construction of the person by the person' (Jary and Jary, 1995:584), and is considered to be heavily influenced by relationships and social experience (Stevens, 1996). Hay (1989) suggests that if the self includes an element of spiritual well-being, it is likely that inner resources will be enhanced. The self also incorporates the notion of embodiment (Frank, 1991; Sweasy, 1997) and has been associated with the process of becoming (Ferrucci, 1993) - an activity that focusses sharply upon the developing, unfolding life, involving reflection and a sense of who one is. Also associated with becoming is the adoption of ultimate

values: love and truth, forgiveness and reconciliation (Stoll, 1989). Beliefs are seen to be pivotal, providing a framework for supporting hope and making sense of the world (Jourard 1971, Clark et al, 1991, Harrison, 1997). Amongst other characteristics, human beings have come to be regarded as imaginative and creative, capable of expressing their spirituality through a variety of media, such as art, literature, music and dance (Kandinsky, 1997; Lewis, 1966; Foley, 1999; Duncan, 1995).

Finding meaning has come to be regarded as a central feature of spirituality. This is due in no small part to Frankl's view that the purpose of human beings is not to avoid pain but 'to see a meaning in life' (1959:115). The personal search for this meaning has been likened to a sacred journey (Mische, 1982) to discovery of the hidden mysteries of life. The metaphor of the journey frequently comes to the fore during illness, thereby acknowledging the altered state of the individual. Notions of quest feature prominently: travelling to a faraway place in search of a special goal or prize. Variations include the idea of a pilgrimage, a journey into sickness or into exile (Hawkins, 1999). On that journey, suffering and mortality occupy significant places, raising questions that concern the ontological meaning of life. Paradoxically, the journey into death is sometimes considered to be the ultimate vehicle for spiritual discovery and transformation (Singh, 1999).

Connectedness - to self and others - inscribes the spiritual domain, where spirituality is both expressed and discovered through community (Hay, 1989). In essence, spiritual life is considered to be embedded in community life (Erricker and Erricker, 2001) – a life that provides opportunities for belonging through the vehicles of language, imagery, ritual and art (Helman, 1990; Froggatt, 1997). Within community, meaning and fulfilment are also to be found through loving relationships (Fish and Shelley, 1988; Burkhardt, 1994). Connectedness also includes relationships with the cosmos. Such

connections promote a sense of awe and wonder in the presence of mystery and the beauty of nature, prompting questions about the existence of a creator and the possibility of life after death. According to Ruth Stoll (1989), those who embark upon a relationship with God may discover an additional source of meaning and hope.

Transcending the self, defined as 'the state or action of exceeding limitation' (Page, 1995:283) is regarded as a feature of spirituality (Fish and Shelley, 1978; Stoll, 1989). Within health care, a body of writers favour the 'vertical' idea of transcendent space: a dualist world view in the Cartesian and Platonic traditions that regards the natural and supernatural as essentially different from one another (O'Brien, 1980; Harrison, 1993). An alternative dualism is put forward by Pamela Reed (1998), who describes transcendence as a process that relates to the inner reaches of the soul and the outer reaches of the spirit. Using this soul-spirit continuum as a vertical axis of ontology, and a modern-postmodern continuum as a horizontal axis of epistemology, she constructs a multiparadigm model that incorporates ways of being with ways of knowing. From a philosophical perspective, Jerry Gill (1998) argues for a re-thought, postmodern view of mediated transcendence – a phenomenon whereby 'intangible reality can be said to be encountered and conveyed *in and through* the particulars constituting tangible reality' (1989:3). This fusion of the tangible and intangible suggests the possibility of fresh insights into the postmodern experience of transcendence on the part of patients. This resonates with Allan Kellehear's (2000) pragmatic view that transcendence may be achieved by searching for meanings in situations, in moral or biographical contexts, and in one's religious beliefs.

Whilst 'religion' appears to have become separated from 'spirituality', it nevertheless remains a primary vehicle for spiritual expression. For some, perceptions of self, others and the cosmos, together with the activities of

becoming, connecting, finding meaning and transcending are inextricably linked to religion. Yet to describe the breadth of contemporary spirituality, a distinction should be drawn between what may be regarded as religiously-oriented spirituality and religion-free spirituality. To facilitate such a distinction, it is helpful to focus not only on faith, but also on the maintenance and control of that faith. The following definition by Daniele Hervieu-Leger (1993) cited by Alan Aldridge (2000), illustrates the point:

(Religion is) ...an ideological, practical and symbolic mechanism through which the individual and collective consciousness of belonging to a particular lineage of faith is constituted, maintained, developed and controlled (Aldridge 2000:119).

From this conceptual model, an operational definition can be devised to inform the research process. It is based on the assumptions that spirituality may be expressed either religiously or non-religiously; that a desire to find meaning is part of the human condition; that transcendence may be achieved by either 'reaching out' or 'going within' - or through the experience of tangible reality; that belief systems may not necessarily include a God; and that relationships with others and with the context of life may become spiritual encounters.

*Definition.* Spirituality may be regarded as both a capacity and an inclination on the part of human beings to find meaning and achieve transcendence by relating to and reflecting upon their inner and outer selves through the criterion of their belief systems and in the light of their relationships with the cosmos and others within it.

The definition and conceptual model I propose, however, should be read with caution - since inclusive definitions and diagrammatic representations may ultimately be misleading. Underlying assumptions or constituent parts

may also be open to challenge: whether spirituality is universal; whether the term is meaningful outside of a faith tradition; whether the desire for transcendence is a basic human need. Furthermore, although attempts have been made to portray key features of the spiritual domain, the conclusion should not be drawn that spirituality is a cohesive, integrated whole, articulated exclusively through any particular manifestation. It is also important that 'spirituality' does not become a new orthodoxy cut adrift from the rigour of checks and balances found in other areas of health care.

To summarise this 3<sup>rd</sup> section on spirituality within palliative care: the spiritual zeal of the founders of modern hospice - articulated through the Christian faith - is acknowledged as a contributory factor that influenced the way in which hospice philosophy resonated with the conditions and climate of the day. Though the Christian perspective of hospice continues to occupy a place within the movement, an interest has developed in the needs of those who subscribe to other faiths or none. Evidence suggests that non-religious patients demonstrate similar needs to their religious counterparts. Consequently, a more encompassing concept of spirituality is coming into being that seeks to recognise both the religious and non-religious perceptions of human beings. Some of the commentary on these changes has focused on perceptions of an unintended, even unwelcome loss of previously shared spiritual – ie Christian - ground. Yet there is another perspective: of a new concept of spirituality arising as a conscious response to changing social circumstances and developing health care environments (Clark, 2000). It is this concept of spirituality that informs and underpins this study.

## **Concluding comments**

In this chapter, I have addressed three key areas that have a direct bearing on the study: concepts associated with illness; the establishment and development of chaplaincy; and the nature of contemporary spirituality.

Issues related to loss, suffering, pain, hope and woundedness impact upon the meaning of illness in the perceptions of both patients and caregivers. These meanings emerge in the phenomena of 20<sup>th</sup> Century pathographies and oral narratives – seen as vehicles through which voices can be recovered and power reclaimed after diagnosis. Of interest to this study are the sources of strength found by people in the face of a life-threatening condition; how people cope with loss; what happens to beliefs; and – when hopes for a cure have faded – the adjusted hopes of patients and carers as death draws near.

Chaplaincy in the United Kingdom has evolved along different lines within hospital and hospice – prompted by the intervention of Government in the case of the former and the vision of pioneers in the case of the latter. However, the contemporary institutions have a number of common features - and common problems. One problem relates to the management of spiritual care: in particular to the relationship between a ubiquitous form of spiritual care that is regarded as a spontaneous gift, freely given and without limit - and a focussed, dedicated spiritual care service administered by a specially designated co-ordinator and delivered by specially trained ‘professionals’. Related issues also cluster around the tensions inherent in ways of relating to the institution and ways of ministering to patients. Relevant to this study are the chaplaincy roles, responsibilities, facilities and resources that impact upon the nature and delivery of spiritual care.

The contemporary notion of spirituality appears to be a late modern construction that has gained ground within health care during the last quarter of the 20<sup>th</sup> Century. It is a concept that is not universally embraced, hence the absence of a generally accepted definition. At the inception of the National Health Service, communications from the Ministry of Health demonstrated a close association between spirituality and religion. Consequently, early guidance on how to meet spiritual needs focussed upon the provision of religious observances, the establishment of chapels and access to a minister of religion. With the growth of a pluralistic society, however, and the spread of received notions about secularisation, interest has developed in the needs of those who hold no personal faith or who subscribe to faiths other than Christian. Consequently, a more encompassing concept of spirituality is coming into being that seeks to recognise both the religious and non-religious perceptions of human beings. Of particular interest to the present study are the ways in which religious and non-religious spiritual needs are identified and met.

As the study progressed, issues associated with these three areas continually arose. They informed the methodological debate surrounding the research design and featured significantly in each phase of the investigation. The following chapters document how these issues were addressed and related questions were resolved.



## CHAPTER 2

### METHODOLOGY

In this chapter, I address some of the enquiry's methodological issues. I understand methodology to be concerned with the philosophical evaluation of investigative techniques: the theory of how an enquiry should proceed within social science. According to Thomas Schwandt (1997:93), it involves 'an analysis of the principles and strategies in a particular field of enquiry'. This analysis determines the subsequent use of research methods to generate data. Chapters 3 to 5 deal with individual phases of the research and each has a section entitled 'methods'. Matters of principle and strategy are dealt with here; matters of application and techniques under the 'methods' headings in each of the three chapters.

In the first section of this chapter, I outline the project's overarching question, state its aim and objectives, and follow in the second section with a discussion of their impact upon the research design. I then address the issues of triangulation and crystallisation, and give my reasons for opting for a three phase, mixed method design of survey, phenomenology and case study.

Taking each of the three phases in turn, I next consider the methodological questions that cluster around a key issue of that phase. During Phase 1 – a survey of all the acute hospitals and inpatient palliative care units in England and Wales – it was to devise a measuring instrument. Consequently, I detail the construction of a questionnaire, from concept to revision, and set it in the context of wider methodological issues that relate to purpose, design, sample, and questionnaire recipients. I then turn to Phase 2 – a phenomenological enquiry into the essence of spiritual care -

and begin by focussing upon the nature of qualitative research. I trace the origins and characteristics of phenomenology and make a case for the appropriateness of the phenomenological approach used during this phase of the study. Finally, I turn my attention to Phase 3: a multiple case study in four health settings. A feature of this phase was the involvement of patients – regarded within palliative care as vulnerable people. Consequently, I address ethical issues associated with consent and confidentiality, and outline the involvement of two district research ethics committees that were approached for approval of the study. To conclude this section, I turn my attention to Allan Kellehear's (2000) theoretical model of spiritual needs, and comment upon its potential for providing a framework within which the spiritual needs of patients may be viewed.

## **The project**

*Research question.* The spiritual dimension of health care is a prime area for research, since holistic and palliative models of care both claim to be spiritually inclusive. Such claims give rise to a number of questions: about the nature of spiritual care and how it is managed within health settings; about the training and roles of caregivers; and about the perceptions of patients and their significant others. Yet a single, overarching question is necessary for the formulation of an effective design. In this enquiry, the key to that question lies with the patients.

Patients with cancer feature prominently in palliative care and are to be found in both hospitals and palliative care units. Furthermore, both types of institution have attempted to incorporate a spiritual care service into their organisation. Certain roles within each institution - such as the chaplain and the nurse - have had long associations with spiritual care. In the light of these factors, the overarching question emerges: *what are the features of the spiritual care of patients with cancer within the specialist inpatient palliative care unit and the acute hospital?*

With this question in mind the following aim and objectives were identified:

*Aim:* To identify the features of the spiritual care of patients with cancer within the acute hospital and the specialist inpatient palliative care unit.

*Objectives:*

- 1 Published Guidelines

- a) To trace the history of national guidelines on spiritual care
  - b) To identify the responses of Health Authorities, hospitals and units to such guidelines
- 2 Assessment of spiritual needs: to gather information about how spiritual needs are identified
- 3 Spiritual care provision: to gather information about the provision of spiritual care in relation to:
- a) physical resources (for example the provision of chapels or multi-faith / prayer rooms)
  - b) human resources (for example spiritual caregivers in the form of chaplains, faith leaders, nurses and volunteers)
  - c) the most frequently required elements of religious care
  - d) the most frequently required elements of humanistic care
  - e) the role of the chaplain
- 4 The views of stakeholders: to discover the perceptions of spiritual care stakeholders regarding spirituality and spiritual care
- 5 Spiritual care delivery: to gather information about how spiritual needs are met

6 The views of patients and relatives: to discover the perceptions of patients and relatives about spiritual care

*Mixed method design.* The main purpose of a research design is to make the research question researchable. It is a way of arranging the environment in which the research takes place: the individuals, the groups of people, the activities and places (Fink, 1995). The objectives of this study require different types of data to be collected from a wide variety of sources. As a result, consideration was given to a mixed method design.

This type of design has its roots in the positivist/ empiricist paradigm that underpins quantitative methods, and in the constructivist/ phenomenological paradigm that underlies qualitative methods. Together, these paradigms are emblematic of the major - though divergent – world views within social science. Since the 1960s, intense debate has surrounded these paradigms; a debate so fierce it became known as the paradigm wars. Central to the debate were notions of validity: internal validity that emphasised the controlled settings preferred by positivists and external validity that emphasised the natural settings preferred by constructivists. More recently, there has been a move to acknowledge the compatibility of the two paradigmatic positions. As a result, researchers have come to adopt the tenets of paradigm relativism, using whatever approach or combination of approaches works best for the problem or phenomenon under investigation (Reichart and Rallis, 1994).

*Triangulation.* Abbas Tashakkori and Charles Teddlie (1998) regard the desire for triangulation as a major influence on the development of mixed methodology, deeming it ‘the intellectual wedge that eventually broke the methodological hegemony of the monomethod purist’ (1998:41). Triangulation is a surveying or nautical term that relates to a process

whereby two or more points are used to establish the position of another. Its use in social research acknowledges the difficulties inherent in producing valid and reliable data, and is based on the assumption that a higher degree of confidence is established if a number of viewpoints can be presented (Shipman, 1997).

Norman Denzin (1984) identified four basic protocols to study the same phenomenon in question. Data source triangulation involves the use of different data sources; investigator triangulation involves the use of different researchers; theory triangulation involves the use of multiple theoretical perspectives; and methodological triangulation involves the use of multiple methods. Other contributions have come from theorists such as Michael Patton (1990) whose work included the multiple use of qualitative techniques within the same study (Tashakkori and Teddlie 1998:42).

Triangulation, however, is not the only reason for the use of mixed method designs. In a review of 57 studies that utilised such designs, Jennifer Greene and her colleagues (1989) identify five purposes for their use. In addition to seeking the convergence of results, studies also sought complementarity – examining both overlapping and different facets of a phenomenon; initiation – discovering paradoxes, contradictions and fresh perspectives; development – so that results from the first method could inform the use of the second; and expansion – or mixed methods that add breadth and scope to a project.

Considering the broadly based religious and non-religious nature of spiritual care and the phenomenon of spirituality that underpins it, some of the purposes of mixed method designs are appropriate to this study. Most notable are the purposes of triangulation, complementarity and development. A design incorporating both across-method and within-

method triangulation would encapsulate the benefits gained from different methodological standpoints, and from multiple sources of data. In addition, complementarity would bring to the study the possibility of constructing a description of spirituality from its constituent parts. Furthermore, in a study such as this, the notion of development is crucial. Once incorporated into the design, it offers an element of reflexivity and incremental progression that is both responsive and iterative.

For a study that relies heavily on triangulation, a word of caution is required. Elizabeth DePoy and Laura Gitlin (1998) exemplify a common assumption when they state that 'triangulation enables the investigator to validate a particular finding by examining whether different sources provide convergent information' (1998:284). While it may transpire that the weakness of one method is outweighed by the strength of another, convergence may not necessarily be achieved. It is at this point that the nautical metaphor is at its weakest, since human phenomena that occur in natural settings do not equate simply to fixed points that are accessible in a linear fashion. Nor should it be assumed that the convergence of data from different sources is always necessary for truth to be revealed. Hammersley and Atkinson (1983), cited by Thomas Schwandt (1997) state:

One should not...adopt a naively 'optimistic' view that the aggregation of data from different sources will unproblematically add up to produce a more complete picture...differences between sets or types of data may be just as important and illuminating...What is involved in triangulation is not just a matter of checking whether inferences are valid, but of discovering which inferences are valid (Schwandt, 1997:199-200).

*Crystallisation.* It is at this point that an added dimension is introduced with the concept of crystallisation or, to be more accurate, a multiplicity of

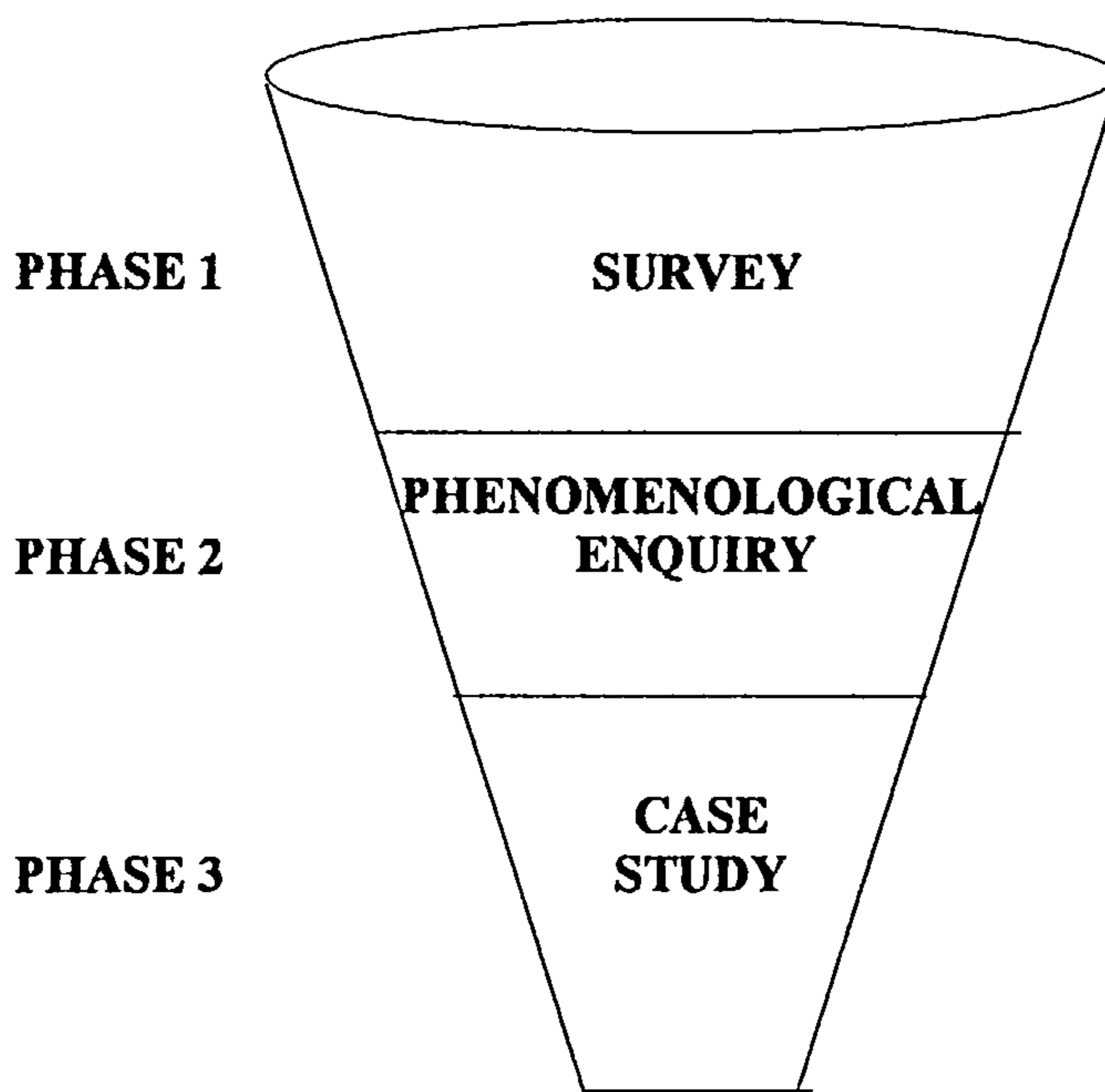
dimensions. Rejecting the phenomenon being studied as a fixed point that can be geometrically triangulated, Laurel Richardson (2000) offers instead the image of the crystal: something mysterious that combines symmetry and substance with an infinite variety of shapes and transmutations. Crystals grow, change, and alter, but are never amorphous. They are prisms that both reflect externalities *and* refract within themselves, creating different colours and patterns. Significantly, what we see depends upon our angle of repose (Richardson 2000:934).

It could be argued that gathering a wide selection of data through a mixed method design involves a loss of depth that may possibly be attained with a single method approach (Denscombe, 1998:84). Furthermore, crystallisation has been thought to provide a thoroughly partial understanding of the topic: 'paradoxically, we know more and doubt what we know' (Richardson, 2000:934). However, when viewed in the context of the multiple world views that underpin spirituality - and the uniquely personal experience of illness and perceived reality, I argue that such an approach offers the best opportunity to relate to a phenomenon that is both diverse and dynamic. Far from being a weakness, an iterative mixed method design offers a more effective way to gaze on the essence of spiritual care and capture a glimpse of its meaning in the lived experience of both the caregiver and the recipient. The approach resonates with the concept of the researcher as 'bricoleur' - a 'Jack of all trades' (Levi-Strauss, 1966:17) who uses that which is 'pragmatic, strategic and self-reflexive' (Nelson et al, 1992:2) to produce a bricolage of experiences and representations. In such circumstances, the researcher - like the quilt maker - stitches, edits, and puts slices of reality together, bringing an element of psychological and emotional unity to an interpretive experience (Denzin and Lincoln 2000:5).



In the context of this approach, quantitative and qualitative research are frequently combined, for example, through the use of a survey, followed by in-depth interviewing – a method that facilitates a ‘mapping’ of the central issue to inform progress in subsequent phases of the study (Bryman, 1996:137; Tashakkori and Teddlie, 1998:23). For this study, a three phase, mixed method design was constructed to provide a view of the spiritual care phenomenon from different perspectives (Figure 3). Phase 1 was a survey

**Figure 3** The mixed method design



of the views of senior chaplains in all of the acute hospitals and inpatient palliative care units in England and Wales. Phase 2 utilised a phenomenological approach to discover the essence of spiritual care in the lived experience of stakeholders. Phase 3 was a multiple case study of spiritual care in four health settings. The design incorporated reflexive and iterative elements so that each phase could inform and shape the next.

*Ethical issues.* In any research project, issues concerning ethics are inescapable and the present study is no exception. Theoretical decisions about the mixed method design and operational procedures relating to data collection, analysis and presentation produced a variety of ethical considerations that needed to be addressed. An overview of these considerations is outlined here. Ethical issues relating to each phase are presented in more detail later in this chapter.

Researchers may be considered to possess a specialised body of knowledge and expertise. In addition, they subscribe to common practices and thereby assume the characteristics of a professional group. Such groups recognise corporate ethics of conduct, both between members and also in relation to clients and the general public (Campbell 1990:83). The American Association for Public Opinion Research has formalised and published its code of professional ethics. This code addresses issues relating to the ways that research will be conducted and the relationships between researchers and others: the sponsors, other researchers, the respondents and the public. It also puts forward a standard for the disclosure of essential information (Czaja and Blair 1996:255).

In this project, made up of three empirical studies, ethical considerations centre around the principles and obligations governing the structure of the research, conduct in the field, the handling of the data and the writing of the report. Issues of trust, confidentiality and consent feature prominently. Unique to Phase 3 – which incorporates interviews with patients coming towards the end of their lives – were additional considerations relating to access and vulnerable people. These considerations and the resultant protocols are outlined in each section below.

## **Phase 1: the survey**

*Survey research.* Surveys are a response to the desire for information. They collect data directly from people by means of questionnaires (self-administered or with assistance), or interviews (in person or on the telephone). Some surveys use paper and the postal service, others are constructed and distributed electronically. On occasion, they may appear to be a simple and speedy form of research, but a rigorous approach to methodology is essential if they are to generate the data that is required. For a survey to be successful, attention must be paid to a number of key factors. According to Fink (1995:1) successful surveys include: 'specific, measurable objectives; sound research design; sound choice of population or sample; reliable and valid instruments; appropriate analysis; accurate reporting of survey results'. These features were acknowledged as being important for this study and attempts were made to incorporate them into the survey.

*Objectives.* The objectives of the survey relate to the overarching aim of the project – to identify key features of the spiritual care of patients with cancer within the acute hospital and the specialist inpatient palliative care unit. While patients with cancer may be in the majority within the palliative care unit, they may be one group amongst many within the acute hospital. Consequently, the hospital spiritual care service is likely to accommodate the requirements of patients with cancer within the global requirements of all patients within the institution. Such requirements may be approached in a variety of ways: by face to face contact between human beings, or by the provision of facilities that enable patients to feel supported in their spiritual beliefs and practices. The survey seeks data from both approaches. The objectives of this survey, therefore, are to discover a) the spiritual care provision and b) the spiritual care requirements of patients with cancer in

two health settings: the acute hospital and the specialist inpatient palliative care unit.

*Design.* A variety of survey designs are possible. These include variations of the longitudinal designs (collecting data over time), comparison group designs (comparing an experimental group with a placebo group, for example), and normative and case control designs (making use of comparison groups). The design used here is that of a descriptive rather than analytical survey, and as it collects data within a single time frame - it utilises a cross-sectional structure.

*Sample.* Having decided that the population of interest was comprised of acute hospitals and inpatient palliative care units, questions then arose concerning the sample and its boundaries. These were answered in relation to an overall objective: to trace the history of published guidelines that relate to spiritual care and to identify the responses of health authorities, hospitals and hospices. As England and Wales have been regarded as one administrative unit for health care purposes, it was thought that the influence of such guidelines could be traced more effectively if only the hospitals and hospices located within these two countries were included.

Other considerations related to the size of the sample. Many changes were under way within the National Health Service at the time of the survey. Would it be possible to draw a representative sample? Was a representative sample needed? Indeed, could an up-to-date sampling frame be identified? Extensive discussions took place with Beechwood House Publishing Ltd, managers of *Binley's Database of NHS Management*. Those discussions revealed that 1053 hospitals offered acute services in the United Kingdom and that a database could be produced of hospitals offering acute services in England and Wales. Yet questions remained: how could the presence of

people with cancer be assured? How could the smaller, cottage hospitals be eliminated? How could specialist mental health hospitals and hospitals within community trusts be excluded?

Similar conversations were held with Avril Jackson at the Hospice Information Service based at St. Christopher's Hospice, London. Enquiries revealed over 700 hospice services within Britain and Ireland, including 193 specialist inpatient palliative care units in England and Wales. Subsumed within this figure were 127 voluntarily managed units, 51 NHS managed units, 8 Marie Curie Units and 7 Sue Ryder Units. Further discussions revealed that some units were situated within a hospital as a discrete ward and some were 'mini units' of just two or three beds.

In the light of these considerations, ideas of a probability sample were discarded in favour of a whole population study for both hospitals and hospices. What remained was to define the populations – a process described in the methods section of chapter 3.

*Questionnaire recipients.* Ronald Czaja and Johnny Blair (1996) make the point that 'when studying groups, we must decide who in the group or organisation is the most knowledgeable individual and can provide accurate information' (1996:14). Much thought was given to the problem of the questionnaire's recipients. Who would have the information that the survey sought to elicit? In hospitals, the Director of Operations may know about the facilities; the Director of Nursing Services about the delivery of spiritual care, the Director of Finance about spending on spiritual care. In the palliative care units, the Medical Director, Matron, or Director of Patient Care Services may have an overview of all forms of care. It was felt important, however, that in this case, the questionnaire remained with one person - thereby increasing the likelihood of its completion and return.

A case emerged for the questionnaire to be sent to the chaplain. This was because both hospitals and hospices usually include a chaplain amongst their staff. Furthermore, although spiritual care may be delivered by a variety of personnel, there appears to be a growing trend to include a responsibility for spiritual care within the job description of the chaplain. In addition, chaplains working in acute hospitals and inpatient palliative care units are likely to come across patients with cancer as a matter of routine. That being the case, it would be appropriate to elicit background information from the chaplain which could then be utilised developmentally during Phases 2 and 3. Chaplains, therefore, were nominated as respondents for the questionnaire.

*The instrument.* Reflecting the paucity of research in this area, no established or validated instrument was available. Consequently, it was necessary to create a tool that fulfilled the purpose of the survey and was valid and reliable in both health settings. The questionnaire, therefore, became not only a means of generating data, but a focus for methodological issues regarding the study's boundaries, rationale, matchability of settings, sources of information, inclusion criteria and sampling frame.

Bram Oppenheim (1998) states that 'research techniques...are concerned with measurement, quantification and instrument building and with making sure our instruments are appropriate, valid and reliable' (1998:6). As questionnaires only make sense within the context of sampling, data processing and data analysis, attention was paid to matters of language, to the clarity of instructions, and to the generation of content validity.

Modules of questions fell into two main categories - spiritual care infrastructure and spiritual care delivery. A detailed process of question construction focussed upon key issues within each category. Modules

relating to the infrastructure were concerned with chapels and special rooms, chaplaincy personnel, job descriptions, funding, policies, and personnel. Modules relating to spiritual care delivery sought information regarding religious and non-religious spiritual care. Items within each module were included only after an analysis of their purpose, their place in the literature and the type of data they generated. Attention was paid to the build-up of modules within the questionnaire and the sequence of questions within each module. 'Closed' questions were favoured in most cases, with pre-coded answer categories. Questionnaires for chaplains in the palliative care units were similar – though not identical - to the questionnaires for chaplains in hospitals. Any differences solely reflected the nature of the hospital or palliative care setting.

*Ethical issues.* Careful consideration was given to factors that might encourage the questionnaire recipients to respond. Ethical issues assumed a high priority in this respect. Consequently, strategic decisions were taken about the method of approach to questionnaire recipients. Steps were taken to ensure that consent was informed and that privacy, anonymity and confidentiality was guaranteed. Thought was given as to how information regarding the purpose of the research and the use of its findings would be presented to the recipients. Honesty regarding the time and effort required to complete the questionnaire was essential, as was a general indication of the data and the opportunity for recipients to express concerns they might have. As a result, a letter was devised to accompany the questionnaire that incorporated specific features (Appendix 10). These included the following elements, designed specifically to facilitate informed consent and ensure confidentiality:

- Details about myself, my place of work and my role within the institution

- The main objective of the study
- The research design and its rationale
- The reason why chaplains were chosen as questionnaire recipients
- An indication of how long it would take to complete the questionnaire
- Reassurances that no assumptions had been made about the willingness of the recipients to be included in the study
- A guarantee of confidentiality and anonymity
- A contact address and telephone number with an invitation to recipients to make contact regarding any concerns they may have or points that needed to be clarified

These elements are in keeping with the code of professional ethics and practices drawn up by the American Association for Public Opinion Research (Czaja and Blair 1996:255). This code addresses the principles of ethical practice in relation to the researcher's maintenance of scientific competence, integrity in the conducting of surveys and in relationships with survey respondents, clients and users of the research.

On the following pages I show the layout of the questionnaires. Each module of questions is shown in turn. Where hospital and hospice modules are identical, only the hospital module is shown: where they differ, both are shown. To amplify the process of construction, I outline the rationale for each module, its data source and the type of data generated by each item.



**Figure 4 Phase 1 draft questionnaires**

**THE HOSPITAL QUESTIONNAIRE**

**Question 1:**

**These questions are about Hospital Chapels and other Special Rooms.**

- 1 (i) How many hospitals is the Trust responsible for? \_\_\_\_\_
- 1 (ii) How many of the Trust's hospitals have a chapel? \_\_\_\_\_
- 1 (iii) How many of the Trust's hospitals have a multifaith room? \_\_\_\_\_
- 1 (iv) How many of the Trust's hospitals have a special room for viewing the deceased? \_\_\_\_\_

In questions 1(v) to 1(vii) please tick all the boxes that apply.  
Two chapels opened in the same decade should show two ticks.

	Pre 1940	40s	50s	60s	70s	80s	90s
1 (v) During which decade was the chapel(s) opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 (vi) During which decade was the multifaith room(s) opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 (vii) During which decade was the viewing room(s) opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**THE HOSPICE QUESTIONNAIRE**

**Question 1**

**These questions are about Chapels and other Special Rooms.**

	Yes	No
1 (i) Does the Unit have a chapel?	<input type="checkbox"/>	<input type="checkbox"/>
1 (ii) Does the Unit have a multifaith room?	<input type="checkbox"/>	<input type="checkbox"/>
1 (iii) Is there a special room for viewing the deceased?	<input type="checkbox"/>	<input type="checkbox"/>

	Pre 1960	60's	70's	80's	90s
1 (iv) During which decade was the chapel opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 (v) During which decade was the multifaith room opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 (vi) During which decade was the viewing room opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Data.* Responses to hospital questions 1(i) to 1 (iv) provide interval data. Responses to hospice questions 1 (i) to 1 (iv) provide categorical data. Responses to hospital and hospice questions 1 (v) to 1 (vii) provide ordinal data.

*Rationale* 1 (i) This hospital question sets a base line, since one trust may have several hospitals under its umbrella. This question is not relevant to hospice/palliative care units.

1 (v) to 1 (vii) Identifying the decade during which chapels/multifaith rooms were established offers the possibility to construct a national profile and consider its relationship to published guidelines or emerging trends.

*Literature* 1 (ii) to 1 (iv) The construction of these questions is based on:

- RHB 48 (76)
- The patient’s charter (Department of Health, 1991)
- HSG 92/2 (Department of Health, 1992)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)

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**THE HOSPITAL QUESTIONNAIRE**

**Question 2**

**These questions are about Chaplaincy/ Spiritual Care Department provision**

	Yes	No
2 (i) Is Chaplaincy/ Spiritual Care Department accommodation for the exclusive use of the Department?	<input type="checkbox"/>	<input type="checkbox"/>
2 (ii) Does the accommodation provide a room for confidential discussions?	<input type="checkbox"/>	<input type="checkbox"/>
2 (iii) Does the accommodation include computer access to a patient database?	<input type="checkbox"/>	<input type="checkbox"/>
2 (iv) Is the Chaplaincy/ Spiritual Care Department equipped with pagers/ bleeps?	<input type="checkbox"/>	<input type="checkbox"/>

## THE HOSPICE QUESTIONNAIRE

### Question 2

These questions are about Chaplaincy Provision.

Yes      No

- |         |  |                          |                          |
|---------|--|--------------------------|--------------------------|
| 2 (i)   | Is accommodation provided for the exclusive use of chaplains?    | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 (ii)  | Do chaplains have access to a room for confidential discussions? | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 (iii) | Do chaplains have computer access to a patient database?         | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 (iv)  | Do chaplains have a pager/ bleep?                                | <input type="checkbox"/> | <input type="checkbox"/> |

*Data*            Responses to hospital and hospice questions 2 (i) to 2 (iv) provide categorical data.

*Rationale*      Special facilities for chaplaincy have been recommended since 1963. This question sets the provision in the context of current technological support.

*Literature*      2 (i) to 2 (iv) The construction of these questions is based upon:

- HM (63) 80 para 2
- Tunbridge report 'The hospital chaplain' (Joint Committee for Hospital Chaplaincy, 1973)
- A handbook on hospital chaplaincy (Hospital Chaplaincies Council, 1978; 1987)
- The patient's charter (Department of Health, 1991)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

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## HOSPITAL QUESTIONNAIRE

### Question 3

These questions are about Chaplaincy/ Spiritual Care Personnel.

- 3 (i) How many Chaplaincy/ Spiritual Care Department sessions (of 3.5 hours) are funded weekly by the Trust? \_\_\_\_\_
- 3(ii) How are these sessions utilised?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_
- 3 (iii) How many religious leaders voluntarily contribute to the Chaplaincy/ Spiritual Care Department?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_
- 3 (iv) How many volunteers (including Eucharistic Ministers) are formally associated with the Chaplaincy/ Spiritual Care Dept?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_

## THE HOSPICE QUESTIONNAIRE

### Question 3

These questions are about Chaplaincy Personnel.

- 3 (i) How many Chaplaincy sessions (of 3.5 hours) are funded weekly by the Unit? \_\_\_\_\_
- 3(ii) How are these sessions utilised?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_
- 3 (iii) How many religious leaders voluntarily contribute to Chaplaincy?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_
- 3 (iv) How many volunteers (including Eucharistic Ministers) are formally associated with Chaplaincy?  
a) Anglican \_\_\_\_\_ b) Roman Catholic \_\_\_\_\_ c) Free Church \_\_\_\_\_  
d) Other Faith \_\_\_\_\_ please specify \_\_\_\_\_

*Data*            The responses to Questions 3 (i) to 3 (iv) provide interval data.

**Rationale** Guidelines that relate to the recruitment of hospital chaplains from different traditions have been in existence since 1948. This question looks at the range of traditions currently represented within hospital and hospice chaplaincies on both a salaried and voluntary basis.

**Literature** 3 (i) to 3 (iv) The construction of these questions is based upon:

- RHB 48(76)
- A handbook on hospital chaplaincy (Hospital Chaplaincies Council, 1978; 1987)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- HSG92/ 2 (Department of Health, 1992)

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**QUESTIONS 4 TO 8 ARE IDENTICAL IN BOTH HOSPITAL AND HOSPICE QUESTIONNAIRES.**

**Question 4**

**These questions are about the Chaplain's role.**

**4 (i) Does the Trust expect the Chaplain to assume a general responsibility for the spiritual care of:**

- |               |                          |                          |              |                          |                          |
|---------------|--------------------------|--------------------------|--------------|--------------------------|--------------------------|
|               | Yes                      | No                       |              | Yes                      | No                       |
| a) Patients?  | <input type="checkbox"/> | <input type="checkbox"/> | c) Staff?    | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Relatives? | <input type="checkbox"/> | <input type="checkbox"/> | d) Students? | <input type="checkbox"/> | <input type="checkbox"/> |

4 (ii) Are spiritual care responsibilities itemised in the chaplain's job description or letter of appointment?  Yes  No

4 (iii) Does the Trust expect the chaplain to assume a liaison role between patients and religious leaders?  Yes  No

4 (iv) Does the chaplain contribute to any spiritual care training programmes?  Yes  No

4 (v) Does the chaplain have any management/ co-ordinating responsibilities within the area of bereavement care?  Yes  No

*Data* The responses to Question 4 (i) to 4 (v) provide categorical data.

*Rationale* The debate about the chaplain's role continues to attract attention, particularly in the current climate of mergers, accountability, job descriptions and audits.

*Literature* 4 (i) to 4 (v) The construction of these questions is based upon:

- Pastoral care in hospitals (Autton, 1968)
- Images of inadequacy (Pattison, 1980)
- Spirituality and sector ministry (Moody, 1999)
- A handbook on hospital chaplaincy (Hospital Chaplaincies Council, 1978; 1987)
- HSG92/ 2 (Department of Health, 1992)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Framework for spiritual, faith and related pastoral care (NHS E, 1995)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

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### Question 5

These questions are about funding and spending in the area of spiritual care.

5 (i) Where might financial resources for spiritual care be found:

a) Within the chaplaincy budget?

b) Within other budgets?

please specify \_\_\_\_\_

5 (ii) Are financial resources available for:	Usually	Sometimes	Rarely
a) Training courses: fees, residential costs, travel?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Educational hardware: TV, Video Recorder, OHP?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Educational materials: books, videos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 (iii) Are financial resources available for locum cover?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Data* The responses to Questions 5 (i) and 5 (iii) provide ordinal data.

*Rationale* These items address the impact of financial constraints and a bidding culture on chaplaincy provision and spiritual care training

*Literature* 5 (i) to 5 (iii) The construction of these items is based upon:

- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Framework for spiritual, faith and related pastoral care (NHS(E), 1995)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

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**Question 6**

These questions are about policies and guidelines.

	Yes	No
6 (i) Has the Trust published a statement about spiritual care?	<input type="checkbox"/>	<input type="checkbox"/>
6 (ii) Is written information about spiritual care given to patients around admission?	<input type="checkbox"/>	<input type="checkbox"/>
6 (iii) Has the Chaplaincy/ Spiritual Care Department a policy statement about spiritual care?	<input type="checkbox"/>	<input type="checkbox"/>
6 (iv) Are there guidelines to assist health professionals to meet the spiritual and cultural needs of members of religious faiths?	<input type="checkbox"/>	<input type="checkbox"/>
6 (v) Is a form used to record information about a patient's spiritual needs?	<input type="checkbox"/>	<input type="checkbox"/>

*Data*            The responses to Questions 6 (i) to 6 (v) provide categorical data.

*Rationale*      In the context of an increasingly pluralistic society, these items address the issues of policy and communication.

*Literature*      6 (i) to 6 (v) The construction of these items is based upon:

- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Framework for spiritual, faith and related pastoral care (NHS(E), 1995)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

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**Question 7**

**These questions are about identifying the patient's spiritual, religious and cultural requirements**

	Yes	No
7 (i)    Is there usually an assessment of the patient's spiritual, religious and cultural requirements?	<input type="checkbox"/>	<input type="checkbox"/>

**In questions 7(ii) to 7(iv) please tick all the boxes that apply.**

7 (ii)    When does the assessment usually take place:

a)    around the time of admission? <input type="checkbox"/>	b)    during the patient's stay? <input type="checkbox"/>
--	---

7 (iii)    Is the assessment conducted by:

a)    a clerk? <input type="checkbox"/>	c)    a nurse? <input type="checkbox"/>
b)    a chaplain? <input type="checkbox"/>	d)    another person? please specify _____



7 (iv) Does the assessment include:

- |   |                          |  |                          |
|---|--------------------------|--|--------------------------|
| a) religious affiliation?                                   | <input type="checkbox"/> | g) wish to fast?   | <input type="checkbox"/> |
| b) wish to worship?   | <input type="checkbox"/> | h) dietary requirements?                                     | <input type="checkbox"/> |
| c) wish for own faith leader?                               | <input type="checkbox"/> | i) washing requirements?                                     | <input type="checkbox"/> |
| d) sacramental support?                                     | <input type="checkbox"/> | j) wish for special clothing?                                | <input type="checkbox"/> |
| e) objection to shaving body/<br>facial hair?               | <input type="checkbox"/> | k) wish for religious objects?                               | <input type="checkbox"/> |
| f) objections to being bathed<br>by member of opposite sex? | <input type="checkbox"/> | l) objections to anything<br>which might contradict beliefs? | <input type="checkbox"/> |

*Data* The responses to Questions 7 (i) to 7 (iv) provide categorical data.

*Rationale* Guidance from the Ministry of Health on the collection of information regarding a patient's religious affiliation has been in place since 1963. These items arise from contemporary publications that give guidance on the collection of religious and cultural information in a pluralist society.

*Literature* 7 (i) to 7 (iv) The construction of these questions is based upon:

- Caring for dying people of different faiths (Neuberger, 1987)
- HSG92/ 2 (Department of Health, 1992)
- The patient's charter (Department of Health, 1991)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Framework for spiritual, faith and related pastoral care (NHS(E), 1995)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

**Question 8**

**These questions are about various aspects of spiritual care.**

8 (i) In your experience, how frequently do patients need someone to:

	Frequently	Occasionally	Rarely
a) listen to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) 'be there' to support them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) provide information for them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) other, please specify _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8 (ii) In your experience, how frequently do patients seek to address the following issues:

	Frequently	Occasionally	Rarely
a) why me?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) the meaning of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) value of one's own life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) suffering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) forgiveness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) transcendence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) nature of God	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) concern for relatives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) death and dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) afterlife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) other, please specify _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8 (iii) In your experience, how frequently do patients require the following aspects of spiritual care:

	Frequently	Occasionally	Rarely
a) prayer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) texts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) worship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) rituals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) baptism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) confession and absolution	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) communion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) anointing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) last rites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) other, please specify _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Data* The responses to Questions 8 (i) to 8 (iii) provide ordinal data.

*Rationale* A form of contemporary spirituality frequently found within health care suggests that all people are spiritual beings with spiritual needs, whether or not those needs are expressed religiously. Such a view incorporates the humanistic need for another person to 'be there', the supposed need for transcendence and forgiveness, and the religiously oriented needs found (in this instance) within the Christian tradition. These items address issues associated with this view.

*Literature:* 8 (i) to 8 (iii) The construction of these questions is based upon:

- The essence of spirituality (Stoll, 1989)
- Spiritual care of the dying adult (Jacik, 1989)

- The nurse's role in spiritual care (Ross LA, 1998)
- Health care chaplaincy standards (Hospital Chaplaincies Council, 1992)
- Framework for spiritual, faith and related pastoral care (NHS (E), 1995)
- Spiritual care in the NHS (National Association of Health Authorities and Trusts, 1996)

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*Validity and reliability.* Devising, editing, revising and preparing the final version of the questionnaires took some three months. During this time, helpful comments were received through the process of academic supervision. In addition, other strategies were employed to render the instrument as valid and reliable as possible. These included presentations of the questionnaire to different groups of colleagues, then inviting their comments. Presentations were made to:

- staff, researchers and fellow students at a research meeting of the Sheffield Palliative Care Studies Group (11th March 1999)
- staff and fellow students at the Lincoln Theological Institute (18<sup>th</sup> March 1999)
- a group of hospital chaplains and chaplaincy volunteers (25<sup>th</sup> March 1999)

In addition, one chaplain recorded the time it took to complete the Palliative Care Unit Questionnaire.

*The comments.* There was considerable interest in the questionnaires and many comments were received. All were carefully considered. An indication of the comments and the categories they fell into is given below:

a) General

- Why focus on cancer patients?
- Why not include more links between chaplains, patients and parishes?
- Should more recognition be given to the breadth of personnel who deliver spiritual care?

b) Concept

- Should a definition be given of the concept of spiritual care?

c) Clarity of questions

- Is each question explicit and unambiguous?
- Is only one question being asked?

d) Formatting

- Extra spaces are required in certain places
- The consistency of layout within questions needs checking

e) Instructions

- In places, more help is needed about how many boxes to tick

f) Scales

- In some places, the ordinal scales may include unnecessary elements
- Are the labels on the scales consistent with the dimension being measured?

When all the comments had been considered, the questionnaires were revised and then referred to Jonathan Bright, Senior Consultant at the Statistical Services Unit (University of Sheffield) for comment. This was to gain the opinion of a professional statistician, before embarking on the Pilot. Finally, camera-ready copies of the questionnaires were sent to the University of Sheffield Print Unit for preparation. Twenty copies of each questionnaire were produced, Hospital Questionnaires on green paper and Palliative Care Unit Questionnaires on blue. Unique identifiers appeared in the corner of each questionnaire. As far as could be known at this stage, the questionnaires embodied an acceptable level of content validity and were ready for testing in the field. This testing took the form of a pilot study and is described in the methods section of chapter 3.

To summarise this section: the absence of a previously established instrument impacted significantly upon the nature and progress of the survey. Yet in spite of a delay to the data collection process, attention paid to the construction and detail of the questionnaire proved to be beneficial. The resulting instrument was grounded in a comprehensive literature. It

became the subject of widespread consultation and careful revision. Eventually, I argue that it became uniquely suited to the purposes of the present enquiry.

## **Phase 2: the phenomenological enquiry**

The second phase of the present study employs a qualitative methodology that is fundamentally different from the methodology of Phase 1. The purpose of Phase 2 is to discover the essence of spiritual care in the lived experience of a group of 16 stakeholders – defined here as spiritual caregivers who have the opportunity to influence practice. I outline below the general nature of qualitative research and then address the key features of the phenomenological approach employed by this enquiry.

*Qualitative research.* Norman Denzin and Yvonna Lincoln (2000:2) consider that qualitative research operates in a complex field that cross cuts seven historical moments which ‘overlap and simultaneously operate in the present’. These are defined as the traditional (1900-1950); the modernist or golden age (1950-1970); blurred genres (1970-1986); the crisis of representation (1986-1990); the postmodern, a period of experimental and new ethnographies (1990-1995); postexperimental enquiry (1995-2000); and the future - which is now (2000 onwards). According to this thesis, successive waves of epistemological theorising cut across these moments. Significantly, the future moment is concerned with moral discourse, with conversations about democracy, race, gender, class, nation-states, globalisation, freedom and community. I suggest that human spirituality fits comfortably into this list.

Unlike quantitative research, qualitative methods take the researcher’s communication with the field, and members within it, as an explicit part of

knowledge production (Flick 1998:6). This engagement between researcher and the participant has become emblematic of a type of enquiry that has rejected the scientific paradigm, seeking instead to emphasise questions of meaning in making sense of human behaviour and social life (Clark, 1997:159). Consequently, qualitative researchers will be favourably disposed to inductive reasoning, thick description and purposive sampling.

Inductive logic has been defined as:

the process in which a general statement, suggesting a regular association between two or more variables, is derived from a series of empirical observations (Jary and Jary, 1999:314).

The contrasting activities of inductive and deductive reasoning are frequently described in general terms: inductive reasoning as the movement from the particular to the general, deductive reasoning as the movement from the general to the particular (Crookes and Davies, 1998). Whilst helpful as far as it goes, the description should not obscure the fact that the two types of reasoning represent different approaches to knowledge. A researcher using a deductive approach begins with an *a priori* acceptance of truth. Beginning from a theoretical framework, s/he seeks verification of what is already accepted. The researcher using inductive reasoning has no *a priori* acceptance of truth. Theory is developed rather than tested. Concepts are based on the repetition of patterns. An holistic perspective is employed. Multiple realities are thought to exist (DePoy and Gitlin, 1998). Within this scenario, Schwandt (1997) makes the point that analysis within qualitative research involves all forms of inference including induction, deduction and abduction (selecting a hypothesis that gives the best explanation of the available evidence). To claim that qualitative studies employ deductive reasoning, therefore, may just be a short hand way of saying that the



hypothetico-deductive method of explanation is rejected (Schwandt, 1997:70).

'Thick description' lies at the heart of qualitative research and stems in part from the seminal work of Clifford Geertz (1973). Yet its roots reach back to the careful, detailed descriptions found in the ethnographic method located within earlier work in social anthropology. This is not just a record of observations in the field, but rather a precursor to interpretation: an account of the contexts and meanings that inscribe a particular event or set of circumstances. In order to discover such meanings it may be necessary for the researcher to choose a case, a respondent or an interviewee on the basis of subjective or purposive criteria. This is in contrast to the random selection procedures favoured by quantitative researchers. Significantly, it means that where a sample is drawn using purposive procedures, other cases within a population do not have an equal chance of being selected. Furthermore, claims cannot be made that the case is representative. Within qualitative research, the case is selected because - in the opinion of the researcher - it is of particular interest to the study, and has the potential to further understanding.

*Objectives.* The notion of spiritual care is conceptually rich. Within health care, a growing literature bears testimony to the interest of professionals across a range of disciplines. Yet few empirical studies have been conducted into the nature of spiritual care, or into the demands that spiritual care delivery places upon the caregivers. Questions, therefore, inevitably arise: how does spiritual care relate to spirituality? Is spiritual care transferable across cultures and faiths? Are there generic elements? What difficulties are associated with the delivery of a spiritual care service? What hopes are there for the future? Underpinning all others, however, is the fundamental question: what is the essence of spiritual care? The objectives of this phase

of the research is to answer these questions and to discover the essence of spiritual care.

*The phenomenological approach.* In the debate concerning a research paradigm for palliative care, attention is coming to focus on the benefits of phenomenology (Seymour and Clark 1998). Derived from two Greek words: *phainomenon*, meaning 'appearance' and *logos*, meaning 'word' or 'reason' phenomenology has come to be seen as a reasoned inquiry that discovers the inherent essence of appearances. As an appearance is anything of which one is conscious, then anything which appears to consciousness is a legitimate area of investigation. Phenomenology therefore is inextricably linked to both appearances and their meanings – in other words, to how human beings make sense of the world. This point is summarised by the French philosopher Peirre Thevenaz, (1962, cited by Stewart and Mickinus, 1974:10) who says 'to make the world appear as a phenomenon is to understand that the being of the world is no longer its existence or its reality, but its meaning'.

Contemporary phenomenology is based on the philosophy of Edmund Husserl (1962) - later developed by Martin Heidegger (1962) and Maurice Merleau-Ponty (1962). Husserl was a mathematician, who subsequently accepted a chair of philosophy at Gottingen before moving to Freiburg until his retirement in 1930. Rooted in the thinking of both Plato and Descartes, Husserl seeks to describe the meaning of a phenomenon through the lived experience of human beings. From the 1960s, this approach gained ground within the human sciences - particularly sociology (Berger, 1991) and psychology (Giorgi, 1985) - and since the 1980s has come to be regarded as a useful paradigm within which to conduct qualitative research within health care (Oiler, 1986). As a result, phenomenological approaches have been used in a variety of health care enquiries including: the experience of

having cancer (Hallorsdottir and Hamsin, 1996); the nature of the caring interaction (Reiman 1986); and the nurse-family spiritual relationship (Styles, 1994).

Significantly, such approaches have also been used to investigate the essence of religious experience. In addition to the influence of Husserl, Clive Erricker (1999) acknowledges the effect that Hegel (1806) had on the thinking of Gerardus van der Leeuw, whose book - *The Phenomenology of the Spirit* (1933) - is regarded by Erricker as 'the first significant publication to outline a phenomenological approach to the study of religion' (Erricker, 1999:77). Although the authors would not describe themselves as phenomenologists, similar approaches can also be found in *The Varieties of Religious Experience* by William James (1902), and in Rudolph Otto's *The Idea of the Holy* (1923). Most notable has been the way that Rudolph Bultmann (1960) utilised the views of Heidegger to focus upon the essential message of the New Testament by stripping away its mythical attachments. Once 'demythologised', Bultmann thought this essence could then be re-stated and re-communicated in existential terms; a view that was to promote considerable debate during the 1950s and 1960s.

Since phenomenological approaches have found favour within both health care and religion, the method is of particular relevance to this study. Based on the Husserlian tradition of transcendental phenomenology, this phase of the enquiry sought to discover the objective 'essence' of a phenomenon - spiritual care - from the viewpoint of a detached observer 'stepping out' of the world (Seymour and Clark, 1998) As such, it contrasts with the existential tradition of phenomenology - influenced by Heidegger - that regards the observer and the world as inseparable.

Issues surrounding validity are fiercely debated within qualitative research. In this instance, critics might voice epistemological concerns that challenge the notion of an unmediated knowledge of the world that is absolute and true. Concerns may also be raised about the operational measures designed to collect and analyse the data, suggesting that in view of the 'subjective' nature of the enquiry it may be lacking in construct validity. Phenomenology has also been accused of treating the accounts of individuals as 'unproblematic descriptions of phenomena, rather than as one aspect of a wider, multifaceted explanation of which the individual research respondent may not be fully aware' (Seymour and Clark, 1998:130).

In spite of the difficulties, however, the approach offers a starting point: an opportunity to collect data about a phenomenon that attracts much debate but little research. A basic problem, however, lies in the link between the phenomenon experienced by the interviewee and the description of it outlined by the researcher. In such circumstances, validity may be seen in the light of how well the description of the phenomenon is grounded in the data. In other words: does the description provide an accurate portrait of the common features and structural connections that are manifest in the collected examples?' (Polkinghorne, 1989:57). One way to establish such accuracy is to present the draft report to the interviewees to establish whether their views are accurately portrayed. As a result, the production of data becomes a starting point for the establishment of their validity. Such a strategy was used in this study.

*Ethical issues.* A number of issues related specifically to the collection of data during this phase of the research. Featuring prominently was the amount of information that would be presented to the proposed interviewees. Other considerations clustered around the procedures to protect anonymity, whether the researcher would become involved in

dialogue, and what would happen to information gathered outside of the recorded interview. A protocol was devised that included the following information:

- Details about myself, my place of work and my role within the institution
- The main objective of the study
- The research design and its rationale
- The reason why the proposed interviewee had been approached
- An indication of the purpose of the interview
- A guarantee of confidentiality and anonymity
- A contact address and telephone number with an invitation to the proposed interviewees to make contact regarding any concerns they may have or points that needed to be clarified

These points were made verbally to the proposed interviewee during an initial conversation that took place either face to face or by telephone. They were also incorporated into a letter (Appendix 12) confirming the date, place and time of the interview and re-iterated before the interview began. At that stage, participants were also reminded that they could stop at any time, without giving a reason. Information gathered outside of the recorded interview was regarded as 'background information', and not incorporated into the main body of data.

To summarise this section: qualitative research seeks to make sense of human behaviour and social life. Within this type of research, phenomenological approaches have found favour within the fields of both religion and health care. Consequently, I consider such an approach to constitute an appropriate methodology to investigate the essence of spiritual care in the lived experience of stakeholders.

### **Phase 3: the case study**

*Case study research.* John Cresswell (1998:61) points out that a 'case' may be regarded as either an object of study (see Stake, 1995) or a methodology (see Merriam, 1998). Within both approaches, the case study is an exploration of a 'bounded system' through detailed, in-depth data collection that involves multiple sources of information which may include observations, interviews, documentation and physical artefacts (Yin, 1989). Account is also taken of the context of the case. This involves situating the case within its social, historical or developmental setting and may include a chronology of major events. The overriding aim of this approach is to focus exclusively on the particular, thereby gaining a deeper understanding by learning about an individual case. Such a study may be designated as 'intrinsic' - when the case itself is of primary interest; 'instrumental' - where research is undertaken on a case to find out something else; or 'collective'- a study of several cases within the same project (Stake, 1995:3). The demands of this enquiry, with its focus upon the hospital and the hospice, dictated the need for a collective (or multiple) case study.

*Objectives.* By the time Phase 3 began, the project was rich in data relating to spiritual care provision, spiritual care requirements and the essence of spiritual care. It was time now to reflect upon how that data would inform the third phase of the research. What was still missing were data on the

nature of spiritual caregiving in individual institutions and the perceptions of patients regarding their own spiritual care. The objectives of this final phase, therefore, were to discover how the spiritual needs of patients were identified and met within the hospice and the acute hospital.

*The case.* Much thought was given as to how a case may be constructed to enabled the objectives outlined above to be met. As patients were to be interviewed in both hospital and hospice settings, it was necessary to identify at least two sites. There could be added gains, however, by including variations of each institution: a secular hospice and a hospice with a religious foundation; a district general hospital and a university hospital.

Purposive sampling procedures eventually discovered such a mix. Hospice 1 was a secular unit located in close proximity to hospital 1 – a district general hospital offering acute services. Hospice 2 was founded by a Roman Catholic order of nuns and still maintained its religious perspective; it was located within three miles of a large university hospital. These four settings made up the parameters of the multiple case. As each pair of institutions - comprised of one hospital and one hospice - fell within different health authorities, submissions were required to two ethics committees to gain approval for the study.

*Patient inclusion.* A feature of this phase of the research was the collection of data from patients - a factor that presented both ethical and logistical considerations. Patients who are terminally ill have been described as vulnerable people, and the debate continues as to whether vulnerable people should be included in research studies (Beaver et al, 1999). Richards and his colleagues (1998) make the point that the need for research - alongside the delivery of compassionate care - was recognised at the inception of the modern hospice movement, and consider that research offers the potential to

make significant contributions to palliative care. These contributions fall especially within the quality of life arena, the public understanding of death in society, and the wider dilemmas of health care.

*Ethical issues.* At the centre of the debate are ethical issues surrounding the way in which patients are recruited to a study and dealt with during it. Access can be problematic, particularly if there is an element of 'gate-keeping' by health professionals. It was for these reasons that presentations were offered to key personnel – the multidisciplinary team in hospices, ward staff in the hospitals and the palliative care team in hospital 1 – to ensure they understood the research's purpose when broaching the issue with patients and relatives. At these presentations, issues relating to confidentiality, use of the data, reporting and disseminating were also discussed. A research report was offered to each institution.

In the present study, questions of trust and deception, benefit and harm came into sharper focus due to the fact that some patients were coming to the end of their lives. Consequently, attention was given as to how the research process – beginning from the initial approach to patients, to the final recorded interview - would be managed. Thought was also given to what might happen if a patient became distressed either during or after the interview.

*Protocol.* In order to safeguard patients, a protocol was devised that incorporated the following features:

- A presentation to unit staff regarding the purpose and procedures of the study



- Nurses to speak about the study to patients they deemed well enough to be included
- Information sheets left for patients and their relatives to discuss (Appendix 1). Staff to speak with relatives during visiting times
- Information sheets to be collected after 24 hours
- Those information sheets that indicated a patient's willingness to know more, to be passed to the researcher
- A meeting to be arranged between the researcher and the patient – with relatives present if possible. Details of the research and issues such as confidentiality to be explained
- Patients who gave their consent to be reminded that they could stop the interview at any time, without giving a reason. This information to be also included on the patient's consent form (Appendix 2)
- If patients became sad or distressed, they had a number of options: terminating the interview; continuing the interview; having a break; or having additional support either during or at the end of the interview from a nurse, or chaplain

Matters concerning this protocol were of particular interest to members of the two district research ethics committees that were approached for approval of the study. Clarification was sought by one ethics committee on inclusion/ exclusion criteria and assurances were required about

confidentiality: in particular that all tapes containing interview recordings would be destroyed at the end of the study (Appendix 4, 5). The second committee wanted clarification on procedural details (Appendix 6, 7). Once these points were clarified, approval was granted by both committees (Appendix 8, 9).

This part of the research raised some logistical problems. It was originally intended to interview three patients and three matched relatives on each of four sites that comprised the multiple case study - two hospices matched with their neighbouring acute hospital. It was envisaged that in the hospice scenario, this process would be relatively simple, given that staff understood what the research was about and how it would be conducted. More difficulties were anticipated in the hospital scenario, where medical patients were sought in one hospital and surgical patients in the other. In the larger hospital, such patients may be located on a number of wards. Consequently, links were established with a named manager/ sister in each hospital and on each appropriate ward. In the case of medical patients, this included a member of the palliative care team.

*Patient interviews.* The patient interviews were loosely based on the guidelines for spiritual assessment developed by Ruth Stoll (1979). An aide memoir contained a number of open-ended questions that asked patients about their fears, their sources of strength, their beliefs and their hopes for the future. Consideration was given to the construction of the questions to encourage an answer that contained as much depth and richness of data as possible. Typical of qualitative research, the intention was to go beyond ordinary listening and hear the meanings of the data (Rubin and Rubin, 1995:8).

Unlike the previous interviews conducted during Phase 2, these patient interviews were not disaggregated and broken into cross-interview categories with the help of NUD\*IST software. Instead, they were regarded as a structural whole, an interpretive account of life experiences that describe significant occurrences and turning points in people's lives. Consequently, this set of interviews were treated as oral history and analysed according to what Denzin (1989) calls the biographical method. Such a method is designed to give weight to chronology or life stages, to stories and epiphanies, to questions of meaning.

*Model of spiritual needs.* Allan Kellehear (2000) proposes a theoretical model of spiritual needs that provides a framework within which the spiritual concerns of patients - as indicated in their narratives - may be located and articulated. Based on the idea that human beings have a desire to transcend their suffering and find meaning, Kellehear suggests that spiritual needs such as purpose, hope, affirmation, connectedness and social presence may lead to what he calls situational transcendence. The need for peace, reconciliation, reunion, prayer, moral and social analysis, forgiveness and closure may lead to moral and biographical transcendence. The need for religious reconciliation, divine forgiveness and support, religious rites and sacraments, visits by clergy, religious literature and discussion about God, eternal life and hope, may lead to religious transcendence. This model was thought to provide a useful means of viewing such data and was used, therefore, in the analysis of patient narratives.

To summarise this section: the case study occupies a prominent place in the present enquiry. Informed by the findings of both the survey and the phenomenology, it provides a context in which to explore how the spiritual needs of patients are both identified and met. For the first time, data are collected from patients – in this instance, vulnerable people approaching the

end of their lives. Consequently, ethical issues took on an extra dimension. Ethics committees became involved. Protocols were devised to safeguard patients and relationships with gatekeepers became crucial.

### **Concluding comments**

In this chapter I have addressed some of the major issues of methodology that are associated with the study. I have outlined the rationale underpinning its mixed method design, explored the notion of triangulation and shown the appropriateness of the concept of crystallisation. While some depth may have been lost by the adoption of such a design, it is nevertheless in keeping with the multifaceted nature of contemporary spirituality, and reflects the breadth of its individual and collective interpretation. Central to the discussion of this mixed method design is the nature of qualitative research, its accompanying world view and associated notions of knowledge acquisition.

Each phase of the three-phase design – the survey, the phenomenological enquiry and the case study – has been taken in turn and its key methodological features discussed. For the survey, these clustered around the need to develop an instrument. The phenomenological approach raised questions of reality and essences; the case study - of how to include vulnerable people coming towards the end of their lives.

Questions that arise from issues of methodology are not unproblematic, and contain many pitfalls for the researcher. These are accentuated in areas associated with palliative care, where a universal acceptance of research and an appreciation of its benefits – which may come too late for individual participants - has yet to be achieved. Consequently, if the research culture within palliative care is to broaden its base, it is important to pay attention

to the methodological, ethical and procedural questions that offer safeguards to the participants on the one hand and the integrity of the research process on the other. Attempts were made to conduct this study in accordance with these criteria.

## CHAPTER 3

### CHAPLAINCY IN HOSPICE AND HOSPITAL: FINDINGS FROM A SURVEY IN ENGLAND AND WALES

In this chapter, I outline the first phase of the research: a cross sectional descriptive survey of the perceptions of senior chaplains in 151 hospices and 194 hospital trusts throughout England and Wales, undertaken in the summer of 1999. Data were collected by means of a postal questionnaire, revised in the light of a pilot study. The questionnaires sought information about a) the infrastructure to support spiritual care and b) patient requirements of religious and non-religious spiritual care. The overall response rate was 76%.

Findings regarding infrastructure were as follows: *Physical resources* - the survey found a rise in the establishment of multifaith rooms during the 1990s. The establishment of chapels within hospices has declined; 15% of hospices had neither chapel nor multifaith room. *Communication* - multifaith guidelines were in place in 86% of hospitals and 60% of hospices. Around 70% of hospitals and 90% of hospices undertook spiritual assessments. Within both subgroups the nurse was involved in over 90% of such assessments. *Chaplaincy* - personnel within funded chaplaincies were 98% Christian within hospitals and 99.5% Christian within hospices. The role of chaplain has come to include spiritual care plus other responsibilities such as education and the management of bereavement care. Around 70% of hospices funded Chaplaincy hours; within this hospice subgroup, statistically significant associations were found between funded chaplaincy and other chaplaincy variables such as spiritual care documentation, special accommodation, computer support, a delegated budget and funding for training and locum cover.

Findings regarding patient requirements were as follows: *Religious care* - patients required religious care more frequently in hospital rather than hospice. Of 9 items within Christian care, patients most frequently required communion, prayer and worship. *Non-religious care* - 90% of patients frequently wanted someone to listen to them. Of 11 categories of spiritual issues, patients most frequently wanted to address their concern for relatives, death, and suffering; forgiveness and transcendence appeared least frequently. These findings suggest i) a trend away from establishing chapels as the spiritual focal point within hospitals and hospices ii) the development of broader roles for chaplains iii) a different level of service provision between hospices with funded chaplaincies and hospices with voluntary chaplaincies iv) a wide range of non-religious spiritual care requirements on the part of patients v) a more frequent requirement for religious care in hospitals rather than hospices.

## **Methods**

*Objectives.* The objectives of this survey were to identify a) key features of spiritual care provision and b) the spiritual requirements of patients in hospices and acute hospitals throughout England and Wales.

*Data collection.* Data were collected by means of a postal questionnaire sent to trusts offering acute services and specialist inpatient palliative care units within England and Wales. The questionnaires sought information about the infrastructure to support spiritual care and patient requirements for both religious and non-religious, humanistic care. The infrastructure to support spiritual care focussed upon physical resources (chapels, multifaith rooms, chaplaincy accommodation) human resources (chaplains, visiting ministers, volunteers) financial resources and the presence of policies or guidelines. Religious (Christian) care focussed upon 11 items that included prayer, holy

communion, baptism and last rites. Humanistic care included some one 'being there' for patients and meeting the patient's need to address issues such as 'why me?', suffering, forgiveness, concern for relatives and the meaning of life.

*Questionnaire recipients.* The questionnaires were sent to chaplains, since chaplains frequently have a responsibility to delivery spiritual care as well as religious/ denominational care. Discussions with Malcolm Masterman (Director of Training) at the College of Health Care Chaplains revealed the presence of some 360 whole time chaplains in the United Kingdom. These were generally located in hospitals with more than 400 beds, or where several hospitals were being amalgamated under the umbrella of one NHS trust. In addition, it emerged that over 3000 part time sessions (of 3.5 hours per session) were currently being deployed on a funded basis.

Reference to the Directory of Whole Time Chaplains (1998) revealed the names and professional addresses of whole time hospital chaplains within the United Kingdom. Whole time chaplains are usually employed by the larger NHS trusts and scrutiny of the database identified those chaplains working in trusts that offer acute services. Telephone calls confirmed that trusts listed in the directory with 'A' (offering acute services) or 'DGH' (District General Hospital) included facilities for surgical and medical patients, some of whom would be patients with cancer.

An indicative list of hospital chaplains was compiled and cross-checked with the new Directory of Whole Time Chaplains when it was published in the spring of 1999. Several differences emerged: new chaplains had been appointed at 13 trusts; chaplains were included at 12 trusts which did not appear in the 1998 directory and 8 trusts listed with a chaplain in 1998 did not appear in 1999. Action was taken, therefore, to include the names of the



13 newly appointed chaplains, together with the 12 chaplains listed at trusts appearing in the 1999 directory for the first time. In addition, it was decided to send a questionnaire addressed to 'The Senior Chaplain' at the 8 trusts which were listed in 1998 but did not appear in 1999; this in case a chaplain was 'acting up' on a temporary basis, or a new chaplain had been appointed since the current directory was published.

The substantive group of hospital chaplains was made up of whole time chaplains who worked in NHS trusts offering acute services. Chaplains employed by trusts concerned exclusively with mental health, rehabilitation or the elderly were excluded. Where more than one chaplain was employed at a trust offering acute services, only the Senior Chaplain/ Chaplaincy Manager was included. Where the directory listed more than one chaplain within a trust – but did not specify who fulfilled the role of Senior Chaplain/ Chaplaincy Manager – a telephone call clarified the situation. These calls resulted in the exclusion of 4 Roman Catholic Chaplains, 1 Free Church Chaplain and 1 Muslim Chaplain on the grounds that none of them occupied the role of Senior Chaplain/ Chaplaincy Manager. Chaplain's Assistants were also excluded.

The group of palliative care unit chaplains could not be identified by name. Difficulties arose because few palliative care units employ whole-time chaplains. In many cases, chaplaincy services are provided by parochial clergy who give time voluntarily to their local hospice – sometimes in rotation. In the case of the palliative care units, therefore, the relevant person could only be identified as 'The Senior Chaplain.'

*Exclusions.* The following NHS hospital trusts were excluded: Birmingham Women's Hospital, Birmingham Children's Hospital, Great Ormond Street Children's Hospital and the Bristol Royal Hospital for Sick Children. The

following hospice units were excluded: 17 specialist children's hospices in England, 1 specialist children's hospice in Wales; 2 specialist HIV/AIDS hospices in England; 10 palliative care units situated within hospitals - either as a hospital ward, or as a few beds within a ward; 5 units listed as 'mini units' or as units containing a small number of beds; 6 units where the chaplain was already included in the hospital sample.

*The Pilot Study.* Oppenheim (1998:49) states that: 'It is essential to pilot every question, every question sequence, every inventory and every scale in your study'. As this was a new questionnaire, it was decided to undertake a pilot of the main survey. Using purposive procedures, a sample was drawn which located a hospital and a palliative care unit within the same town in each of the 8 former health regions within England. In addition, 1 hospital and 1 palliative care unit was added from within Wales. These procedures produced a sample of 9 hospitals and 9 adjacent palliative care units. Of the palliative care units, 1 unit was NHS managed, 1 was a Marie Curie Centre. The original intention was to include 1 hospital and 1 palliative care unit from within London. It emerged, however, that another study had begun in London that was investigating the nature of hospital chaplaincy in the capital city. In an attempt to keep any overlap between the two studies to a minimum, it was decided to exclude London from this pilot sample. On Wednesday 21<sup>st</sup> April 1999, questionnaires were posted to the 9 chaplains in each of the two pilot subgroups. Two weeks later, 3 hospital and 4 hospice questionnaires had been returned. Follow-up letters were sent to those who had not responded and by Friday 21<sup>st</sup> May, 4 hospital questionnaires (44%) and 8 hospice questionnaires (88%) had been received.

The recipients had been informed that the questionnaires were part of a pilot study and were invited, therefore, to comment on both the layout and content of the questionnaires. Although none of the hospital respondents

used the space provided, some comments, were written against particular questions. The hospice respondents wrote comments in both the allocated space and against certain questions. All comments relate to the questionnaires described in Figure 4 (see page 55 and following):

The hospital chaplains:

- a) The hospital makes no denominational distinction between volunteers, so I found it hard to answer Question 3iv (see page
- b) 'No' was written against Question 5iii, indicating that financial resources were never available for this item
- c) Question marks written against Question 7iv, f, g, i, j, k, l, suggesting an unfamiliarity with some requirements of patients from ethnic minorities

The hospice chaplains:

- a) Question 5i, ii, iii, had another column entered in which 'No' had been written, suggesting the range of the scale needed extending
- b) 'There was no mention of 'laying on of hands' or 'healing ministry', or involvement of other staff who meet the spiritual needs of patients. The form is very easy to understand and to use'
- c) 'Our room may not be called a multi-faith room but may be used by all. It is a Quiet Room'

‘Some hospices are now on two sites and the sites may differ. Perhaps there is a way of covering this?’

‘Is the postage going to be covered on the future survey?’

In the light of these comments it was decided to make the following changes prior to the main survey:

- a) to change hospice Question 3 to read ‘hours’ instead of ‘sessions’, thereby acknowledging that ‘sessions’ was a term that related primarily to hospitals
- b) to include a column ‘never’ in Question 5, thereby responding to those who indicated that financial support was never given for these items
- c) to change 8ii d to read ‘the value of *the patients* own life’ instead of ‘the value of *one’s* own life’, thereby clarifying the question
- d) to include ‘FREEPOST’ when asking for the questionnaires to be returned, thereby ensuring that respondents knew the replies did not need postage stamps

*Main survey.* The questionnaires had now been through a rigorous process of construction, review and revision and had been tested in the field by means of a pilot. All comments had been taken into account and final changes had been made. The process had been a lengthy one, yet reflected the benefits outlined by Oppenheim (1992):

Pilot work can also be immensely rewarding. There is an intellectual challenge in conceptualising and re-conceptualising the key aims of the study and in making preparations for the fieldwork and analysis so that not too much will go wrong and nothing will have been left out. There is satisfaction in seeing the emergence of a short, reliable scale from the mass of pilot data. And there is gratification in finally producing a really effective set of multiple choices which respondents can use and which neatly embody the purpose of the question (Oppenheim, 1992:64).

I now considered that the questionnaires had gained an additional level of validity and could be regarded as reliable.

The questionnaires were submitted to the University of Sheffield Print Unit on Wednesday, 26<sup>th</sup> May 1999. The main survey began on Friday 11<sup>th</sup> June, when questionnaires with prepaid return envelopes were sent to named chaplains in 184 NHS trusts and to 'The Senior Chaplain' 141 hospices. An accompanying letter (Appendix 10) explained the purpose of the survey and asked for the co-operation of the recipient; the letter also stated that a reply within two weeks would be helpful. Each questionnaire had a unique identifier in the top corner. Three weeks later, on Friday 11<sup>th</sup> June, follow-up letters (Appendix 11) - accompanied by a second questionnaire - were sent to the non-responders. Up to that point 100 (54%) hospital questionnaires had been returned and 65 (46%) hospice questionnaires.

At this point the pilot responses of 4 hospital questionnaires and 8 hospice questionnaires were included in the main survey responses. This uplifted the subgroup totals to 194 NHS trusts and 151 hospices. After the follow-up letter, the total response rate from the hospice sample was 77% (116 respondents) and from the hospital sample 75% (145 respondents); it was 76% overall.

*Data analysis.* Once collected, data were coded and imported into SPSS. Special categories were included for free text. Longer comments and clarifications were transferred to word documents. Numerical data were summarised using charts, frequency tables and crosstabulations; they were analysed using the chi-squared test. Text was prepared and imported into the NUD\*IST software programme where it was coded, classified, and subsequently analysed.

## Findings

### Special rooms

*Chapels and multifaith rooms.* Within the hospitals 73 chapels and 86 multifaith rooms opened during the 1990s. This represents 29% of all chapels and 91% of all multifaith rooms. Of the 94 hospitals opening a chapel or multifaith room since 1990, only 4 (4%) were new hospitals. Within the hospices, 38 chapels opened during the 1980s, 35 (92%) of them during the same decade as the hospice. During the 1990s 41 chapels opened, 28 (68%) of them during the same decade as the hospice. As in the hospital group, multifaith rooms were almost unknown before 1980. They are now a facility to be found increasingly within hospices. Of 90 hospices with a chapel 17 also had a multifaith room. Multifaith rooms were also found in 9 hospices without chapels. Seventeen hospices (15%) had neither a chapel nor a multifaith room. Of these 17, 2 were opened before 1967 (when St Christopher's Hospice was opened), 7 during the 1980s and 8 during the 1990s (Table 1).

**Table 1** Hospital and hospice chapels and multifaith rooms opened by decade

	Pre 1940s	1940s	1950s	1960s	1970s	1980s	1990s
Hospital chapels	48	15	11	28	36	37	73
Hospice chapels	0	0	4	2	8	38	41
Hospital multifaith rooms	0	0	0	0	1	8	86
Hospice multifaith rooms	0	0	0	0	0	13	16

## Chaplaincy

*Funded hours.* Within the hospitals, all chaplaincies were funded, with a minimum of 30 hours per week and a maximum of 368 hours per week (Table 2). Ninety eight percent of these hours were allocated to Christians;

**Table 2** Profile of hospice and hospital chaplaincies

	Hospice <i>n</i> (%)	Hospital <i>n</i> (%)
Funding		
-units funding chaplaincy hours	83 (72)	145 (100)
-chaplaincy budget	52 (45)	116 (80)
Allocation of funded chaplaincy hours		
-to Christian ministers	1,397 (99.5)	13,213 (98)
-to Anglican ministers	976 (70)	8,140 (60)
-to Roman Catholic ministers	156 (11)	2,191 (16)
-to Free Church ministers	156 (11)	2,198 (16)
-to Ecumenical (Christian) ministers	111 (8)	682 (5)
-to ministers of faiths other than Christian	7 (0.5)	294 (2)
Total hours	1,404 (100)	13,507 (100)
Chaplaincy job description	77 (73)	126 (88)
Spiritual care responsibilities		
-for patients	110 (96)	145 (100)
-for relatives	102 (89)	144 (99)
-for staff	103 (92)	144 (99)
-for students	59 (71)	114 (85)
Other responsibilities		
-liaison with religious leaders	97 (85)	141 (98)
-spiritual care education	93 (82)	125 (86)
-bereavement care management	42 (37)	75 (52)
Chaplaincy support		
-pagers / bleeps	43 (38)	143 (100)
exclusive chaplaincy accommodation	45 (39)	138 (97)
-a room for private discussion	109 (94)	122 (86)
-a patient database	45 (41)	74 (51)
Voluntary ministers (other than nominated chaplains)		
-Anglican	133 (42)	220 (36)
-Roman Catholic	84 (26)	201 (32)
-Free Church	83 (26)	84 (14)
-Faiths other than Christian	18 (6)	114 (18)
Total voluntary ministers	318 (100)	619 (100)
Lay volunteers		
-Anglican	156 (52)	2,028 (50)
-Roman Catholic	72 (24)	1,012 (25)
-Free Church	70 (23)	447 (11)
-Ecumenical	0 (0)	478 (12)
-Faiths other than Christian	2 (1)	115 (3)
Total volunteers	300 (100)	4,080 (100)

60% to Anglicans. Within the hospices, 72% of chaplaincies were funded with a minimum of 3 hours per week and a maximum of 88 hours per week; 99.5% of these hours were allocated to Christians; 70% to Anglicans

*The role of the chaplain: responsibilities.* Around 90% of hospital chaplains and 70% of hospice chaplains held job descriptions. Within both groups, almost all the job descriptions included spiritual care responsibilities for patients, relatives *and* staff. In addition, more than 80% of chaplains within both groups were given responsibility for spiritual care education; 98% of hospital chaplains and 85% of hospice chaplains were responsible for liaison with religious leaders, and around one half of hospital chaplains and one third of hospice chaplains were responsible for the management of bereavement care.

*Support for the chaplaincy role.* To support the responsibilities of chaplaincy, all hospital departments were provided with pagers or beeps. Almost all departments had exclusive chaplaincy accommodation and around one half had computer access to a patient database. Within the hospice group, around 40% of chaplains were provided with pagers or beeps. Some 40% were equipped with exclusive accommodation, though almost all had access to a room for confidential discussions; 41% of hospice chaplains had access to a computerized database.

*Chaplaincy volunteers.* Three hundred and eighteen ministers voluntarily supported hospice chaplaincy, of whom 300 (94%) were Christian. These voluntary ministers were in addition to the nominated hospice chaplains, who may also give their services voluntarily. Within the hospital group, 619 ministers gave voluntary support, of whom 505 (82%) were Christian. Lay volunteers also supported chaplaincy. In total, the hospice volunteers



numbered 300, of whom 298 (99%) were Christian. Within the hospitals, 4,080 volunteers provided support, of whom 3,965 (97%) were Christian.

*Chaplaincy budget.* Eighty per cent of hospital chaplains and 45% of hospice chaplains stated that funding for spiritual care was found within the chaplaincy budget (Table 3). Funding to attend training courses was usually available for 76% of hospital chaplains and 70% of hospice chaplains. Thirty per cent of hospital chaplains and 60% of hospice chaplains indicated that funding was never available for locum cover.

**Table 3** Chaplaincy funding for education and locum cover

	Hospice				Hospital			
	Usually <i>n</i> (%)	Sometimes <i>n</i> (%)	Rarely <i>n</i> (%)	Never <i>n</i> (%)	Usually <i>n</i> (%)	Sometimes <i>n</i> (%)	Rarely <i>n</i> (%)	Never <i>n</i> (%)
Training courses	80 (70)	19 (17)	8 (7)	7 (6)	108 (76)	24 (17)	11 (8)	0 (0)
Educational hardware	46 (46)	23 (23)	8 (8)	24 (24)	44 (33)	40 (30)	23 (17)	28 (21)
Books/ materials	57 (53)	30 (28)	10 (9)	11 (10)	76 (54)	41 (29)	14 (10)	10 (7)
Locum cover	17 (18)	6 (6)	15 (16)	56 (60)	54 (39)	19 (14)	23 (17)	42 (30)

Eighty three hospices (72%) funded chaplaincy hours; 33 (28%) did not. Analyzing the data by funded and voluntary chaplaincy subgroups revealed significant associations between funded chaplaincy and other chaplaincy variables (Table 4).

**Table 4** Chi-squared values for crosstabulations between funded chaplaincy and other chaplaincy variables

		Exclusive accommodation		Chaplaincy budget		Pagers/ bleeps		Patient database		Liaison with religious leaders		Spiritual care education		Management Of bereavement care	
		Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Funded Chaplaincy	Yes	43	40	49	34	41	39	40	38	79	3	73	8	38	45
	No	2	30	3	30	2	31	5	27	18	14	20	12	4	28
		$X^2 = 20.12$ P<0.001		$X^2 = 23.81$ P<0.001		$X^2 = 20.23$ P<0.001		$X^2 = 11.93$ P<0.001		$X^2 = 29.15$ P<0.001		$X^2 = 12.01$ P<0.001		$X^2 = 11.03$ P<0.001	

However, even within funded chaplaincy, facilities vary. In the free text section of the questionnaire, a hospice chaplain wrote:

Although I work 20 hours per week, I have no office, no desk, no telephone, no bleeper, no filing cabinet, no locker/ cupboard, nowhere to hang my coat! I do have a pigeon hole and some-one will usually type one of my very rare letters. As a result of the above, I do virtually no paperwork/ record keeping other than writing in patient files. (I am completing this questionnaire at someone else's desk whilst they are seeing a family).

## **Communication**

This section of the questionnaire asked about the inclusion of spiritual care information in hospice and hospital documentation. It also sought data about the collection of information relating to the spiritual, religious and cultural requirements of patients (Table 5).

*Documentation.* Sixty two hospices (57%) and 56 hospitals (40%) published a policy statement on spiritual care. Chaplaincy department statements were to be found in around half of the hospices and three quarters of the hospitals. Around 70% of both hospitals and hospices gave spiritual care information around the time of admission. Multifaith guidelines were in place in 86% of hospitals and 60% of hospices.

*Timing of spiritual assessment.* Ninety seven trusts (71%) and 102 (88%) hospices indicated that an assessment was made of the patient's spiritual, religious and cultural requirements. Of those who responded within the hospital group, 59% indicated that this was undertaken around the time of admission. Within the hospice group, assessments undertaken during the patient's stay featured more prominently.

*Assessment inclusions.* Among the 118 trusts and 100 hospices that responded to this question, 99% of trusts and 98% of hospices included the religion of the patient in the assessment. The questionnaire also enquired about a) religious preferences: to worship, to fast, to consult a personal

**Table 5** Communication about spiritual care provision and patients' spiritual, cultural and religious requirements

	Hospice <i>n</i> (%)	Hospital <i>n</i> (%)
<b>Documentation</b>		
Unit statement of spiritual care policy and practices	62 (57)	56 (40)
Spiritual care information on admission	74 (68)	108 (74)
Chaplaincy statement about spiritual care	48 (45)	112 (78)
Existence of multifaith guidelines	64 (60)	124 (86)
<b>Spiritual assessment</b>		
Units undertaking an assessment	102 (88)	97 (71)
<b>Spiritual assessment: content</b>		
-religious affiliation	98 (98)	117 (99)
-wish to worship	74 (74)	53 (45)
-wish for own faith leader	75 (75)	55 (47)
-wish for sacramental support	70 (70)	47 (40)
-objection to shaving body hair	19 (19)	17 (14)
-objection to being bathed by member of other sex	26 (26)	28 (24)
-wish to fast	17 (17)	25 (21)
-dietary requirements	55 (55)	61 (52)
-washing requirements	30 (30)	23 (20)
-wish for special clothing	23 (23)	16 (14)
-wish for religious objects	32 (32)	25 (21)
-objection to anything which contradicts beliefs	37 (37)	27 (23)
<b>Spiritual assessment: timing</b>		
-on admission	44 (42)	64 (59)
-during stay	22 (21)	13 (12)
-on admission and during stay	37 (38)	31 (28)
<b>Spiritual assessment: personnel</b>		
-clerk	0 (0)	3 (3)
-chaplain	7 (7)	4 (3)
-nurse	49 (48)	53 (46)
-clerk + chaplain	0 (0)	2 (2)
-chaplain + nurse	26 (25)	13 (11)
-clerk + chaplain + nurse	2 (2)	4 (3)
-clerk + nurse	3 (3)	23 (20)
-other	0 (0)	0 (0)
-clerk + other	0 (0)	0 (0)
-chaplain + other	0 (0)	3 (3)
-nurse + other	8 (8)	3 (3)
-clerk + chaplain + other	0 (0)	0 (0)
-clerk + nurse + other	0 (0)	3 (3)
-clerk + chaplain + nurse + other	0 (0)	1 (1)
-chaplain + nurse + other	8 (8)	3 (3)

minister, to receive sacramental support; b) religious beliefs and health care issues: the shaving of body hair, objections to treatments which might conflict with beliefs, being bathed or seen naked by a member of the opposite sex; c) everyday customs: washing requirements, diet, special clothing and the significance of particular objects. Differences were evident between hospital assessments and hospice assessments. Around three quarters of hospices included items about worship, sacraments, and preferences for a personal minister; less than half of the hospitals included these items.

*Personnel.* Within both groups, the nurse was involved with spiritual assessments in around 90% of cases. The chaplain was involved with 26% of hospital assessments and 42% of hospice assessments. The clerk featured in 32% of hospital assessments and 5% of hospice assessments.

'Other personnel' were involved in 26% of hospice assessments and 13% of hospital assessments. Within the hospices, a total of 12 responses (75%) meant that doctors comprised the largest subgroup of others; this compared with 1 response (8%) within the hospital subgroup. Chaplaincy personnel - with a total of 5 responses (38%) - made up the largest subgroup within hospitals.

### **Spiritual care delivery**

This section of the questionnaire was concerned with the non-religious and religious requirements of patients (Table 6).

*Patient requirements of others.* Eighty nine per cent of respondents within both hospital and hospice indicated that patients 'frequently' required

somebody to listen to them. Someone to 'be there' - 86% in the hospice group, 74% in the hospital group - followed closely behind.

*Addressing spiritual issues.* Within this section, respondents were asked how frequently patients wished to address specific items in a list of 11 spiritual issues. Responses were recorded on a scale of 'Frequently', 'Occasionally' and 'Rarely'. When the responses in the 'Frequently' and 'Occasionally' categories were combined, the highest responses - in rank order - were the same in both groups: concern for relatives, death and dying, and suffering. Analysis of responses in the single category of 'Frequently' produced similar findings. Forgiveness and transcendence appeared 10<sup>th</sup> and 11<sup>th</sup> in each analysis.

**Table 6** Chaplains' perceptions of the frequency of patients' religious and non-religious spiritual care requirements

	Hospice			Hospital		
	Frequently <i>n</i> (%)	Occasionally <i>n</i> (%)	Rarely <i>n</i> (%)	Frequently <i>n</i> (%)	Occasionally <i>n</i> (%)	Rarely <i>n</i> (%)
<b>Non-religious requirements</b>						
Some-one to listen	103 (89)	13 (11)	0 (0)	128 (89)	15 (10)	1 (1)
Some-one to 'be there'	100 (86)	16 (14)	0 (0)	106 (74)	37 (26)	1 (1)
<b>Opportunities to discuss</b>						
-why me?	43 (37)	67 (58)	5 (4)	81 (56)	57 (40)	6 (4)
-pain	81 (71)	28 (25)	5 (4)	81 (57)	58 (41)	4 (3)
-meaning of life	36 (32)	70 (61)	8 (7)	51 (36)	81 (57)	11 (8)
-value of one's own life	51 (45)	52 (46)	10 (9)	53 (37)	74 (52)	16 (11)
-suffering	51 (44)	59 (51)	5 (4)	84 (58)	57 (40)	3 (2)
-forgiveness	13 (11)	74 (64)	28 (24)	16 (11)	87 (61)	40 (28)
-transcendence	5 (5)	42 (38)	64 (58)	6 (4)	45 (32)	91 (64)
-the nature of God	15 (13)	67 (58)	34 (29)	26 (18)	71 (50)	45 (32)
-concern for relatives	102 (88)	14 (12)	0 (0)	116 (81)	26 (18)	2 (1)
-death and dying	79 (69)	34 (30)	2 (2)	83 (58)	58 (41)	2 (1)
-afterlife	22 (19)	78 (68)	15 (13)	24 (17)	89 (64)	27 (19)
<b>Religious requirements</b>						
-prayer	49 (43)	64 (56)	2 (2)	88 (61)	52 (36)	4 (3)
-texts	3 (3)	55 (50)	53 (48)	16 (11)	86 (60)	42 (29)
-worship	25 (22)	75 (66)	13 (12)	51 (36)	79 (55)	13 (9)
-special rituals	9 (8)	61 (57)	37 (35)	39 (28)	84 (60)	17 (12)
-baptism	0 (0)	17 (16)	92 (84)	11 (8)	71 (50)	61 (43)
-confession/ absolution	7 (6)	56 (49)	51 (45)	6 (4)	71 (50)	66 (46)
-communion	51 (44)	55 (48)	9 (8)	94 (65)	46 (32)	4 (3)
-anointing	10 (9)	58 (52)	44 (39)	19 (13)	86 (60)	38 (27)
-last rites	15 (14)	61 (56)	33 (30)	42 (30)	80 (57)	19 (13)

*Religious care.* Of the activities of the Christian faith, chaplains perceive that patients within both hospice and hospital most frequently wish to receive communion, to pray and to worship. Last rites are most frequently required after that. Baptism is listed as a 'frequent' requirement in only 8% of hospital responses, and not at all within hospice.

A comparison of responses in the 'frequent' categories reveals that with the exception of 1 item - confession/ absolution - hospital patients require religious care more frequently than hospice patients.

## **Discussion**

*Chapels and multifaith rooms.* Traditionally, chapels have been regarded as a spiritual focal point within both hospice and hospital. Guidance issued in 1948 (NHS, 1948) suggests that the government of the day regarded the chapel as a tangible feature of spiritual care provision - a view re-iterated in 1986 when a circular from The Department of Health and Social Security stated that there should be a chapel in every hospital (NHS, 1986).

Of particular interest, however, are data indicating that the number of newly opened hospital chapels increased to 73 during the 1990s, and that 86 multifaith rooms - 91% of the total - were also established during that time. Significantly, only 4 of the hospitals opened as new units. This suggests that funding was made available to provide the chapels and multifaith rooms as additional facilities in existing hospitals.

Multifaith rooms are a relatively new phenomenon. Recognising the multicultural nature of contemporary society, a report on the future of multiethnic Britain (2000) argues for the recognition of a wider range of religious and cultural identities. The increase in both multifaith rooms and

hospital chapels during the 1990s may well be a response to this changing climate, encouraged by expectations regarding respect for religious and cultural traditions as outlined in the Patient's Charter (1991). However, with increasing secularization and lower church attendance, perhaps assumptions can no longer be made about a Christian chapel representing the spiritual focal point of the hospital community.

In *Hospice Care on the International Scene*, (1997) Cicely Saunders reiterates her view that St Christopher's was established and grew as a Christian foundation. Significantly, the chapel provided a visual statement about the underpinning philosophy of modern hospice. It also reflected the Christian orientation of the movement's early leaders. Indeed, since the founding of St Christopher's in 1967, no hospice in this study opened during the remainder of the 1960s nor throughout the 1970s without a chapel.

The data indicate that 79 hospice chapels opened during the 1980s and 1990s. Using The Hospice Time Line - constructed as part of The Hospice History Project undertaken by The University of Sheffield - the opening of the chapels were cross-referenced with the opening of the units ([www.hospice-history.org.uk](http://www.hospice-history.org.uk)). The results revealed that 92% of the 1980s chapels and 68% of the 1990s chapels opened in the same decade as the unit. This suggests that - unlike the hospital chapels - hospice chapels established during the 1980s and 1990s do not represent an additional facility.

This is not the case with regard to the multifaith rooms within hospice. The opening of 17 multifaith rooms in hospices already having chapels, suggests a deliberate decision on the part of the hospice administrators to provide an extra facility. Furthermore, the fact that 9 hospices opened a multifaith

room *instead* of a chapel may indicate that the multifaith room is coming to be regarded as a more spiritually inclusive facility than the Christian chapel. Ann Bradshaw (1994) believes this developing trend is a direct result of the contemporary dislocation of religion from spirituality:

The distancing of religion from spirituality means that hospice workers are taught to believe that spirituality is about exploring personal meaning...The concept of God is generally excluded...The objective place of worship...in building hope and trust loses relevance (Bradshaw, 1994:416).

These developments, when viewed against the backdrop of the 15% of hospices without either a chapel or a multifaith room, seem to indicate a significant shift in the spiritual care infrastructure within hospice.

*Chaplaincy.* The data presented here reflect the changing responsibilities of chaplains. They also point to an increasing commonality between hospital chaplaincies and funded hospice chaplaincies. As in the hospital context, those hospices that provide funded chaplaincies are also likely to provide chaplaincy accommodation, computer facilities and a chaplaincy budget; the responsibilities of chaplains are also more likely to include liaison with religious leaders, education and bereavement care management. This suggests that a different level of provision exists between the two-thirds of hospices that fund chaplaincy services and the one-third that does not.

The debate continues around the role of the chaplain (Carey, 1997). Norman Autton (1968) made much of the centrality of priesthood and the current emphasis on 'doing' raises questions about the chaplain's main purpose. In essence, the priest is not called to *do* something but to *be* something (Allan et al, (1993) - a person who grows into the likeness of Christ in a way that builds up the Church. This concept of 'being' however, is at odds with the



secular, task-oriented nature of health care institutions; it is also at odds with the culture of management, throughput and outcomes.

Heiji Faber's (1971) radical vision of the chaplain as clown articulates the notion of an amateur amongst professionals; skilled - yet different; belonging - yet a stranger; included - yet apart. Alistair Campbell (1986) examines further the relationship between the carer and the cared-for, suggesting that it does not rest on the acquisition of knowledge, but rather on the carer's personal experience of pain and loss - an idea developed by Henri Nouwen in *The Wounded Healer* (1994). It is an idea that resonates with the views of a hospice chaplain in this survey:

The whole time chaplain has a role in giving spiritual care to the institution - hospital or hospice; we can't heal the patients brokenness or society's brokenness without addressing our own. We can't provide a caring service to the patient, unless we are a caring institution.

Christopher Moody (1999) suggests the generic nature of chaplaincy is that of a 'wilderness ministry' to those cut adrift from the normal ties that secure a sense of identity and self-worth. Encounters within such a ministry make demands and include risks; they may also be a source of confusion and uncertainty, since chaplains:

...work with short term contracts, meeting the needs of a transitory group of people. At the most a relationship will last a few years and many relationships can last an hour or less. To give each of these relationships their proper value requires a particular kind of spiritual awareness: the willingness to accept the stripping away of old certainties, for example. One is never sure when one has crossed the boundary between what is religious and what is secular (Moody, 1999:23).

In the light of role ambiguity and the impetus towards a broader chaplaincy service, there are likely to be continuing opportunities for such 'old

certainties' to be stripped away. As a result, speculation may arise regarding the transition of chaplains into other areas of responsibility - such as the management of bereavement care - especially if those responsibilities are not accompanied by education and training. Significantly, previous research (Beckford and Gilliat, 1996) found evidence of a re-shaping of the chaplain's sense of identity through an emphasis on managerial functions and 'professional' status. The question may be asked, therefore, whether - in the changing and uncertain context of British health care - management responsibilities offer a welcoming cluster of quantifiable outcomes against the backdrop of a more amorphous chaplaincy role?

*Communication: documentation and spiritual assessment.* Guidance about ascertaining the religious persuasions of patients has been in place in the United Kingdom since 1963 (NHS, 1963). The growth of a multicultural society, however, has promoted an increasing awareness that for some people, spirituality and religion are woven into the cultural fabric of daily life. This has major implications for health care, especially involving the care of the dying. Since the publication of the Patient's Charter (1991) increased attention has been given to the relationship between health care and religious beliefs (Andrews and McIntosh, 1993). Consequently, the inclusion of spiritual care information in hospital and hospice documentation and the existence of multifaith guidelines to support people across a multiplicity of faiths, are telling innovations.

As attention is being paid to patient entitlement, the practice of merely recording the patient's religion has come to be regarded as inadequate. Under the heading 'Assessment of Spiritual Needs' the authors of *Spiritual Care in the NHS* (NAHAT, 1996) suggest that a patient's spiritual needs should be assessed at an interview - conducted by a nurse or a chaplain - shortly after admission. The interview would focus on the interface between religion and

health care; information would be collected on the patient's religious and cultural requirements. If appropriate, there would be an exploration of the patient's wishes surrounding a terminal condition, or in the event of death.

Spiritual assessment has become an important issue. With the rising interest in patient spirituality, attempts are increasingly being made to produce meaningful assessments (Ellerhorst-Ryan, 1985; Kirschling and Pittman, 1989; Hay, 1989; Catterall et al, 1998). Ruth Stoll (1979) set the scene when she published her spiritual history guide, based on patient interviews. In England, Michael King and his colleagues (1995) have developed an instrument designed to measure the beliefs of people hospitalised with acute illness, and developments are currently taking place within the quality of life arena (Wyatt et al, 1996).

Assessments within the spiritual domain are particularly complex, however - illustrated, perhaps, by the fact that 29% of hospital respondents do not undertake them. Even within the hospitals that make assessments, practice may vary considerably. Responding to the survey, a hospital chaplain wrote:

A full assessment...is carried out in our Macmillan Continuing Care Unit and on the oncology ward. All other areas only ask for patients' religion and here 40% are recorded as "unknown", suggesting many patients are not asked even this basic question.

Questions inevitably arise about what is being assessed. Recording that a patient wishes to worship or receive a special diet might be seen as recording spiritual *behaviours*, rather than assessing spiritual *needs*. Identifying spiritual needs is problematic. Allan Kellehear (2000) puts forward a conceptual model based on what he terms the situational, religious and moral/ biographical dimensions of spiritual need, and outlines

its implications for theory and practice. Mark Cobb (1998) suggests that Bradshaw's (1972) taxonomy (developed within social policy debates) of social need: normative need, felt need, expressed need and comparative need, helps illuminate the issues for both patients and health professionals. Difficult to assess, however, are the pertinent but elusive 'felt needs': the need for meaning, purpose and fulfilment in life.

It is hardly surprising that within both subgroups in the survey, the nurse is involved in around 90% of spiritual assessments. Even after Nightingale's secularisation of nursing, perceptions of the spiritual dimension of care remained within the nursing tradition (Bradsaw, 1994) and contemporary theorists continue to acknowledge the spiritual domain. Sister Callista Roy (see Phillips et al, 1998) and Betty Neuman (see Cross, 1995) both identify the place of the spiritual self, and Jean Watson (see Patten et al, 1998) articulates the need for a supportive spiritual environment. In the United Kingdom, the UKCC (1994) confirms that spiritual care is a responsibility of nursing, and that Project 2000 should provide opportunities for the student nurse to identify the spiritual needs of patients and devise a plan of care (UKCC, 1986).

*Patients requirements of others: 'being there' and listening.* The survey data presented here provide strong evidence that patients require someone to 'be there' for them and someone to listen to them. Challenged by the impact of illness, solitude is an added burden, whereas human contact may make a difference to the patient's state of being (Lynch 1999). 'Being there' assumes a willingness to accompany the patient in the experience of illness as spiritual journey (Hawkins, 1999). It is also to share in the patient's hope; an act that can only be well done together (Roy, 1998). In particular, 'being there' assumes a sharing of the patient's space (Speck, 1995:36). Within

hospice, Katherine Froggatt (1997) suggests this is a sacred space, inhabited uniquely by the patient during a time of transition.

Positive responses from around 90% of both hospice and hospital subjects indicate a significant need for someone to listen. Free text responses recognised these listening encounters as vehicles for actualisation and recovery. A hospital chaplain wrote on a questionnaire:

Listening (actively) is probably the most important component of spiritual care. 'Actively' means with attention, with time, reflecting and at times interpreting what the patient is seeking to express. In this meeting, a patient can become a person, recovering their status, identity and integrating their lives.

In recovering status and identity the patient offers a resistance to the disempowering, diagnostic identity of medical systems, as legitimised by Talcott Parsons (1951). Through the telling of the story, the ill person re-affirms that the story is worth hearing and that the patient is still there as an audience for him/ herself. Becoming ill, then, is a call for stories; stories that repair the damage that illness has inflicted on the person's sense of perspective and balance. Arthur Frank (1997) shows how, through stories, a new relationship develops with the listener:

As wounded, people may be cared for, but as story-tellers, they care for others. The ill, and all those who suffer can also be healers. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathetic bonds between themselves and their listeners...Because stories can heal, the wounded healer and the wounded story-teller are not separate, but are different aspects of the same figure (Frank, 1997:xii).

The activity of listening, then, is a collaborative act. In that the storyteller regains the voice that has been lost, it is also an act of compassionate creativity.

*Addressing spiritual issues.* Transcendence is a recurring theme within health care literature, particularly from North America. Pamela Reed (1998) describes transcendence as a process that relates to the inner reaches of the soul and the outer reaches of the spirit. This reaching out is frequently thought to include a desire for forgiveness. Ian Ainsworth-Smith and Peter Speck (1999) suggest that patients might be encouraged to examine their lives, to consider their relationship with God, with other people and with themselves - perhaps also to seek forgiveness. The findings of this study, however, suggest that in the opinion of chaplains, patients do not frequently seek to address spiritual issues around either transcendence or forgiveness; instead they frequently seek to address issues surrounding concern for relatives and suffering.

*Religious Care.* Religious care is given by members of a faith community and centres around practices and procedures having meaning for that community. Serious illness confronts the belief systems of both the individual and the community, focussing attention upon ultimate values and relationships. William Clebsch and Charles Jaekle (1967) describe these 'helping acts' in terms of their capacity to support, sustain and reconcile during times of crisis, whereas Autton (1968) sees them as primarily centred around the sacraments:

When the sacramental ministry lies at the centre of hospital work, new life is released to work effectively within the bodies and souls of its patients (Autton:1968:33).

Peter Speck (1995), however, notes that The Archbishop of Canterbury's Commission (1958) on the ministry of healing took the view that those called to minister to the sick should set free all God's resources for health. These include prayer and bible reading, confession and absolution, the laying on of hands and anointing.

A striking feature of this study is the data suggesting that hospital patients more frequently require religious care than hospice patients. This is of particular interest in view of the Christian influence on the foundation of modern hospice, and the continuing presence of Christian groups within the hospice movement. Of the hospices in this study, 38 were named after a Saint and another 7 had an overt Christian association - 39% of the total. Nevertheless, it appears that hospital chaplains are more frequently involved in religious care than hospice chaplains.

There are similarities, however. Of 9 categories of religious care, it is evident that within both groups, prayer, communion and worship appear most strongly. It is also noticeable that within these items, the generic needs of a broad section of Christian traditions might be found. Rites relating to illness or approaching death supplement these items. Required least frequently is baptism, suggesting that admission to hospice or hospital is not usually a prompt for entry to the faith on the part of non-believers. This is underlined by the fact that last rites - a means of saying farewell - feature more prominently than baptism.

In the context of declining religious practice and the emergence of an increasing distance between spirituality and religion, it is possible to under-estimate the place of religion in the lives of believers. A hospital chaplain seeks to redress the balance by responding to the survey on behalf of those with an unambiguous religious perspective:

The literature uses spirituality and religion as distinct entities and so frequently misunderstands them. The typology reminds us that spirituality may not be associated with religion, but for some, spirituality is only understood in terms of religion.'

### **Concluding comments**

In this chapter, I have outlined Phase 1 of the research: a survey of the perceptions of chaplains regarding the spiritual care infrastructure and spiritual care requirements of patients within hospitals and hospices in England and Wales. Clearly, the role of the chaplain has come to include more than spiritual care. It is a role, however, that remains almost exclusively Christian, and dominated by the Church of England.

Within the hospice group, differences were found between hospices with funded chaplaincies and hospices with voluntary chaplaincies. Significant associations were discovered between hospices that provided funding for the chaplain and other chaplaincy variables relating to resources and responsibilities. In particular, hospices that funded chaplaincy were also likely to provide chaplaincy accommodation, access to a patient database and a dedicated budget - together with a role description that included spiritual care education, liaison with religious leaders, and the management of bereavement care. These associations point to a different level of service provision between hospices with funded chaplaincies and hospices with voluntary chaplaincies.

In hospitals, 18% of voluntary ministers represent faiths other than Christian. However, the low level of funding allocated to ministers of other faiths, and the small number of other faith volunteers, suggest that spiritual care is largely operationalized within a Christian context and tradition. The absence of any assessment of the patient's spiritual, religious and cultural



requirements in 29% of hospitals, and the lack of multifaith guidelines in 40% of hospices, add weight to this point. Seen in this light, multifaith rooms are an interesting phenomenon. Moreover, they are to be found increasingly in both hospitals and hospices, indicating a trend away from establishing Christian chapels as the spiritual focal point within health care settings.

An assessment of the patient's spiritual, religious and cultural requirements occurs in 88% of hospices and 71% of hospitals. As nurses are involved in more than 90% of such assessments, questions arise concerning both nurse education and practice in relation to the spiritual domain. The data here suggest that patients have a wide range of non-religious requirements; these include wanting some-one to listen to them and some-one to 'be there' for them. Patients frequently wish to address non-religious issues - concern for relatives, suffering, and death and dying - which raises questions surrounding the availability of both time and personnel within the organizations. Within both groups, patients with religious (Christian) needs frequently desire opportunities to pray, to worship and to receive the sacrament, thereby requiring the availability of ministers from different traditions. A striking finding of this study is that hospital patients require religious care more frequently than hospice patients.

The data presented here suggest that changing patterns are emerging concerning spiritual care infrastructure and spiritual care requirements within both hospice and hospitals in England and Wales. These patterns raise questions for managers and providers relating to the scope and nature of spiritual care within secular organizations; they also place demands on the adaptability and resourcefulness of spiritual care-givers within health settings. Further research is needed into the delivery of spiritual/ religious care within hospital and hospice, the spiritual, religious and cultural needs

of faiths other than Christian, the nature and usage of multifaith rooms, and the perspective of patients and relatives on spiritual care issues.

## **CHAPTER 4**

### **THE ESSENCE OF SPIRITUAL CARE: A PHENOMENOLOGICAL APPROACH**

In this chapter, I outline a phenomenological enquiry into the essence of spiritual care. Based on the Husserlian tradition, the study seeks to discover the essence of spiritual care in the lived experience of a group of relevant stakeholders. Semi-structured, recorded interviews were conducted with 16 participants identified by purposive and snowball sampling. These participants held a variety of roles linked to palliative care and were of different religions and none. The tapes were transcribed and analysed using NUD\*IST software. Significant statements were identified and clusters of themes compiled.

The essence of spiritual care was drawn from the analysis, suggesting suggests that amongst these participants, spiritual care is founded on the assumption that all people are spiritual beings. It recognises the relationship between illness and the spiritual domain and acknowledges the search for meaning in the big questions of life and death. It responds to both religious and humanistic needs by meeting the requirements of faith and the desire for someone to 'be there'. Within the context of health care constraints and hopes for service improvements, spiritual care seeks to affirm the value of each and every person based on non-judgemental love.

## **Methods**

*Objectives.* Within the World Health Organisation (1990) definition of palliative care, the control of spiritual problems is paramount. By claiming to be spiritually inclusive, palliative care looks beyond the control of symptoms and adopts a more holistic approach (Stoter, 1991; Hilliard, 1998) that relates ultimately to the human spiritual core (Amenta, 1997). Significantly, it has come to encompass the view that the spiritual dimension is the integrating factor that holds together the physical, psychological and social components of care (Twycross et al, 1991, Twycross, 1997). Consequently, increased attention is being paid to the spiritual domain and its relationship to factors such as quality of life (Brady et al, 1999), the importance of beliefs (Puchalski and Roma, 2000) and the nature of spiritual care (Chung, 2000).

Entering the spiritual domain of patients appears to make special demands. Rosemary Elsdon (1995: 642) considers that spiritual pain in the dying may be not so much 'a problem to be solved' as 'a question to be lived': a shift in emphasis that requires different qualities amongst health professionals. Evidence suggests that these qualities are neither uniformly developed nor universally available. Spiritual issues have come to be overlooked within nurse education, resulting in a widening gap between the processes of nursing and the spiritual domain of patients (Oldnall, 1996). This situation is compounded by the nature of the human condition, since those who work with the dying are frequently confronted by feelings that relate to their own death and to past experiences of their own losses ( Speck, 1998).

Little research has been conducted into the nature of spiritual care or into the demands that spiritual care delivery places upon the caregivers. In the absence of a definition, questions arise as to what is being delivered under

the umbrella of spiritual care, and into the training that spiritual caregivers have undertaken to equip them for the task. The objectives of this phase of the enquiry is to discover stakeholder perceptions of the essence of spiritual care, including: the nature of spirituality; the range of spiritual prompts; difficulties involved in spiritual care delivery, and hopes for the future.

*The phenomenological approach.* Based on the Husserlian tradition of transcendental phenomenology, this enquiry seeks to discover the objective 'essence' of a phenomenon - spiritual care - from the viewpoint of a detached observer 'stepping out' of the world. A feature of the phenomenological approach is that the researcher identifies the assumptions s/he brings to the research. These assumptions are then 'bracketed' so that the experiences of the participants are not contextualised within the preconceived ideas of the researcher. In relation to this study, the researcher assumes that the essential nature of spiritual care can be extracted from the interviewees' descriptions of their experience of the phenomenon. The researcher's other assumptions – located around the spiritual domain - are summed up in the following extract from 'Mud and Stars'<sup>5</sup>:

... 'spiritual' embraces the essence of what it means to be human. It is concerned with 'right relatedness' and includes those experiences in human life which transcend sensory phenomena. Such experiences tend to give rise to theological reflections, religious responses and ethical beliefs. The spiritual aspect...is often perceived as being concerned with meaning and purpose. For those nearing the end of their life, it is commonly associated with a need for forgiveness, reconciliation and affirmation (Twycross et al, 1991).

*The sample.* For the purposes of this part of the research, stakeholders were defined as people who regard themselves as having first hand experience of spiritual care-giving and have opportunities to draw on that experience to influence praxis. Purposive sampling identified the first two participants;

others were identified using both purposive and snowball techniques (Table 7). This meant that by drawing on the recommendations of those already interviewed, the sample became iterative, responding developmentally to the requirements of the research question and the opinions of the stakeholders.

**Table 7** Stakeholder details

Participant	Gender	Role	Other details	Religion
1	Male	Hospital Chaplain	Writer and researcher. Experience in hospice	Anglican
2	Male	Hospital Chaplain	Senior position: College of Health Care Chaplains	Anglican
3	Male	Hospital Chaplain	Imam. Adviser on Islamic issues	Moslem
4	Male	Hospital Chaplain	Background in mental health. Regional training officer	Anglican
5	Male	Hospice/ Hospital Chaplain	Joint position in hospice and hospital	Anglican
6	Male	Diocesan Bishop	Senior position: College of Health Care Chaplains	Anglican
7	Male	Chaplaincy volunteer	Co-ordinator of eucharistic ministers	Roman Catholic
8	Male	Training Officer	Senior position: College of Health Care Chaplains	Anglican
9	Female	Artist	Hospice 'artist in residence'	None
10	Male	Hospice/ Hospital Chaplain	Member of pain management team: expertise in 'spiritual pain'	Roman Catholic
11	Male	Medical director	Member of hospice and hospital MDT	Hindu
12	Female	Director of Charitable Trust	Background in palliative care education	Anglican
13	Female	Chief Executive	Rabbi: writer and broadcaster	Jew
14	Female	Director of Nursing Services	Responsible for chaplaincy	Unknown
15	Male	Nurse Administrator	Long experience in hospice	Buddhist
16	Male	Music Therapist	Writer and broadcaster	Anglican

The sample included interviewees from different religious traditions: Jewish, Christian, Hindu, Muslim and Buddhist; one was a Rabbi, one was a Bishop and one was an Imam. The sample also included those of no religious faith, but who regarded themselves as 'spiritual'. The participants performed a variety of roles: chief executive, manager, nurse, medical director, therapist, artist, volunteer and chaplain. Backgrounds, job descriptions and length of service varied. Not everyone was born in Britain.

*Data collection.* Data were collected by means of semi-structured, recorded interviews. Prior to each interview, the purpose of the research was re-stated, together with the boundaries of confidentiality. Time was taken to answer questions and to deal with the format of the interview. The interviewees were invited to speak for as long as they wished. It was explained that interjections would be kept to a minimum, although supplementary questions would be put where necessary. To avoid duplication, if a participant addressed a question planned for later in the interview, the latter question was manually deleted from the aide memoir - resulting, perhaps, in a momentary loss of eye contact. To ensure that recording difficulties had not occurred during the interview, a brief glance at the equipment would be undertaken at strategic points. These details were fully explained so that the participants felt comfortable with either brief activity on the part of the interviewer or momentary loss of eye contact during the interview. Once the interview began, each participant was asked a number of similar, open-ended questions around spiritual caregiving:

- What do you understand by the word 'spirituality'?
- Why do people become interested in the spiritual domain?
- What are the main ingredients of spiritual care?
- What difficulties are associated with spiritual care?

- What hopes have you for the future of spiritual care?

The interviews lasted between 31 minutes and 90 minutes, and generated around 140,000 words of text.

*Data analysis.* Once the interviews were completed, data from all 16 interviews were analysed and classified. Five major themes emerged - spirituality; prompts to spirituality; spiritual care; difficulties associated with spiritual care; and hopes for the future of spiritual care. A description of the essence of spiritual care was eventually drawn from these themes.

A detailed description of the analysis is given below:

- 1 Each interview was transcribed (Appendix 13 gives a transcript in full)
- 2 The transcription was checked against the recording
- 3 The transcription was prepared for entry into the NUD\*IST computer program
- 4 The text was divided into units, saved as plain text, then imported into the NUD\*IST document explorer
- 5 Each unit of text was coded and categorised (Appendix 14, 15)
- 6 Reports were constructed containing similarly categorised units of text from all of the interviews (Appendix 16)
- 7 The reports were scrutinised for text units containing significant statements. Each statement was noted. Duplications were withdrawn. Tables were then constructed containing *significant statements* from all interviews relating to spirituality (Table 8.1), prompts to spirituality (Table 9.1), spiritual care (Table 10.1) difficulties associated with



spiritual care (Table 11.1), and hopes for the future of spiritual care (12.1).

The procedure is exemplified using the following transcript:

‘And one of the perhaps most telling aspects of spirituality for me, is what I’d call the aspect of transcendence, and I think you see this, not only in the work that we do with people, but in the research, and in the, sort of, writings about spirituality - *transcendence being the ‘going beyond’* - and for some, that’s a ‘going beyond’ in an inner way, *finding a depth of self*. Perhaps *some concept of ‘soul’* might be the sort of language that people would use, or it might be an outer sort of ‘going beyond’. Often, *people feel it in relationships with others*. Or it may be in a sense of *relationship to the universe, to creation’*.

The words in italics were identified as *significant statements* and incorporated into a table of significant statements: Table 8.1 (Significant statements: Spirituality), as follows:

38 transcendence – ‘going beyond’

39 finding a depth of self

40 some concept of soul

41 people feel it in relationships with others

42 a relationship to the universe, to creation

7 From the tables of significant statements, *significant meanings* were formulated by combining related statements. For example: significant statements 38-42 (itemised above) were combined with other, statements as follows:

- Spirituality is concerned with the intangibility of transcendence and the tuning in to something both beyond and within, something deeper, something wider, something bigger (statements number 32, 33, 34, 38, 39, 29)

- Spirituality is concerned with the soul and its link with the spirit (40, 44)
  - Spirituality is concerned with something other than just the body; it is concerned with feelings, relationships, personal awareness and the mystery of our understanding of ourselves (31, 43, 41, 25, 63)
  - Spirituality is being at one with the universe and being in touch with nature and creation (14, 35, 42)
- 8 These statements were then incorporated into a *table of formulated meanings*: Table 8:2 (Formulated meanings of significant statements: Spirituality). A similar process produced other tables of formulated meanings that related to prompts (Table 9.2), spiritual care (Table 10.2), difficulties (11.2), and hopes (12.2)
- 9 From the formulated meanings, clusters of themes were devised (Table 13)
- 10 An exhaustive description of the essence of spiritual care was drawn from the themes listed in Table 13
- 11 All the data were saved to compact disk

Once the data was analysed, the interviewees were asked to confirm whether their views were represented in the findings. The positive responses enhanced both the validity and credibility of the enquiry.

## **Findings**

As I have previously stated, the data in this set of interviews fall within five main categories: spirituality; prompts to spirituality; spiritual care; difficulties associated with spiritual care; and hopes for the future of

spiritual care. In this section, I present a summary of the findings within each category, supported by the tables mentioned above.

The tables are set out in pairs. Within each pair, the first-mentioned table (Tables 8.1, 9.1, 10.1 for example) contains significant statements in the each category ('Spirituality', for example) from all 16 transcripts. Included in each of these tables is a short transcription from the interview. Text in italics were incorporated into the table as significant statements. The purpose of including the transcription is to provide a link between the raw data and the table of significant statements.

The second table (Tables 8.2, 9.2, 10.2, for example) contains the formulated meanings of significant statements, arrived at by combining a number of related significant statements. Figures in brackets after each formulated meaning (19, 20, 47, for example, at the end of statement 1 in Table 8.2) show which of the significant statements from the previous table were combined to produce the formulated statement.

*Spirituality* (Table 8.1 and 8.2). All people are spiritual beings. Spirituality may be expressed religiously or humanistically. Within both contexts, what may be termed 'personhood' (including values and beliefs) and relationships (with self, others, and God) figure prominently. Spirituality transcends the here and now by reaching both beyond and within the self, and searches for meaning by addressing the big questions of life and death.

**Table 8.1 Significant statements: Spirituality**

1	can be religious without being spiritual	35	being in touch with nature
2	can be spiritual without being religious	36	it can give me peace
3	religious things help my spiritual journey	37	a calling into love
4	religion offers answers to big questions	38	transcendence - 'going beyond'
5	religion links the universal/the individual	39	finding a depth of self.
6	religion explains individual role	40	some concept of 'soul'
7	spirituality and religion should work together.	41	it's in relationships with others
8	spirituality: part of a religious set of beliefs	42	relationship to the universe, creation.
9	spirituality for me is about God	43	affects our feelings, responses
10	it comes in the form of worship	44	soul and the spirit could be linked.
11	devotion and prayer	45	that which is linked to another life.
12	the commands of God	46	shaped by culture, history
13	sense of well-being	47	different forms in a child, teenager, adult
14	being at one with the universe,	48	ritual plays a major part
15	in my life that there is a life force	49	questing, searching, journey, struggle
16	spirituality is this calling by God	50	to do with peace, love and forgiveness
17	and the effects of that calling.	51	about commitment, sacrifice, caring.
18	life that is patterned by Christ	52	discovering purpose for your life
19	we are all spiritual beings	53	it's about understanding suffering
20	spiritual awareness varies	54	it's about learning to die properly
21	the Holy Spirit links it all up for me	55	preparing yourself to die
22	spirituality is a life orientation	56	putting a perspective on your existence
23	includes values, beliefs, practices, customs	57	making your life free and loving
24	beginning to waken up to what life is	58	being the person - accepted and loved
25	you become more aware of who you are	59	it's about letting go
26	the meaning of your life	60	knowing you're a steward
27	direction in your life -	61	the big questions of life, death/ universe
28	achievements in your life	62	seeing the individual as unique
29	tuning in	63	the mystery of our understanding of ourselves
30	internal values: linked to a purpose of being	64	it's like being on fire
31	something other than just your body	65	all that's possible, flourishing and quickening
32	that which is not tangible		
33	something wider -bigger		
34	something within me		

Example: Statements 51 - 54 are based on the following transcription: ' it's about *commitment*, it's about *sacrifice*, it's about *caring*. It's about *discovering your* meaning and *purpose for your particular life*. It's also about *understanding suffering*, I think, as well. It's about developing through all of that. It's also about dying too, I think - and *learning to die properly*'.

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**Table 8.2 Formulated meanings of significant statements: Spirituality**

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- 1 All people are spiritual beings - though spiritual awareness varies both between individuals and in different phases of life (19,20,47)
  - 2 Spirituality is a life orientation shaped by culture and history, incorporating values and beliefs, practices, customs and ritual (22,23,30,46,48)
  - 3 Spirituality is being at one with the universe and being in touch with nature and creation (14,35,42)
  - 4 Spirituality is concerned with the intangibility of transcendence and the tuning in to something both beyond and within, something deeper, something wider, something bigger (32,33,34,38,39,29)
  - 5 Spirituality recognises each individual as a unique person (62)
  - 6 Spirituality is an awakening to life and a focus upon the meaning, direction, purpose and achievements of individual lives (26,27,28,24,52,56)
  - 7 Spirituality can bring a sense of well-being and peace (13,36)
  - 8 Spirituality is concerned with something other than just the body; it is concerned with feelings, relationships, personal awareness and the mystery of our understanding of ourselves (31,43,41,25,63)
  - 9 Spirituality is concerned with the soul and its link with the spirit (40,44)
  - 10 Spirituality is about questing and searching - that journey, that struggle - addressing the big questions of life, death, another life and the universe (49,61,45)
  - 11 Spirituality is about commitment, sacrifice, caring, peace, love and commitment (37,51,50)
  - 12 Spirituality is about understanding suffering, learning and preparing to die, and letting go (53,54,55,59)
  - 13 Spirituality is about knowing you're a steward, making your life free and loving, and being the person who is accepted and loved (60,57,58)
  - 14 Being spiritual is not the same as being religious (1,2)
  - 15 Spirituality can be expressed religiously (7,8)
  - 16 Religion offers answers to the big questions, explains the role of the individual and assists with the spiritual journey (3,4,5,6)
  - 17 Spirituality is being aware of a life force - sometimes called God (15,9)
  - 18 Spirituality is a submission to the commands of God (12)
  - 19 Christian spirituality orientates towards a life that is linked to the Holy Spirit and is patterned by Christ (18,21)
  - 20 Spirituality is related to God's call and to the effects of that call (16,17)
  - 21 Spirituality is expressed in worship, devotion and prayer (10,11)
  - 22 Spirituality is like being on fire; all that's possible are flowing and quickening (64,65)
- 

*Prompts to spirituality* (Tables 9.1 and 9.2). Spiritual activity is prompted by dissatisfaction with materialism and science, by personal experience of life, and by the decline in organised forms of religion. Other prompts relate to the recognition of something spiritual at the centre of life, and a sense of calling or commitment to God. Illness and the prospect of death have the capacity to touch something profoundly spiritual, pulling on the soul and creating opportunities for re-assessment, forgiveness and reconciliation.

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**Table 9.1 Significant statements: Prompts**

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1	I see my life as a spiritual journey	42	nursing asked what is meant by spirituality
2	I wanted to know more	43	those with severe illness ask fundamental questions
3	I've discovered this quest	44	(illness) generates worries and anxieties
4	when I was young I almost drowned	45	-about personal life
5	my life is an unfolding story with God	46	-about the life of their families
6	I became a Rabbi	47	-about the life of their children
7	conscious of something other being there	48	-about the life of the community in general
8	I became aware of God's presence	49	-worries as big as the requirements of faiths
9	wanted to know how and why people tick	50	-worries about halal food
10	intrigued about how people cope with life	51	-about missing a prayer
11	people of patience taught me spirituality	52	-about not doing ritual ablution
12	others taught me the breadth of spirituality	53	-about reading the Qur'an
13	this giant of a man kneeling in front of God	54	(sickness) isn't an intellectual process
14	something spiritual at the centre of our lives	55	-this is an emotional process
15	people kneeling at the communion rail	56	-a spiritual process
16	my life has had God's mark on it	57	-about coming to accept yourself
17	my life has been meant for God's use	58	-you might describe it as your fate
18	I began searching for something	59	-your destiny
19	God just called me	60	pulls on the spirit to get understanding
20	as you get older you turn to the spiritual life	61	forced into the perspective of needing to let go
21	it was to integrate my faith with my profession	62	sense of you not being the owner
22	got to know Jesus, the puzzle took shape	63	I think it pulls on the soul
23	pain is about the whole person	64	time for the soul to sift out what's important
24	we should look for other languages	65	this experience is a final one
25	loss deepened my understanding	66	people are afraid and don't want to die
26	my belief systems and behaviour are important	67	I think cancer is a spiritual disease
27	people get hungry for something deeper	68	-it's a silent disease
28	we've seen a decline in organised religion	69	-it sneaks up on you
29	I feel the Church has failed its people	70	-undermines ways in which life operates
30	I think there's total disillusionment	71	-suddenly turns people's lives upside down
31	people are dissatisfied with the materialistic	72	-carries the why questions - spiritual questions
32	people are dissatisfied with the scientific	73	getting house in order has spiritual dimension
33	people recognising lots of issues in life	74	a sudden awareness of their own mortality
34	what seemed answers are not answers	75	where am I with God right now?
35	Feminist Movement kept the flame going	76	illness gives people a chance to reassess
36	spiritual element in the Green Movement	77	he needed to feel he could be forgiven
37	spiritual dimension in Hospice Movement	78	there is this sense of guilt
38	palliative care includes the spiritual	79	there is this chance of reconciliation
39	spiritual care important within healthcare	80	death touches something profoundly spiritual
40	we are not machines	81	I think the child in us needs the security
41	full recovery unlikely without spiritual care	82	here comes the concept of letting go

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Example: Statements 44 -52 are based on the following transcription: '(Illness) generates a lot of worries and anxieties about their personal life, about the life of their families, life of their children, life of the community in general. I mean - and the scope of these worries can - can be as big, you know, as the - as the requirements of faiths, you know, can be. Now, for example, in the case of Muslims, if people - a person coming into hospital may worry about food, the halal food, yes, may worry about missing a prayer, you know, which is obligation, may worry about not being able to do a ritual ablution, which is necessary to perform a prayer or to read part of the - read the Qur'an,

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**Table 9.2 Formulated meanings of significant statements: Prompts**

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- 1 Life is a spiritual journey encompassing a quest, a search for knowledge or search for other languages (1,2,3,18,24)
  - 2 People recognise lots of issues in life and are hungry for something deeper (33,27)
  - 3 A turning to the spiritual life as one gets older (20)
  - 4 Personal experiences of loss and near death experiences deepen understanding (25,4)
  - 5 The importance of personal belief systems and behaviour (26)
  - 6 An interest in why people tick and how people cope with life (9,10)
  - 7 Disillusionment and recognition that what seemed to be answers were not (30,34)
  - 8 A dissatisfaction with the materialistic and scientific (31,32)
  - 9 The teaching of others about the breadth of spirituality (11,12)
  - 10 People kneeling at the communion rail; a giant of a man kneeling before God (15,13)
  - 11 An awareness of 'something other', something spiritual at the centre of our lives (7,14)
  - 12 An awareness of God's presence
  - 13 Knowledge of Jesus enabled the puzzle to take shape (22)
  - 14 An awareness of being called by God, that one's life has God's mark on it and is meant for God's use (19,16, 17, 6)
  - 15 A desire to integrate faith with professional life (21)
  - 16 Spiritual elements figure within the Green Movement and the Feminist Movement (36,35)
  - 17 The spiritual dimension features within the hospice movement and within the language of palliative care (37,38,39)
  - 18 Nursing has addressed the meaning of spirituality (42)
  - 19 A decline in organised religion (28)
  - 20 The Church has failed its people (29)
  - 21 Illness generates worries and anxieties – about oneself, one's family, one's community and the requirements of faith (44,45,46,47,48,49,50,51,52,53)
  - 22 Human beings are not machines; those with severe illness ask fundamental questions and a full recovery is unlikely without spiritual care (40,41,43,75)
  - 23 Sickness is about coming to accept oneself and recognising one is not 'the owner' (62)
  - 24 Sickness is not an intellectual process but an emotional and spiritual process; pain is about the whole person (54,55,56,57,23)
  - 25 Cancer is a spiritual disease in that it silently sneaks up and turns people's lives upside down, undermining the ways in which life operates and carrying with it the 'why questions' – the spiritual questions (67,68,69,70,71,72)
  - 26 Illness gives people a chance to re-assess, to try and get understanding, address guilt, be forgiven, and affect reconciliation (60,76,77,78,79)
  - 27 Illness pulls on the soul and gives time for the soul to sift out what's important (63,64)
  - 28 The prospect of death touches something profoundly spiritual, prompting an awareness of mortality and forcing people into the perspective of needing to let go (80,74,65,61)
  - 29 People are afraid and don't want to die; the child in us needs security (66,81)
-

*Spiritual care* (Tables 10.1 and 10.2). Spiritual care affirms the value of each and every individual. It acknowledges the place of cultural traditions and personal relationships. It is based on empathy and non-judgemental love, affirming the worth of each person in the eyes of God. It responds to religious and non-religious spiritual needs by meeting both the requirements of faith and the humanistic desire for some-one to be there, to listen, and to love. It acknowledges the dignity and nobility of life, respecting each person as themselves up to the point of death. A wide range of people can deliver spiritual care although within health care, chaplains are frequently seen as representing both religion and the spiritual domain.

**Table 10.1 Significant statements: Spiritual care**

1	meeting religious needs	28	a clear understanding of your role as caregiver
2	includes anointing and last rites	29	it's about recognising need and responding
3	the patient receives holy communion	30	it's about seeking to understand
4	rites of passage mark the stages of life	31	caring for the person
5	you need somebody with responsibility	32	-ask whether the medicine is working
6	can be provided by a variety of people	33	-whether the pain is less
7	domestics least trained but probably best	34	-sitting with someone while they cry or laugh
8	need people with a sense of spirituality	35	-enable patients or those close to them to talk
9	we're looking at models of assessment	36	-engage in the big questions with people
10	recognising every person is an individual	37	-enabling people to talk about fears, anxieties
11	the individual has needs	38	-about worries about the dying process
12	needs can be met in a variety of ways	39	-what will happen to them and those left
13	spiritual care is about you.	40	-supporting them to leave or say or do things
14	care is extended to family and friends	41	-try to let people tell us how they want things to be and making it be that way
15	main ingredient is quality time	42	-respecting people as themselves up to death
16	acceptance and a non-judgemental approach	43	it's mainly about respecting individuality
17	based on love for each single human being	44	some people might want to forgive
18	respect for the dignity, nobility of life	45	picking up the person's dis-ease that's not picked up by treatment
19	the worth of everybody in the eyes of God	46	it's just being there with that patient
20	people are lovable as children of God	47	people may be questioning their beliefs
21	it's about listening to someone's story	48	it's seeing the person behind the pathology
22	it's about receiving	49	people entitled to ministers of their own faith
23	about reflecting, interpreting and helping	50	chaplains presenting religion and spirituality
24	it's the interaction that matters	51	spiritual needs can be met by the nurse, the doctor, the psychologist or whoever
25	about giving value, meaning and purpose		
26	it's based on empathy, compassion		
27	a tuning in to the other person		

Example: Statements 31-35 are based on the following transcription: 'I think it's about - firstly about *caring for the person* and that involves all the elements of care ...whether it's going back after a while to *ask whether or not the medicine that's been given is working, whether the pain is less* or whether it's *sitting with somebody whilst they cry or whilst they laugh* or whether it's trying to *enable patients and those close to them to talk about things*. I mean it's all those things



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**Table 10.2 Formulated meanings of significant statements: Spiritual care**

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- 1 Spiritual care recognises and assesses the needs of the individual and responds to them in a variety of ways (11,9,29,12)
  - 2 Spiritual care responds to the patient's dis-ease that is not going to be picked up by treatment (45)
  - 3 Spiritual care recognises patients may be questioning beliefs or wanting to forgive (47,44)
  - 4 Patients are entitled to ministers of their own faith (49)
  - 5 Spiritual care meets religious needs by including holy communion, anointing and the last rites (1,2,3)
  - 6 Rites of passage mark significant stages in people's lives (4)
  - 7 Spiritual care can be provided by a variety of people including the nurse, the doctor and the psychologist (6,51)
  - 8 Spiritual care givers need to be people with some active sense of spirituality since, spiritual care is also about the care giver and clarity is needed about your own role(8,13, 28)
  - 9 There needs to be someone with responsibility for spiritual care and chaplains are generally seen as representing both religion and spirituality (5,50)
  - 10 Domestic staff are the least trained but probably the best at providing spiritual care (7)
  - 11 Spiritual care sees the person behind the pathology, and recognises and the uniqueness of the individual (10,48, 43)
  - 12 The person is cared for and respected as themselves up to the point of death (31,42)
  - 13 Spiritual care acknowledges the worth of everybody in the eyes of God and recognises that people are lovable in themselves as children of God (19,20)
  - 14 Spiritual care is extended to the individual's family and friends (14)
  - 15 Spiritual care responds to the patient's dis-ease that is not going to be picked up by treatment (45)
  - 16 The main ingredient of spiritual care is time – quality rather than length – and just being there with that patient (15,46)
  - 17 It's the interaction that matters, receiving with a warm acceptance and non-judgemental approach (24,22,16)
  - 18 Spiritual care is based on empathy and compassion – a tuning in to the other person (26,27)
  - 19 Spiritual care is based on love for each single human being, and respect for the dignity and nobility of human life (17,18)
  - 20 Spiritual care is about listening to someone's story- reflecting, interpreting and helping, and giving value, meaning and purpose (21,23,25)
- 

*Difficulties associated with spiritual care* (Tables 11.1 and 11.2).

Difficulties arise due to the varied meanings of spiritual care and the absence of a generally accepted definition. These difficulties are compounded by the close association between spiritual care and the Church, and by the growth of a spiritual care industry. Also problematic is the speed with which patients pass through the health care system, together with the high number of patients involved. These factors contribute to a

service that is crisis driven and triggered by anxiety, distress or death. The presence of cultural or religious inappropriateness is a further inhibitor. In addition, spiritual care incorporates intangible, immeasurable features that contrast sharply with the contemporary focus on high-tech, physical care that has lost the human touch. Running parallel is an increasing lack of confidence on the part of health professionals to enter the spiritual domain of patients, seeking instead what are deemed to be a safe pair of hands.

**Table 11.1 Significant statements: Difficulties**

1	speed the patients pass through the system	24	the loss of the human touch
2	-crisis driven sort of service,	25	it was personally challenging for myself
3	-death, distress anxiety are trigger points	26	it was starting to affect my health a bit
4	it's an area where you can do damage	27	why God doesn't answer prayers is a difficulty
5	nurses are becoming less confident in it	28	a few staff have biased attitudes
6	nurses want to pass it to a safe pair of hands	29	cultural and religious inappropriateness make services inaccessible to certain groups
7	chaplains go in as a professional rather than work alongside a team	30	you never know what you have started
8	need more chaplains	31	we talk a lot about spiritual provision but its not been clearly defined
9	-more funding	32	the spiritual gets lost off into bits of this and that - the pick and mix.
10	practice focusses on the physical	33	they always think religious people can do it better
11	clerk wouldn't ask people their religion	34	the growth of a spiritual care industry
12	don't look after individuals as individuals	35	the cosiness of what goes as spiritual care
13	not on everyone's agenda-especially doctors	36	sweet sugary gluck stuff is worse than useless .
14	'spiritual care' means different things to every single person	37	interest in the church has dropped and we've been left bereft in a spiritual sense
15	it's meaningless unless you explain it	38	changes failed to keep pace within the church
16	it gets reduced to meeting people's religious needs	39	associated in people's minds with the church
17	it's become a bit of a political football	40	certainty might frighten off people who are searching
18	there's a false belief that religious symbols are interchangeable	41	this work take more of you than just a job
19	the 1948 Act gave chaplains but set low levels		
20	getting back to the head counting game		
21	the intangible is not measurable		
22	spiritual care givers face a demanding philosophical and intellectual task		
23	dependence on high tech care is getting us nowhere		

Example: Statements 1-3 are based on the following transcription: 'I think in acute services, one of the big difficulties these days is the *speed with which patients pass through the system*, and it inevitably, it seems to me, weights spiritual health care to a *crisis driven sort of service*, which means *death, distress, anxiety as trigger points for bringing in some sort of spiritual care*.

Chaplains are generally seen in this light, but low staffing levels, under-funding, and the demands of spiritual care-giving are sources of tension. Within this scenario, spiritual care frequently becomes substituted by religious care.

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**Table 11.2 Formulated meanings of significant statements: Difficulties**

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- 1 Spiritual care means different things to every single person, and is meaningless unless explained (14,15)
  - 2 That which is spiritual gets lost in a pick and mix of this and that (32)
  - 3 Spiritual care is associated with the Church in many people's minds (39)
  - 4 As changes have failed to keep pace within the Church, interest has been lost and we've been left spiritually bereft (38,37)
  - 5 There is much talk about spiritual provision but its not clearly defined (31)
  - 6 Spiritual care is an area where damage can be done; those with spiritual certainty might frighten those who are searching (4,40)
  - 7 The speed with which patients pass through the system results in a crisis driven service where death, distress and anxiety are the triggers for spiritual care (1,2,3)
  - 8 Cultural and religious inappropriateness make some services inaccessible to certain groups of people (29)
  - 9 Spiritual care is a bit of a political football; the 1948 Act introduced chaplains but set low staffing levels (17,19)
  - 10 The intangible is not measurable and now we are getting back to the head counting game (21,20)
  - 11 Funding is needed to provide more chaplains
  - 12 The way practice focuses on the physical and the dependence on high tech care is getting us nowhere (10, 23)
  - 13 Spiritual care gets reduced to meeting people's religious needs (16)
  - 14 Why God doesn't answer prayers is a difficulty
  - 15 There's a view that religious people can do it better (33)
  - 16 There's a false belief that religious symbols are interchangeable (18)
  - 17 The growth of a spiritual care industry, the sweet, sugary, gluck stuff and the cosiness of what passes as spiritual care is less than useless (34,36,35)
  - 18 The human touch has been lost and we don't look after individuals as individuals anymore (24,12)
  - 19 Chaplains go in as professionals rather than work alongside a team (7)
  - 20 Spiritual care givers face a demanding philosophical and intellectual task, never knowing what has been started (23,30)
  - 21 Spiritual care is personally challenging and can affect health (25,26,41)
  - 22 Nurses are becoming less confident in spiritual care and want to pass it on to a safe pair of hands (5,6)
  - 23 Spiritual care is not on everyone's agenda and some staff won't ask about the religion of patients (11)
  - 24 Some staff have biased attitudes (28)
-

*Hopes for the future* (Tables 12.1 and 12.2). Hopes for the future of spiritual care relate to a desire to do better. Key to improvement is a broader recognition of the spiritual domain and less confusion between the spiritual and the religious. Training staff to recognise both spiritual issues and the needs of religious groups is crucial. So is the restoration of the human touch

**Table 12.1 Significant statements: Hopes**

1	I'd want to do better than we do at the moment	27	better networks for sharing information
2	my aim would be to increase awareness	28	regional encouragement and support
3	wider recognition of the spiritual dimension	29	a kind of regional chaplaincy department
4	recognition of spiritual dimension in the care setting		with libraries, email, psycho-spiritual groups
5	not confuse religious with spiritual	30	to have more ministers in the hospital
6	to identify a pioneer to get round health service/ hospice people	31	more prayer for the chaplaincy
7	-gather thoughts and mobilise people	32	more volunteers
8	-see spiritual care as a believable, graspable entity	33	to develop non religious retreats for staff
9	-transform the quality of living for everybody	34	to develop ourselves
10	-breath life back into the hospice movement	35	in training all staff spiritual care was on the agenda
11	-be the catalyst that articulates what the dying have to give to all humanity	36	-recognition of spiritual issues
12	-give vision and meaning for the Church	37	-recognition of needs of religious groups
13	-for all people looking for life	38	recognition that spiritual care might be needed
14	-give hope to the world	39	recognition that people might have quests, questions, a spiritual search
15	we need to bring back the human touch	40	a community team should have a chaplain
16	a philosophy of spirituality for the hospital	41	my wish would be that the revised HSG 92/ 2 could be accepted by The Department of Health
17	all health professionals taking time to listen	42	new HSG 92/ 2 could be implemented as obligatory throughout the country
18	-acknowledge the realities for each dying individual	43	I would like to see more dialogue
19	we need a different way of looking at things	44	Church could see how it slots into the people
20	a different set of values for the dying	45	not only the chaplain who gives spiritual care
21	a consistent approach to spiritual assessment	46	chaplain will very often be the co-ordinator
22	everybody evaluated spirituality in everybody	47	to make chaplaincy more available
23	research to start taking more concrete form	48	I'd say 'here is the number for the chaplain'
24	research on a more national level	49	more proactive in offering clinical supervision, support and time out to the team
25	more people to do the theory/ research part		
26	more resources being given to spiritual care		

Example: Statements 6-14 are based on the following transcription: *'to identify somebody...in palliative care, who would be willing to be a pioneer, a peripatetic, to actually get around all the Health Service and hospice people, gathering these thoughts and mobilising people, so that...the world can see that spiritual care is a totally believable, graspable entity, that - that has great power to transform the quality of living for everybody, not just for the dying... I think that would breathe life back into the hospice movement, enable it to be the catalyst that articulates what the dying have to give to all of humanity. And I think it would have tremendous vision and meaning for the church, for all people who are looking for life that is not bogged down in commercialism, and all the other things that afflict us at the present moment, give real hope to the world.'*

and opportunities for staff to take time to listen. For the dying, this involves the adoption of different values and a different perspective. Fundamentally, a more consistent approach towards spiritual assessment is hoped for, together with an increase in research. While acknowledging that many

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**Table 12.2 Formulated meanings of significant statements: Hopes**

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- 1 To do better, than we do at the moment and not confuse the religious with the spiritual (1,5)
  - 2 To increase awareness and develop a wider recognition of the spiritual dimension, both in life and in the care setting (2,3,4)
  - 3 To identify a pioneer to gather thoughts and mobilise people so that spiritual care is seen as a believable, graspable entity with power to transform the quality of living for everybody (6,7,8,9)
  - 4 That life should be breathed back into the hospice movement, enabling it to articulate what the dying have to give to humanity, thereby providing vision and meaning for the Church – for all people looking for life - and hope to the world (10,11,12,13,14)
  - 5 To bring back the human touch with all health professionals taking time to listen and acknowledging the realities for each individual who's dying (15,17,18)
  - 6 A different way of looking at things, a different set of values for the dying and for everybody (19,20)
  - 7 To evaluate spirituality and adopt a more consistent approach to spiritual assessment (22,21)
  - 8 For more people to undertake concrete research on a national level (25,23,24)
  - 9 More resources given to spiritual care, more ministers and volunteers, and chaplains for community teams, all supported by more prayer (26,30,32,40,31)
  - 10 More dialogue and better networks for sharing information with support from a regional chaplaincy department equipped with email and libraries and facilities for psycho-spiritual groups (43,27,28,29)
  - 11 To develop both ourselves and members of staff through non-religious retreats (34,33)
  - 12 To be more proactive in offering clinical supervision, support, and time out to the team (50)
  - 13 To train staff in the recognition of spiritual issues and the needs of religious groups (36,37)
  - 14 To recognise that people might have quests, questions, a spiritual search, and that spiritual care might be needed (39,38,35)
  - 15 That the revised HSG 92/2 could be accepted by the Department of Health and implemented as obligatory throughout the country (41,42)
  - 16 To recognise that it's not only the chaplain who gives spiritual care, but that the chaplain will very often be the co-ordinator (45,46)
  - 17 To make chaplaincy more available than it is (48,49)
  - 18 For the Church to see how its slots into the people (44)
-

people give spiritual care, recognition of the chaplain's central, often co-ordinating role, is crucial. Hopes abound for increased resources, more personnel, the establishment of better networks and a regional office to support chaplaincy. Ultimately, it is hoped that spiritual care is seen as a believable entity with power to transform the quality of living for everybody.

### **The essence of spiritual care**

Table 13 was compiled from the tables of formulated meanings, displayed above. This table shows the common themes around which the formulated meanings cluster. It was from these common themes that the essence of spiritual care was drawn.

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**Table 13      Clusters of common themes**

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<p><b>Spirituality</b></p> <p>a) Personhood: values, beliefs, achievements</p> <p>b) Relationships: self, others, universe, a 'life force' or God</p> <p>c) Search for meaning: the 'big questions', mortality</p> <p>d) Transcendence: something beyond/ within</p> <p>e) Religion: worship</p>	<p>f) Being there: empathising, valuing, listening and loving</p> <p>g) Respect: of the person to the point of death</p>
<p><b>Prompts</b></p> <p>a) Personal experience: of life and its losses</p> <p>b) Dissatisfaction: with materialism</p> <p>c) Role of others: their example and influence</p> <p>d) Spiritual awareness: 'something other'/ God</p> <p>e) Vocation: the call / commitment to God</p> <p>f) Religious decline: in organised forms</p> <p>g) Illness: its nature and meaning</p>	<p><b>Difficulties</b></p> <p>a) Definition: varied understandings</p> <p>b) Service provision: patient throughput, cultural inappropriateness</p> <p>c) Delivery: focus on physical care, loss of human touch, spiritual care industry</p> <p>d) Personal challenges: to spiritual care givers</p> <p>e) Lack of confidence: amongst health professionals</p>
<p><b>Spiritual care</b></p> <p>a) Personnel: a wide range of care givers</p> <p>b) Focus: religious/non-religious spiritual needs</p> <p>c) Culture: acknowledgement of the cultural aspects of life</p> <p>d) The individual: affirmation of uniqueness and value</p> <p>e) Relationships - with family and others</p>	<p><b>Hopes</b></p> <p>a) Improvement: to do better, bring back the human touch</p> <p>b) Assessment: a more consistent approach</p> <p>c) Research: more national research</p> <p>d) Resources: increased provision,</p> <p>e) Training: recognition of spiritual issues, needs of religious groups</p> <p>f) Chaplaincy: more accessible, co-ordinating role, regional office</p>

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In this study, the essence of spiritual care is founded on the assumption that all people are spiritual beings. It recognises the relationship between illness and the spiritual domain and acknowledges the search for meaning in the big questions of life and death. It responds to both religious and humanistic needs by meeting the requirements of faith and the desire for someone to 'be there'. Within the context of health care constraints and hopes for service improvements, spiritual care seeks to affirm the value of each and every person based on non-judgemental love.

## **Discussion**

In the lived experience of those interviewed for this study, spiritual care is founded on the belief that all humans are spiritual beings with a capacity to reach beyond the self and search for meaning. The giving of care is a response to that belief and a recognition of the commonality of the human condition. As such, spiritual care has a humanitarian capacity to cross the boundaries of faiths, and traditions. That is not to deny the dangers inherent in ascribing a Western concept of spirituality to other religions and cultures (Montilus, 1983), it is rather to acknowledge the capacity of human beings to cross divides and make contact with each other through the activities of being present, listening, respecting, and loving. An interesting feature of this study is that all participants, irrespective of religious affiliation and cultural tradition had an understanding of the word 'spirituality'.

An analysis of the significant statements reveals interesting facets of what has come to be called personhood. Though open to interpretation, personhood is thought to relate to that which characterises human beings. As such, it encompasses embodiment, cognition, emotions and relationships (Stevens, 1996). According to Rose (1996:3), the 'Western' person is 'individualised, intentional, the locus of thought, action and belief'. These ideas resonate with the statements that spirituality is about 'seeing the

individual as a unique person' (62), 'discovering the purpose of your life' (52), 'internal values' (30), 'peace, love and forgiveness' (50) and 'a religious set of beliefs' (8). There is a sense, therefore, in which it is legitimate to establish an association between personhood and spirituality: a relationship that has already been recognised operationally. Writing about patients suffering from dementia, Paul Wilson (1999) cites Bell and McGregor (1995), when he suggests that spiritual care involves the identification of values on which a person has based their life, and that:

through reminiscence and validation, the person is placed in contact with 'the basic core characteristics that made them the person they always were (Wilson, 1999:108)

The findings here also suggest that spiritual care is a response to the requirements of faith. Consequently, it needs to be sensitive to the impact of those requirements upon daily life, and sympathetic to both religious and cultural traditions. This is particularly true where patients are separated from their faith community and dislocated from their normal pattern of daily life. In the United Kingdom, guidance to Health Authorities (Department of Health, 1986) acknowledges the right of patients to be visited by a minister of their choice, and a statement about respect for religious and cultural traditions has been included in the Patients' Charter (Department of Health, 1991). More explicit guidance about recognising the needs of both Christians and non-Christians was circulated in 1992 (Department of Health, 1992), and writers are coming to include broader cultural perspectives in their publications (Twycross, 1997).

The data from this study identify illness and the prospect of death as prime motivators for spiritual activity. As patients face their own mortality, questions come to mind which challenge assumptions and beliefs. Issues of meaning and re-assessment, forgiveness and reconciliation come to the fore.



The evidence here suggests that each participant had been sensitised to the spiritual domain. Though this sensitivity had come about in different ways – ranging from a near death experience to a personal call from God - the end result is the same: a recognition of the caregiver's own spiritual journey, and a willingness to accompany other people on their journey. This resonates with Cornette's (1997) Belgian study, and her suggestion that those entering the spiritual domain of patients should have first begun to address their own spirituality. In spite of the care-giver's raised awareness, however, the data suggest there is a personal price to pay for entry into the spiritual domain of the sick. The point is amplified by Frank (1997).

The voices of the ill are easy to ignore, because these voices are often faltering in tone and mixed in message...These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act...in listening for the other, we also listen for ourselves (Frank, 1997:25).

Central to spiritual care is the dimension of love that underpins the relationship between the care-giver and the patient. On a personal level it is freely given and not constrained by time. Within the context of health care, however, attention is also given to service delivery and the efficient use of resources. Consequently, role responsibilities and ear-marked budgets have resulted in a spiritual care service that runs alongside other services, creating a fissure between the spiritually integrated care of health professionals and the specialist care of the spiritual care-givers (Hall, 1997). As with other services, the delivery of spiritual care operates against the backdrop of value for money and the desire to achieve efficiency through a more rigorous approach to performance (Department of Health, 1997). Evidence of difficulties, therefore, may partially be seen in this light: the attempt to deliver both the breadth and depth of spiritual care within the constraints of secular, task-oriented organisations that focus upon activity and outcomes.

Crucial to the delivery of spiritual care is the continuity of customs, rituals and traditions. These present issues for the organisation as a whole. If patients are to receive respect for their religious and cultural traditions, appropriate awareness is necessary on the part of *all* staff. Recent guidance from the Department of Health (1997) on education and training is unequivocal about the acquisition of appropriate skills and knowledge – including an understanding of cultural need. Education consortia, it says, should work with employers and education providers:

...to ensure that staff with the right skills, aptitude and knowledge are available to support all priorities...An understanding of cultural need should be reflected in education and development programmes (Department of Health, 1997:2).

Hopes for the future of spiritual care are underpinned by a desire to do better. The data suggest that in the context of a health care institution, more complete record-keeping would increase the efficiency of the spiritual care service. Within the United Kingdom, the new strategy of information management for the National Health Service (Department of Health, 1998) is important in this respect. With £70 million set aside in 1999 to support new information systems - and £1 billion committed during the lifetime of the strategy - perhaps opportunities may arise to develop greater reliability and more clarity regarding patient spirituality and religious affiliation.

Sections of the data in this study refer to the role of the chaplain. Significantly, whilst the findings acknowledge that spiritual care can be delivered by a wide range of people, chaplains are seen to fulfil a special role. This role is to bridge both the spiritual and the religious; it is also to ensure the delivery of a spiritual care service within the whole organisation. The chaplain, therefore, occupies a number of positions: care-giver, manager, facilitator and co-ordinator. Often working singly or in a small team, it is not surprising that within the contexts of growing, rapidly

changing organisations, hopes for chaplaincy centre around personnel, resourcing, networking and support.

The data confirm the changing demands on chaplains. These arise in part from changes in health service provision (Department of Health, 1997) the extensive programme of re-organisations and mergers (Doncaster and Bassetlaw Acute Trust, 2000), and demands for rigorous action to improve financial stability (Department of Health, 1997). Nevertheless, the last decade has seen a growth in the number of UK chaplains; around 400 are now in whole-time posts and 5,000 in part-time posts (Hospital Chaplaincies Council, 1998). Olumede (1996) suggests the way forward is for chaplaincy departments to expand and become departments of spiritual care, adopting multi-faith foundations and a wider remit.

Such a remit would continue to make provision for religious expression, but would also include research, education, liaison and the provision of resources. However, amidst these changing situations, other voices are anxious to articulate what may be regarded as the essence of spiritual care – the centrality of love. Citing Alastair Campbell (1995), Georgina Nelson writes:

The role of the chaplain continues to be re-shaped in response to current trends. The fundamental challenge remains that of exercising, in a bewildering and rapidly changing situation, the pastoral care which is in essence to help people to know love, both as something to be received and as something to give (Nelson, 1995:77).

## **Concluding comments**

In this chapter, I have outlined the second phase of the research: a phenomenological enquiry into the essence of spiritual care. In spite of Western undertones to the concept of spirituality, a striking feature of this enquiry was that the word was meaningful to all participants, including those belonging to faiths other than Christian. This implies the existence of common ground between faiths and cultures and supports cross-faith, cross-culture dialogue relating to spiritual care delivery.

While the provision of spiritual care is not confined to any single role or group, the fact that all the interviewees were spiritually aware is significant - confirming the view that it appears advantageous for personnel entering the spiritual domain of others to have first addressed the issue of their own spirituality. An integrated approach to spiritual care delivery, therefore, raises questions about the spiritual awareness of staff and the impact of the approach upon recruitment and education policies.

The benefits of a co-ordinated, multi and inter-disciplinary team are propounded. If the role of co-ordinator is subsumed under the role of chaplain, consideration may need to be given to the both scope and resource needs of an expanded spiritual care department. Where this department represents the focal point of an organisation-wide, integrated service, the support needs of caregivers both within and outside of the department will inevitably impact upon these resources, requiring widespread consultation and liaison.

Information – both to patients and from patients - is an issue. The findings identify a concept of spiritual care that responds to *both* the religious requirements of faith *and* the spiritual needs of the non-religious. The issue is how that concept may be communicated to patients: how misunderstandings can be minimised and how confidence encouraged. An

articulation of the institution's understanding of spiritual care, together with details of its policies and practices may prove beneficial in this respect. If this information were to be combined with a more rigorous approach to the collection of patients' spiritual and religious data, the results may lead to a more inclusive and effective spiritual care service.

## CHAPTER 5

### CARING FOR THE SPIRIT: A MULTIPLE CASE STUDY IN FOUR HEALTH SETTINGS

In this chapter, I detail the research undertaken during Phase 3 of the project. A multiple case study sought to determine how the spiritual requirements of patients with cancer are identified and met within the hospice and the acute hospital. Purposive sampling techniques identified two hospices and their neighbouring acute hospitals and a variety of data collection methods comprised the case study. On each site, semi-structured, recorded interviews were conducted with the senior chaplain and a focus group of nurses. Interviews were also conducted with patients (n=10) and, where possible, a matched relative (n=4). A questionnaire sought the views of five nurses on each site. Other data were gathered from unit documents, policy statements and newsletters.

The 26 interviews were transcribed, producing more than 173,000 words of text. NUD\*IST software was used to analyse the interviews of chaplains and nurses. Biographical techniques were used to analyse the interviews of patients and relatives, along with Kellehear's (2000) theoretical framework of spiritual needs. Documentary analysis procedures were used for the texts. Data from the nurses' questionnaires were summarised in frequency tables.

The spiritual needs of patients were identified by a number of formal and informal means. These included checklists, prompt questions, patient observations and reflection upon conversations. Patient narratives indicated the impact of diagnosis upon self and relationships: the rediscovery of spiritual imagery (pentimento), personal re-assessment and new beginnings. Only 1/10 patient described herself as religious, yet all believed in God, 7

prayed and all sought connectedness. Each service attempted to make patients aware of their spiritual care provision and how that provision might be accessed.

Attempts were made to meet spiritual needs by providing physical resources (such as a chapel or multifaith room), and human resources (such as a chaplain, chaplaincy volunteers or spiritual healers). Within all institutions patients in the study came into contact with spiritually aware personnel: staff and volunteers who had undertaken training in the spiritual dimension of health care. Worship, sacraments, prayer and rituals were routinely available. Each institution attempted to create a spiritual ethos through notions such as 'valuing the individual' and 'helping the patient to find meaning'. In each case, support was available to staff through education and training. Documentary support included multifaith guidelines and caring for the dying and the bereaved.

These findings point to i) a spiritual dimension amongst non-religious patients, together with ii) a greater awareness of spirituality iii) a broader ownership of spiritual care and iv) a higher level of spiritual activity than is generally acknowledged within health care literature.

The constituent parts of the case were different and unique. I list below my reflections upon each of them.

*Hospice 1: 'hospice in harmony'*. My overall impression of this hospice resonates with the words of the medical director when he referred to the newly commissioned chapel: that it should be 'in harmony' – accessible to all. The altar cross seemed emblematic of that harmony: crafted by a Hindu, presented to Christians, removable to accommodate other faiths.

The quest for harmony seemed to underpin the whole setting. It showed itself in the easy relationship between the secular and the spiritual - the way people drifted into the chapel for 'oasis', an inclusive time of stillness and reflection. It was also apparent in the confidence expressed in the management team; in the mutual support of team members and – without minimising the difficulties – the clearly expressed rewards of the job. In the words of a patient 'the spirit of the place gets to you – it builds you up and gives you a reason that you can still enjoy the rest of your life'. A case of spiritual harmony in a secular setting.

*Hospice 2: 'an edge for the Church'*. I consider the special character of this hospice to be summed up in the words of the spiritual care director: that it represents 'an edge for the Church'. The hospice is a tangible, outward-looking engagement between the Roman Catholic Church and a critical area of life. As such, it provides an appropriate context for the mission of the founding sisters - to be with people in the deserts, on the frontiers and on the peripheries. Others are invited to share in that mission, to cluster freely around common concerns for the dying - of any faith and none – but set against the clear backdrop of the Church's vision and ministry. That vision is plainly evident in the literature, practices and ethos of the hospice.

*Hospital 1: 'empathy with the elderly'*. I found the defining characteristic of this case to be its focus upon the elderly. Both interviews were conducted with elderly patients. The practices and ethos of the ward were shaped by the needs of the elderly. The palliative care link-nurse was trained in the care of the elderly.

Within this scenario, spiritual care related to the patient's situation in life. Reminiscence played an important part. The husbands of both patients interviewed for this study had died. One patient had no surviving family



and received no visits; the children of the other lived a great distance away. Companionship, 'being there' and spending time with the patient were seen as important. Although the days could be busy, night-time provided opportunities to talk. Both patients were known to the chaplaincy department and both were visited by its staff.

*Reflections: 'activity amidst uncertainty'*. My overriding impression of this case is the high level of activity on the surgical ward - and the feelings of apprehension and uncertainty on the part of patients, interviewed for the present study. One patient had lost her faith; the other was afraid that a recurrence of her cancer would have to be kept secret from her bereaved father.

These features of ward life were well known to the staff. In such circumstances, spiritual care frequently took the form of listening, clarifying, explaining and discussing. For the dying, more time was made available. Expertise in the care of the dying was gained through special training and links with the neighbouring hospice. In the context of this large institution, information about spiritual care has become a high priority. Use is made, therefore, of chaplaincy leaflets, posters, videotapes and cassettes. Spiritual care is a joint enterprise that includes members of staff, visiting ministers and chaplaincy volunteers: more activity in the midst of uncertainty.

## **Methods**

*Objectives.* The closing years of the twentieth century saw a growing debate about the nature of spirituality in late modern culture (Frankl, 1959; Ferrucci, 1993; Renault and Freke, 1996; Sweasy, 1997; Moody, 1999; Sheldrake, 1999; Singh, 1999). This debate impacted generally upon health care systems and on palliative care in particular (Harrison, 1993; Elsdon, 1995; Speck, 1998). It contributed to a view of spirituality that has become dislocated from religion (Walter, 1997), that acknowledges transcendence (Reed, 1998), yet is difficult to define (McGrath, 2000). Within health care, such a spirituality presents significant challenges, as patients are confronted by ultimate questions that accompany suffering and death. These questions – arising at times of crisis – offer challenges to individual beliefs, to a sense of purpose, and to the understanding of what it means to be human.

Within this scenario, evidence suggests that the confidence of health professionals to enter the spiritual domain of patients appears to be waning. (Golberg, 1998). Even chaplains seem unsure about their role - a finding underlined by Helen Orchard (2000) in her London study of hospital chaplaincy. It is unsurprising, then, that Mark Cobb (2001), in a wide-ranging analysis of spiritual care at the end of life, calls for more consistency and training, together with a more integrated approach to spiritual caregiving.

In the light of this changing health care environment, the concluding phase of this study seeks to discover how the spiritual needs of patients with cancer are identified and met within the acute hospital and the specialist inpatient palliative care unit.

*Case study research.* This enquiry uses a multiple case study approach to explore the issue of spiritual care in four health settings. As we have seen, Cresswell (1998) points out that a 'case' may be regarded as either an object of study (see Stake, 1995) or a methodology (see Merriam, 1998). Within both approaches, the case study is an exploration of a 'bounded system' through in-depth data collection that involves multiple sources of information. These multiple sources may include observations, interviews, documentation and physical artefacts (Yin 1989). Account is also taken of the context of the case. This involves situating the case within its social, historical or developmental setting and may include a chronology of major events. A multiple case study will utilise both within-case and cross-case analysis techniques.

*The cases.* Purposive sampling identified two hospices and their neighbouring acute hospitals. These institutions were selected on the basis of location, ease of access, the proximity of the hospice to its neighbouring hospital, and the nature of the institutions. Hospice 1 was a 16-bedded secular unit; hospice 2 was a larger, 36-bedded unit with a religious foundation. Hospital 1 was a district general hospital located near hospice 1; hospital 2 was a university hospital located near hospice 2. The four institutions provided an interesting mix of differences and similarities. The entrances to hospice 1 and hospital 1 were within 100 metres of each other. The hospital's palliative care physician was the hospice's medical director. Both institutions served the same community. Hospice 2 was one of two hospices within the same city, located some three miles from the university hospital. This hospital was part of a trust containing some 3,200 beds. Coincidentally, both hospitals had their roots in nineteenth century institutions: hospital 1 in an asylum for the lunatic poor, hospital 2 in a school to house the workhouse children.

*Data collection: interviews.* Within each case, semi-structured, recorded interviews were conducted with the senior chaplain and with a focus group of nurses. Occasionally, others were interviewed. These included: the medical director of hospice 1 - who had a special interest in spiritual care; the manager of a cancer centre located in hospital 2; and a 'spiritual healer' who practised regularly in the cancer centre.

Interviews were also conducted with patients and, where possible, a matched relative. Numbers were as follows: *hospice 1* n=2 patients, 2 relatives; *hospice 2* n=4 patients, 2 relatives; *hospital 1* n=2 patients 0 relatives; *hospital 2* n= 2 patients, 0 relatives. Unfortunately, it was not possible to interview relatives of the hospital patient subgroup, due to the absence of relatives (n=2), the discharge of the patient (n=1), or the withholding of permission (n=1). The patient sample was drawn in accordance with the following inclusion criteria:

#### Hospice 1 and hospice 2

- Patients over 18 years of age
- Who had a cancer diagnosis
- Who knew their diagnosis
- Who were willing to be included
- Who were deemed well enough to be included

In addition:

- participants in hospital 1 to be medical patients
- participants in hospital 2 to be surgical patients

*Aides memoir* informed the structure of the interviews. Chaplains were asked about their understanding of spirituality and their views on spiritual care (Table 14).

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**Table 14**                      **Interview guide: chaplains**

---

- |   |   |
|---|---|
| 1 | What do you understand by the word spirituality?  |
| 2 | Why do you think patients sometimes bring forward spiritual or religious needs when they come into hospital/hospice?                              |
| 3 | How do you think spiritual needs might be identified or assessed?   |
| 4 | How would you define spiritual care?  |
| 5 | What do you think are the main ingredients of spiritual care?   |
| 6 | Who are the spiritual caregivers?   |
| 7 | How does your role relate to the spiritual care of patients?  |
| 8 | What do you think are the main difficulties in the area of spiritual health care?   |
| 9 | If you could select one thing from your wish list within the spiritual domain that could come true during the next 12 months, what would that be? |
- 

Nurses were asked about their understanding, training and experience in the spiritual care field (Table 15).

---

**Table 15**                      **Interview guide: nurses**

---

- |    |  |
|----|--|
| 1  | What do you understand by the term holistic care?  |
| 2  | What do you understand by the term spiritual care?   |
| 3  | Who do you think are the main spiritual caregivers?  |
| 4  | What do you think are the main ingredients of spiritual care?  |
| 5  | In what ways might spiritual care relate to the nursing process?   |
| 6  | What sort of attention was given to spiritual care issues during your pre-registration training, and since qualifying? |
| 7  | Do you feel well prepared in the area of spiritual care?   |
| 8  | In what ways are you personally involved in the identification of spiritual needs and the delivery of spiritual care?  |
| 9  | What sort of spiritual needs come to the fore most frequently?   |
| 10 | What do you think are the main difficulties in the area of spiritual health care?                                      |
| 11 | Are there any suggestions you would like to make about how spiritual needs are identified or spiritual care delivered? |
-

Patients were asked about their fears, their sources of strength, their beliefs, religious practices and hopes for the future (Table 16).

---

**Table 16** Interview guide: patients

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- 1 Where are you from?
  - 2 Have you a family?
  - 3 What did you do when you were working?
  - 4 What are your interests?
  - 5 What's brought you into the hospital/hospice?
  - 6 What's it like to be a patient?
  - 7 Would you describe yourself as a religious person?
  - 8 Do you believe in God?
  - 9 Do you ever pray?
  - 10 Have you prayed more/ thought about praying since becoming ill?
  - 11 What has bothered you most about being ill?
  - 12 Has your illness had any affect upon your beliefs or your views?
  - 13 Where do you find your strength and support?
  - 14 What has helped you most?
  - 15 What do you hope for?
  - 16 What do you want most from people just now?
  - 17 Is there anything else you would like to share with me?
- 

Relatives were asked similar questions, but also how they managed to stay supportive and their perceptions of what proved helpful (Table 17).

---

**Table 17** Interview guide: relatives

---

- 1 Would you mind telling me how you're related to (N)?
  - 2 How frequently do you visit?
  - 3 What's it been like for you since (N) came into hospital/ hospice?
  - 4 What bothers you most about (N)'s illness?
  - 5 How have you managed to stay helpful and supportive?
  - 6 Where do you find your own strength and support?
  - 7 Would you describe yourself as a religious person?
  - 8 Do you believe in God?
  - 9 Do you ever pray? Have you thought about praying?
  - 10 Has (N)'s illness had any affect upon your beliefs or your views?
  - 11 What do you think has been helpful to (N) since s/he became ill?
  - 12 What are your most important things in your life just now?
  - 13 What do you hope for?
  - 14 What do you want most from people just now?
  - 15 Is there anything else you would like to share with me?
-

*Data collection: questionnaires.* Information from 5 nurses was gathered by means of a questionnaire. Questions of policy and documentation, religious and non-religious spiritual care were the same as in the questionnaires used in the Phase 1 survey. However, question 1 sought information about the length of service, religious and non-religious spiritual care, about spiritual care training, and about how comfortable nurses felt within the spiritual domain of patients.

## Figure 5 NURSES' QUESTIONNAIRE

### Question 1 These questions are about yourself and your training

Please tick the boxes that apply

1(i)	Do you work in a hospital or a hospice?	Hospital?	<input type="checkbox"/>	Hospice?	<input type="checkbox"/>
		Years	Years	Years	Years
		0-9	10-19	20-29	30-39+
1(ii)	How long have you been nursing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Very prominently	Quite prominently	Hardly at all	Not at all
1(iii)	How prominently did spiritual care issues feature in your initial training?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Very prominently	Quite prominently	Hardly at all	Not at all
1(iv)	How prominently have spiritual care issues featured in your post registration training?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Frequently	Occasionally	Rarely	Never
1(v)	How frequently do you consider yourself to be involved in the spiritual care of patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Very comfortable	Quite comfortable	Quite uncomf'table	Very uncomf'table
1(vi)	How comfortable do you feel approaching the spiritual domain of patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Data* Question 1(1) provides interval data

Question 1(ii) to 1(vi) provides ordinal data

*Rationale* These items were devised to facilitate a comparison of the perceptions of training and spiritual caregiving amongst a small group of nurses within each institution.

*Literature* The construction of these items is based upon the following literature that comments upon nurse education and activity within the spiritual domain of patients:

- Narayanasamy (1993)
- Ross (1994)
- Elsdon (1995)
- Golberg (1998)

*Data collection: documents.* Documents provide a valuable source of data that corroborate evidence from other sources. Time was allocated for a systematic search for documents within each setting. Requests were made to unit staff for assistance in tracing documents that were of interest. As a result, data were gathered from unit documents, policy statements, newsletters and posters; from booklets of prayers, quotations and texts; from care plans and patient notes.

*Data collection: the landscape.* A field visit gives the opportunity for first hand experience of the case study site. This experience is influenced by the site's location, structure, furnishing, displays and decoration: the ambience it creates. Account was taken, therefore, of the 'symbolic landscape' of the unit. Observations were recorded in field notes and photographic records were made of interesting items.

*Analysis.* Data were analysed using a variety of procedures. The 26 interviews – from patients, relatives, chaplains, focus groups of nurses and other health professionals - were recorded and transcribed, producing more



than 173,000 words of text. NUD\*IST software was used to analyse the interviews of chaplains and nurses. These procedures were the same as those used during Phase 2.

Biographical techniques relating to oral histories were used to analyse the interviews of patients and relatives. These procedures left the interview intact, as a life history. Note was taken of chronological events, the turning points of individual lives, and the meanings associated with illness. In addition, the theoretical model of spiritual needs proposed by Allan Kellehear (2000) provided a framework within which the spiritual needs of patients were viewed and articulated, thereby assisting triangulation.

In essence, Kellehear's model links the notions of transcendence and spiritual needs. Based on the idea that human beings have a desire to transcend their suffering and find meaning, he suggests that spiritual needs prompt different types of transcendence. Hope, purpose, affirmation, connectedness and social presence may lead to what he calls situational transcendence. The need for peace, reconciliation, reunion, prayer, moral and social analysis, forgiveness and closure may lead to moral and biographical transcendence. The need for religious reconciliation, divine forgiveness and support, religious rites and sacraments, visits by clergy, religious literature and discussion about God, eternal life and hope, may lead to religious transcendence.

Documentary analysis procedures were used for the texts. The criteria for analysis related to the two objectives of the study: how the spiritual needs of patients were identified and met.

Data from the nurses' questionnaires were summarised in frequency tables.

## Four case studies

*I need to be a human being. I need to be loved – even just to be spoken to nicely. I don't want no special attention. I just want the attention that I get to be given genuinely – a little bit of love, that's all I ask for, don't ask for anything else. Patient E*

### *Hospice 1*

Located on the outskirts of a city, this hospice opened in 1980. Standing in an elevated position, it looks over green fields towards the site of a former colliery, now razed and cleared. It is a single story building, set amongst lawns and flowerbeds. Inside the door, a chapel contains artefacts and symbols: some are Christian, some from other faiths. On the altar stands a cross of equal proportions, hand crafted by the medical director. The day centre is to the left, the ward (16 beds) to the right.

A booklet for patients gives information about the hospice. This information includes details of chaplaincy, worship, and times for reflection. A chaplaincy leaflet offers a service to all, irrespective of faith. Items about chaplaincy feature in the hospice newsletter – a recent edition containing an article about student placements and training links with a theological college. On the chapel wall hangs a mission statement. Booklets containing prayers and texts are freely available in all parts of the hospice. Staff have information concerning on-call chaplains, urgent referrals and how to conduct emergency baptisms. A guide to spiritual care focusses on 10 relevant categories. These include 'religion', 'finding meaning', and 'death, dying and bereavement'. A 'Guide to Faiths' identifies the festivals of major religions and includes information on diet and ablutions. An instrument for use in spiritual assessments focusses on categories of statements, such as: 'to fulfil my religious needs I would like to pray/ to be prayed with' and 'there is meaning to my life through my family and friends'.

The medical director is consultant physician at the neighbouring acute hospital. He helped to plan the hospice after working in the hospital-based palliative care team since its inception in 1979. A Hindu, he describes himself as 'a believer who is actively seeking answers'. Consequently, the spiritual dimension of care features prominently in his thinking:

I was very keen that the fourth element of care should be spiritual, but not necessarily fourth - and it should be changing rank as needed. So now we have a set-up where we would discuss the patient, and the chaplain may be the primary carer, in that sense, for a short time.

Spiritual assessment is intended to be a team activity. Consequently, spiritual awareness is sought amongst doctors at the time of appointment, when candidates are invited to outline their perceptions of whole-person care. Such care is supported by a spiritual assessment tool - broadly accessible to a wide range of staff - and regarded as crucial to the attainment of a spiritual care standard. To help make that standard available to patients of all faiths, the architect was asked to design a chapel that was 'in harmony', but which could be transformed into a Muslim or Jewish place of worship 'within minutes'.

The chaplain belongs to the Methodist tradition. He entered palliative care after a student placement taught him that hospice 'was a place of laughter, joy and life'. Believing that everyone is a spiritual being, he seeks 'to respect where people are', and to promote spiritual care as a team responsibility. To that end, he is committed to a programme of education. He seeks also to encourage an awareness of patient spirituality during daily routines such as bath time. Hospice work is regarded as 'the front line of ministry to the unchurched': a ministry that allows patients to be angry, to talk about death and - if they so wish - to explore the Christian concept of hope. The chaplain's immediate hopes centre around an education

programme for medical students, and the development of a nationally accepted spiritual assessment tool. A member of the National Executive of the Association of Hospice Chaplains, he also hopes to exert a national influence on the development of chaplaincy.

In relation to the chaplaincy styles itemised in Figure 1 (Chapter 1 above), the preferred style of this chaplain falls within Quadrant 4: institutionally embedded with an incarnational view of praxis. The chaplain identifies strongly with the institution; an environment in which he feels 'welcomed and valued'. He regards it as 'a place of joy, a place of living', and feels privileged to be part of the multidisciplinary team. The role of spiritual caregiving is shared with others in the institution, and he himself provides a spiritual care service to doctors, nurses and other staff. As a result, the hospice is regarded by the chaplain as a 'spiritual institution'.

At the time of the study, the chaplain worked half time in local ministry and half time in the hospice – a situation that changed to full time within the hospice as the number of inpatient beds increased from 8 to 16. He took the view that spirituality related to 'the essence of who we are', and expressed the view that all people are spiritual beings who eventually seek answers to the big questions of life. Significantly, he felt that parochial ministry had come to meet the needs of those who go to church, rather than the generality of people in the community. Consequently, he does not wear a clerical collar, but approaches people as a 'spiritual being' himself, facing the implications of his own mortality, 'with the religious bit in the background'. He does not, therefore, speak about God unless the patient does, and feels a special relationship with those who do not go to church or believe in God.

All 5 nurses completed the questionnaire. Each nurse had more than 10 years' nursing experience. Three nurses had more than 20 years'

experience. All respondents felt they were frequently involved in the spiritual care of patients. Four nurses felt either very comfortable or quite comfortable giving spiritual care; 1 nurse felt quite uncomfortable. All nurses thought patients frequently required someone to listen to them, someone to 'be there' for them (see page 108 above for the meaning of this term), and someone to provide information. In addition, all respondents thought that patients frequently wished to address spiritual issues around pain, suffering, concern for relatives and death and dying. Worship (3/5) and holy communion (3/5) were seen as the most frequently required aspects of religious care.

Within the focus group, nurses found the team approach rewarding. So was the opportunity to give 'the best care possible' at the end of life. Spiritual care occupied a minimal place in pre-registration training, but had since been provided within the hospice movement. Some training had also been provided by the chaplain of the district general hospital (hospital 1). There was a consensus that religious care was not the same as spiritual care, and that religious needs (to receive the sacrament, for example) should be seriously addressed. A preference was expressed, however, for a low religious profile overall. According to the nurses, spiritual care was enhanced by the benefit of time. If a patient needed to talk, therefore, there was time to listen. Time was also available to support family members.

In the sections that follow, data is presented from the interviews of patients and relatives. Ten patients were interviewed. To preserve anonymity, they are referred to by a letter (A to J) and a pseudonym. In order to maintain a balance, I present biographical data from only 8 patients here, 2 patients from each setting. In the second part of this chapter, however – the cross-case analysis – all 10 patients are treated as one group.

Patient A – ‘Arthur’ – is 53 years old. He was interviewed 2 days after his admission to hospice (Appendix 17, 18). Arthur has never married, though lives with ‘Karen’, his partner of 12 years. He originally worked in his father’s shop before entering university and taking an Arts degree. After graduating, he taught English to adult learners. A talented and creative man, Arthur had a long involvement with local theatre and played bass guitar and keyboard in numerous bands. Though previously in good health, he now has cancer of the bladder – a diagnosis that ‘shocked’ him. During treatment in hospital, he formed the view that there was ‘inadequate support’ for him there, but anticipates that within hospice he will receive more individual attention.

Arthur was brought up within the Church of England, sang in his Church choir and was confirmed within the faith. As a young man, he ran a youth club and put on shows for its members. Eventually, he became disenchanted with the Church and left. ‘It’s not religion that I fall out with, but the way that it’s organised’, he explained. While Arthur is careful about how to interpret the word ‘God’, he nevertheless believes in something greater, a ‘larger being’ that in some way incorporates the ‘totality of humanity’. He never prays.

As Arthur confronted his mortal self, he struggled with its implications. ‘I’ve accepted that, you know, we’re all going to die eventually, the only thing I find difficult to accept is how that impacts upon other people’. As Arthur found the pain of that impact increasingly hard to bear, he asked members of his wider family not to visit him again, for he could not accept the burden of their grief. He wished also to come to an accommodation with Karen:

She was obviously devastated by (the news) and she said, you know – I suppose the usual things - ‘I love you’ and ‘don’t want you to

go' and things like that. And I had to really say to her, well that's not what I want. I don't want you to be saying how much you're going to miss me, how much you want me to get better, how much you'd like to do things – because that makes it worse for me. If I know that we could both accept together that this is inevitable, and we just try and make the most of whatever else is left for us and not get so emotional about it – I'm sure that would make it easier for me.

Karen, however, was contemplating the future without a relationship within which she'd flourished. A divorcee, she explained how she never 'grew' with her first husband, but that with Arthur, it was different: 'he's such a strength, he's just let me be, and he's such a pleasure to live with'. Past experiences, however, returned to trouble her, not least those concerning the Church. Raised as a devout Catholic, she felt the Church had abandoned her during the breakdown of her marriage. She also felt a residual resentment amongst her family. As the crisis around Arthur's health deepened, her feelings of ambivalence emerged:

We never really wanted to get married because we felt that, I suppose, our relationship was OK as it was - and I'd been married, and - I'm steeped in Catholicism, that's the first thing, steeped in it – I don't practice now, although I do – well, we've just had a family party, and our family parties always start with mass - so it's still very much part of my family. How did I get on to that? But – so there was quite a lot of pressure to marry, and I suppose me mum still thinks that I committed adultery or something.

Karen also confessed to mixed feelings about hospice. After the hospital experience she found hospice a welcome refuge but was terrified at the prospect of what was to come:

It's nice to come here (hospice). It's about respect and dignity, and – so that's lovely - but it's not going to be for long, is it? I get myself into this nice cosy routine and I'm absolutely scared stiff. I

– I don't know what to do when Arthur dies. I've no idea. I'm absolutely useless, and so that worries me, you know - the practicalities of what you do when someone dies - and I know that's going to happen, you see. So – so in a sense you think 'don't get too cosy 'cos there's something coming up that – that I'm really worried about, (crying) and I don't know how I'm going to cope with it.

When Arthur was admitted, it was recorded in the notes that he was a non-practising member of the Church of England. A subsequent note indicated that Karen asked for an appointment with the chaplain. An entry from the chaplain states that a meeting took place between himself and Karen, and that during the meeting, many issues emerged that had been troubling her. Arthur died the following day - 6 days after the research interview. It was a surprise when Karen rang to ask if I – in my role as minister - would conduct Arthur's funeral service. She said it was what she and Arthur both wanted. Since neither of them were associated with a church, they wished someone to conduct the service who knew Arthur. Both felt the interviews had fulfilled that purpose.

Patient B – 'Ben' – is 71 years old. As a young man, he worked down the mines before joining the army and signing up for the Royal Electrical, Mechanical and Engineering Corps (REME). When he left the army, Ben spent the rest of his working life maintaining machinery at a College of Further Education. He eventually took early retirement due to arthritis in his knee. Shortly before he retired, his life changed dramatically when his wife became ill:

Three year after she took retirement, she died of cancer, the bugger. Of course, that shattered me. We were really compatible. I never went out of the house for over a year. Anybody who started saying ow't to me, it weren't long before I got the old crying session out.



Ben now has lung cancer. As he lives alone, he occasionally finds it hard to cope. A former policeman who lives next door has befriended Ben and undertaken the role of informal carer - overseeing Ben's well-being and answering his personal alarm when he needs help. Whenever Ben's spirits become low, he acknowledges the special role played by the hospice: 'the spirit of the place gets to you - it builds you up and gives you a reason that you can still enjoy the rest of your life'.

Having read and travelled extensively, Ben likes to talk about his experiences: about his visits to the Caribbean and Alaska, about sailing up the Yangtze and diving in Bali. He claims to be 'interested in everything and can talk about anything'. That talk includes a dialogue with his genes. 'I get them by the scruff of the neck, give 'em a good shake and tell 'em what their job is'. That job is to locate and destroy the cancer cells in his body:

I'd explain to them everything I know about these cancer cells, and I've told them, I says, anybody you see like that, put your hand out, grab his shoulder and murder him, and it don't matter whether it takes you, or four more like you, to commit suicide murdering him, your sole purpose in life is to protect me. Make a name for yourselves!

Ben never feared a struggle. He had pride in both his physical prowess and his ability 'to look after himself'. Weight training and running were lifelong activities; muscle tone and body image important. He illustrates his attitude in the story of a bar-room fight that occurred shortly before he became ill. Though in his sixties, his patience snapped when a younger man persistently provoked him.

I don't usually waste words saying anything, so I just went *bum, bum* - split all his eye open top and bottom and I just stood there like this, waiting for him - cos I'm a counter puncher. It all came back, just like riding a bike.

Ben's current physical state contrasts sharply with that of his former self. It is a painful loss. 'I get breathless of a night time' he says 'and came in here (hospice) because I could hardly stagger round the house'. Facing the future, Ben has put his affairs in order, attending to every detail. He's even 'sorted and paid the undertaker'. He has also recruited the chaplain to take his funeral service, 'rather than some stranger'. Personal effects have been left to the hospice to raise funds.

As a boy, Ben was brought up within the Church of England, eventually becoming confirmed. He has a strong belief in God, but describes himself as 'not religious'. He regards prayer as a pointless activity - so he never prays. No miracle cure is expected, but Ben does wish to enjoy the time he has left. He does have fears, however:

the only fear I have is if I suddenly got a right lot of pain, that's the only problem - and the fact that they might have to drug me to such an effect I didn't know what time of day it were. You couldn't enjoy your life then, could you? You couldn't read or couldn't watch television or ow't like that. I want to enjoy my life, not be laid asleep all the time.

'Malcolm' - Ben's next-door neighbour and carer - has provided increasing support since Ben became ill. During the interview, he acknowledged that Ben can be both 'cruel and rude' and confesses that neither his wife nor his children like him. He will not withdraw his help, however. That is partly because Malcolm feels he understands Ben's suffering. His own daughter was cared for in the same hospice as Ben, dying at the age of 25 from cancer of the cervix. During that time, Malcolm found support from within his family - the kind of support that Ben does not have:

I thought, I can't leave that man on his own. There was no-one else going to come and see him. I am not going to drop him now like I would drop a hot brick. When I came to see him (in the hospice), the way he had changed reminded me of how much

good they had done for my daughter. So when I am going, Ben says 'see you later Malcolm' and he knows that I'll be back, and he's got something to look forward to – whereas before, we were over-the-garden-fence friends, we are now very close friends.

Malcolm has a strong Catholic faith. He believes in God and prays every day - but broke away from the Church in his mid thirties. When his daughter became ill, he first hoped for her recovery, then for peace. As the pain became severe, the second hope became more prominent. Malcolm's first hope is that Ben may recover, although he knows that in reality it is not going to happen. Nor can Ben cope at home any longer. Discussions are under way, therefore, for Ben to enter a nursing home – somewhere nearby, where Malcolm can visit.

The notes confirm that Ben talks openly about his death, has arranged his funeral and made his will. They also record that Ben will not inform anyone about his pain unless it becomes unbearable, since he wants to know what is happening to his body. Ben was discharged to a nursing home, where he died 6 weeks later. The chaplain conducted the funeral service, as Ben had requested.

*Reflection: 'hospice in harmony'.* My overall impression of this hospice resonates with the words of the medical director when he referred to the newly commissioned chapel: that it should be 'in harmony' – accessible to all. The altar cross seemed emblematic of that harmony: crafted by a Hindu, presented to Christians, removable to accommodate other faiths.

The quest for harmony seemed to underpin the whole setting. It showed itself in the easy relationship between the secular and the spiritual - the way people drifted into the chapel for 'oasis', an inclusive time of stillness and reflection. It was also apparent in the confidence expressed in the

management team; in the mutual support of team members and – without minimising the difficulties – the clearly expressed rewards of the job. In the words of a patient ‘the spirit of the place gets to you – it builds you up and gives you a reason that you can still enjoy the rest of your life’. A case of spiritual harmony in a secular setting.

### *Hospice 2*

Located in the city suburbs, this hospice is named after a saint. It was opened in 1978 by an order of Catholic sisters in response to local need. A convent is included in the accommodation. Originally, there were 9 beds, but extensions were added in 1982 and a study centre opened in 1991. It now has 26 beds. Building work is in progress that will add a further 16 single rooms and 4 additional 4-bedded rooms. A statue of Christ - with arms outstretched – is positioned over the main door. A chapel is situated inside the front entrance. The director of spiritual care (chaplain) explains how the Catholic tradition blends with hospice care:

it's like the backstage curtain to a theatre performance, and the Catholic tradition is the backstage curtain, but the people on the stage are from all walks of life and from all manner of belief systems, but the unifying thing is they all want to be involved in palliative care service, and they all want the quality of care for the patient and that's it - we're coming together around that

Attempts are made to recognise other faiths and traditions. The foyer has a notice saying welcome in 17 different languages. Displays are mounted in the reception area to acknowledge the festivals of non-Christian religions (such as Diwali and the Passover). A room has been set aside for use by members of other faiths. Islamic and Jewish advisers have been appointed; so have Jewish volunteers.

The spiritual roots of the hospice are evident in its publications. A biography of the order's founder includes information on the work of the sisters. A leaflet explaining the newly-adopted logo states that it 'represents the Christian foundation of the hospice and the interdependence that lies at the heart of the interdisciplinary team'. A history of the hospice contains a prayer on its centre pages, which asks that its staff 'may be filled with your spirit of love'. Booklets commemorating the hospice's 20<sup>th</sup> anniversary outline a project that produced a mosaic for each of the 20 years of its existence. One mosaic is entitled 'Fish' - noted as 'a sign of Christianity from the days of St Peter'. A recent newsletter devotes a whole page to spiritual care, highlighting the diverse nature of spirituality and approaches to it within the hospice. Near the foyer, a wall rack contains over 100 leaflets that give information on issues such as bereavement, living with loss and finding peace. Literature containing prayers and religious texts are prominently displayed - found all around the hospice as well as in the chapel. On the wards, information is available concerning the needs of faith communities. A publication entitled '*Spiritual needs in palliative care*' acts as a reference point for staff. Written by the spiritual care director, it contains the hospice mission statement and philosophy of care; it also offers guidance on spiritual distress.

The director of spiritual care has worked at the hospice for 3 years and is a member of the founding religious order. She suggests that her role resonates with her own spiritual journey, her sense of vocation and the mission of the sisters: to be in the deserts, on the frontiers and on the peripheries. 'Death is a frontier, and many people find themselves in a desert-type situation in themselves'. Working with the dying is considered to be special. Within hospice, spiritual care begins with 'respect for the person, recognising their identity and culture and history'. The care of staff also features prominently, both to support the care of patients and to create space for personal

reflection. Consequently, a 'spirituality forum' and a series of 'psycho-synthesis weekends' have been established. These run alongside other forms of support such as de-briefing and education. Hopes for the future are to create more quiet spaces, to become more inclusive, and to ensure that all multidisciplinary team members feel confident talking about spiritual issues.

The chaplaincy style of the spiritual care director falls within Quadrant 4 of Figure 1 (see Chapter 1 above): institutionally embedded with an incarnational view of praxis. Although she is the only sister currently on the staff, five sisters of the founding order serve on the board of directors. She lives in the on-site convent and speaks of her generic role that seeks to facilitate 'some kind of integration' for everyone within the hospice. In addition to education, her role makes a contribution to the institution's management of stress and incorporates networking on the hospice's behalf with community groups and members of the local faith communities.

With regard to praxis, spiritual caregiving in a hospice context is regarded by the director as 'an edge for the Church': a form of outward-looking engagement in a critical area of life. She considers such care to be less concerned with religion and more about 'whether you can sleep in your bed at night'. Though providing rituals for those who think them important, the director is generally concerned with a broad range of spiritual needs. As a result, uniqueness is celebrated; other faiths acknowledged; advocacy undertaken; and special moments facilitated - an approach that seeks to recognise both the spiritual dimension of life and the shared woundedness of human beings.

Of the 5 nurses who completed the questionnaire, 4 had more than 10 years' nursing experience. One nurse had more than 20 years' experience. Three

respondents felt they were frequently involved in the spiritual care of patients. One nurse thought she was only rarely involved. None of the nurses felt very comfortable in the spiritual domain; 4 nurses felt quite comfortable, and 1 nurse felt quite uncomfortable. All nurses thought patients frequently required someone to listen to them; 4 felt patients frequently required someone to 'be there' for them, and 3 nurses thought patients frequently required someone to provide information. All respondents thought patients most frequently wished to address spiritual issues around concern for relatives. Holy communion (3/5) was seen as the most frequently required aspect of religious care.

Within the focus group, nurses outlined the attempts made by the hospice to address the religious needs of patients. At the initial assessment, patients were asked about their religion - whether they were practising or non-practising; about their relationship with their local church; and about any desire to see their own priest, to receive the sacraments or to attend mass. The nurses felt strongly that the spiritual encompassed more than just the religious, embracing questions about the meaning of life and what one's own life means and has meant. Many people worry about how their family will cope after they themselves have died. These issues may be raised with doctors when patients are asked about their future hopes, or what they want from the hospice. Spiritual care, therefore, allows for the expression of individual needs and for reflection upon guilts and regrets, since 'those people that have spiritual peace often die in a more relaxed way than those who don't'.

Nursing within hospice was seen to be different from nursing within the acute sector. With more time to listen, it was possible to get closer to patients. Consequently, patients were thought to talk more and trust more. There was less denial. One nurse said:

I had a lady say to me once that she was looking forward to hers (death) because she said 'when I die I'm going to see it as a door opening and when the door is open, it's going to be full of colours, and do you know, I haven't seen them colours for a long time'. And I think she was describing how ill she'd been, so when she dies it's going to – yeah, she's going to feel that relief and see all colours.

In some ways nursing was seen to be less stressful than in the acute sector where curing and caring ran side by side. Yet pressures did exist – around difficult questions and the deaths of younger patients; around those who died before a relationship could be established, and around those who did not have a 'good death'. At such times, reflective meetings, the presence of the team and personal peace were very helpful. Future hopes centred on more funding, the extension of home care and the possibility of hospice for all.

Patient C – Christine – is 62 years old. She was born in Scotland and belonged to a family of 14 children. When her father became unemployed, he looked for work in England, bringing the whole family with him. Christine has lived locally for 40 years. She has 3 children from her first marriage and 2 children from a second relationship – with a man who became physically abusive towards her. 'He beat me up - and he's been dead nearly 10 years, which I don't miss him' she says. He died of cancer. Christine now has cancer of the rectum.

Afraid of seeing her GP, Christine delayed making an appointment for 2 years. 'I had an idea that I had cancer', she says, 'but I denied myself it'. She now believes she suffers as a result. While she has hopes of living 'a few years yet', she says, 'I'm not afraid of dying - I know that I am'. As she reflects upon her life, Christine regrets a number of things: leaving her husband, entering an unfulfilling relationship, losing contact with her



children and stepchildren. She now thinks that some responsibility may rest with herself and with her life-long inability to express her emotions. Significantly, as her illness has progressed, Christine's relationship with her youngest daughter, June, has improved and developed: 'I could never show me feelings, but this last fortnight when she's 'phoned I've told her I love her'.

During her hospital stay, Christine was unhappy, feeling that staff had little time for her. Since moving to the hospice, she was very pleased to find a different approach. 'The nurses are fantastic - they'll sit and chat to you'. Christine is not religious, but gains strength from her faith in God: 'he giveth and he taketh - he's there at the end for you'. She prays every morning and evening - more than she used to before becoming ill - and finds that she needs the help of God to get through each day. She believes in an afterlife, though asks that she might have a bit more time on earth. She hopes very much to go home.

Christine's daughter, 'June', is a team leader in a finance company; her son-in-law, 'Malcolm', builds computers. Together, they organise their work routines to care for Christine when she is at home and visit her every day in the hospice. They are critical of the care she received in hospital and for that reason, 'wouldn't give hospital staff houseroom'. They acknowledge the staff are over-worked and there were shortages on the wards - yet feel they received few answers and fewer courtesies: 'they won't even give you the time of day'. Within the hospice, however, the difference was very marked. Requests were dealt with and questions were promptly answered, so there was 'not a bad word to say'. June demonstrated her appreciation by undertaking a parachute jump for hospice funds.

Having seen her father die of cancer, June is fearful for her mother's future. Watching her slowly die is 'very, very hard, almost unbearable'. Although she retains a hope that her mother might recover, June wishes at times 'that it would end' - then feels guilty. She worries constantly and succumbs to changes of mood: 'when I let go in one of these mood swings - I let go! Crying is my release'. June is helped, however, by the companionship of her husband and by the honesty of the hospice. She feels her own needs have been recognised. June believes that her mother knows she is going to die, and is getting frustrated about it. Her main concern is that she now remains comfortable and pain-free.

The patient notes state that Christine 'does not want to be told what the lump is', but that she does know she cannot be cured (Appendix 18). She wants no more chemotherapy and is 'taking each day as it comes'. She has a fear of dying in her sleep. Spiritual distress from her previous relationships has been recorded. A note states that she was encouraged to voice her concerns. Christine died 18 days after the research interview. Her body was left to science and the director of spiritual care conducted a service for her in the hospice chapel.

Patient D - 'David' - is 89 years old. He was born in a Working Men's Club and gives that as a reason for enjoying 'a whisky at bedtime'. As a young man he worked in a department store. One day, while temporarily distracted, he put his hand through a plate glass door and suffered cuts and heavy bleeding. Until the ambulance arrived, a young female assistant cared for him. It was 'love at first sight'. They married shortly afterwards and enjoyed a honeymoon in Blackpool - albeit just for the weekend, for they had to be back at work on Monday morning. The relationship produced a daughter and the marriage has survived for 64 years. David now has cancer of the bladder and prostate.

David describes the cancer as 'a bit of a blow', but takes the view that 'life will just go on'. What is distressing, however, is that he can no longer support his wife in the way he would like. Her heart condition exacerbates his feelings of isolation and helplessness.

It's the fact that I can't, I can't get to help my wife when she's – when you see a woman of 90 struggling with the garden (crying), I think such an awful lot about...

David finds support from his strong belief in God. He was brought up an Anglican and during his youth, sang in the choir. He stopped going to church 'when the vicar tried to make everybody Catholics'. Though he never returned, he supported the Methodism of his wife and speaks with affection about attending the sermons of Leslie Wetherhead. He never lost sight of the spiritual side of life and when he joined the masons, felt that in some way he was 'back in touch with the Church again'. Significantly, David did not feel 'confined to the bible or anything like that' but enjoyed what he called the 'mixtures amongst the members'. He prays every night – 'simple prayers', that ask for strength and courage – and finds that he prays more since his diagnosis. David hopes to regain the strength in his legs so he can go home and do more for his wife.

David's daughter, Annette, visits three or four times per week. She usually brings Dorothy, her mother, but that depends upon Dorothy's state of health. Born with a heart defect, 'she's a very long sufferer, and never says anything'. One of Annette's concerns is the toll that her father's illness takes on her mother. She is the one that 'takes the brunt of it all and gets on and copes with it'. It is not easy for her. The cumulative effect of cancer and a more recent stroke has left David 'more disabled and unable to do things for himself – and it also just affected his mind a little bit'. As a result, David

has been in and out of hospital several times before admission to the hospice. Annette found stark contrasts in the two settings:

(the hospice) is clean for a start-off, whereas I think (the hospital) is not very clean, and I don't think the care's there either; the nurses - whether there's only a few for a lot of patients, or these nurses stations that they have - I think they spend a lot of time there when they ought to be attending to the patients, actually. But there's always somebody here (hospice), always looking round, providing tea or meals. It seems to be very, very good, and the staff are extremely friendly. Yesterday the staff nurse, occupational therapist and the physiotherapist were all talking around my father going home next week and what was available for him. We have been kept informed - very well actually.

Annette prays on occasions - usually when her father 'is not so good'. She is able to accept her father 'as he is on that particular day' and finds it helpful to 'just get on with life'. Being busy at work means there is little time to think; and that enables her 'to just take it as it comes'. She knows her father is eventually going to die. Having experienced the death of her grandmother and mother-in-law, however, she feels 'able somehow to cope with father'. 'I just accept it really, there's nothing else you can do, is there?' Annette's main hope is that her father does not suffer in any way.

In the patient notes, under the 'psycho-spiritual' heading, David is described as being 'worried about his wife', and that he 'wants to go home'. He did go home and lived for a further three months.

*Reflection: 'an edge for the Church'*. I consider the special character of this hospice to be summed up in the words of the spiritual care director, that it represents 'an edge for the Church'. The hospice is a tangible, outward-looking engagement between the Roman Catholic Church and a critical area of life. As such, it provides an appropriate context for the mission of the founding sisters - to be with people in the deserts, on the frontiers and on

the peripheries. Others are invited to share in that mission, to cluster freely around common concerns for the dying - of any faith and none - but set against the clear backdrop of the Church's vision and ministry. That vision is plainly evident in the literature, practices and ethos of the hospice.

### *Hospital 1*

This hospital is found within an acute trust which employs 2500 staff across five sites that contain a total of 1240 beds. The site of this hospital originally housed an asylum for pauper lunatics, opened in 1818 in an attempt to provide better care for the local insane. As numbers grew, an acute hospital was built in 1900 to accommodate the health care needs of the asylum patients. During the Second World War, it became an Emergency Medical Services Hospital and subsequently, a District General Hospital - achieving NHS trust status in 1997.

Religious instruction was seen as a primary aim of the original institution. The hospital's first director, a devout Methodist, sought to incorporate Christian principals into his management style. He also conducted a regular service in a room used as a chapel on the first floor. The first chaplain was appointed in 1828 in accordance with the Lunatics Act of that year, beginning a formal commitment to the spiritual care of patients. After much deliberation, a chapel was built in the grounds - at some distance from the asylum - to afford the patients a pleasant walk and a setting physically removed from asylum business. It opened in 1861 with a congregation of 600. Though the chapel is now closed, the diaries of the chaplain and artefacts such as the chalice and plate still remain.

A strong spiritual perspective continues to date, though it takes account of a changed situation. A Muslim prayer room has been established, with

adjoining facilities for ablutions. A chapel is now located within the hospital, where services are held on Sundays and Fridays. The site has two whole-time Anglican chaplains, with Catholic and Free Church chaplains working on a sessional basis. A group meets weekly to pray for the hospital. Eighteen volunteers – recommended by their ministers and trained by the chaplains - support the work of the department. The chaplain is involved in the broader life of the hospital, and has become associated with the Health and Safety at Work Committee, the Investors in People initiative, bereavement groups and a policy group for fetal loss. He is also involved with education – teaching within the palliative care programme – and the induction course for junior doctors.

Both hospital and ward publications give general information about the chaplaincy service. This is supplemented by a leaflet, which states that chaplains offer:

an alternative, accepting presence, a relationship that enables the process of finding meaning in whatever is being experienced, a point of contact with the appropriate faith community.

Holy communion, worship and prayer is also available - either in the chapel or at the bedside. Attention is drawn to the location of memorial books, and the site of a Forget-Me-Not garden of remembrance. Outside the chapel is a quiet area with a prayer board and selection of leaflets. Booklets such as '*Daily Strength*' and '*Day by Day*' are available - containing prayers and extracts from the bible. Articles written by the chaplain appear in two hospital newsletters.

The Anglican chaplains have produced a comprehensive booklet outlining a model of spiritual care. Its tone is encapsulated in a quotation from *The Shoes of the Fisherman* (West) printed on the preface:

It costs so much to be a full human being that there are very few who have the enlightenment or the courage to pay the price. One has to abandon altogether the search for security and reach out to the risk of living with both arms. One has to embrace the world like a lover. One has to accept pain as a condition of existence. One has to court doubt and darkness as the cost of knowing. One needs a will stubborn in conflict, but apt always to total acceptance of every consequence of living and dying.

Written for health professionals, the publication suggests that spiritual care is the therapy of the human spirit: 'the art of giving and receiving love in the journey towards meaning, wholeness and health'. Within the document, aspects of spiritual care are treated as quality issues. A statement of principle outlines the department's spiritual care position. An assessment tool has been constructed in keeping with this position. A further document - the '*Aid to Spiritual Care*' - has also been published, supplemented by '*Faiths and Practice*': a guide to responding to patients from diverse religious backgrounds. Both are available on each of the wards - and were also to be found in hospice 1. Also on the wards were on-call procedures for chaplains. A number of ward notice boards displayed a poster inviting readers to respond and 'make a new beginning by discovering the healing powers of Reiki'.

The chaplain has been in post for over 20 years. He believes that spirituality is the 'journey to know God'. For Christians this is inextricably linked to the gift of the Holy Spirit; his guidance and leadership. A turning point occurred in the life of the chaplain when he attended a conference in Poland and had the opportunity to visit Auschwitz. For him, the concentration camp represented the antithesis of hospice. It was a place where people felt isolated, fragmented and full of despair; where there was no love, no hope, 'no care at all'. In contrast, the opposite seemed true within hospice.

Consequently, the chaplain came to believe that quality care and spiritual care were synonymous. From subsequent reflections emerged his model of spiritual care and the publication of the departmental booklet.

The spiritual care service responds to people's need to feel valued, to be loved, to find hope and to be forgiven. In the hospital context, it involves dealing with issues around anger, loss and death and dying. It concerns those intimate areas of people's lives that necessitate gentleness and sensitivity. In essence, good spiritual care is the way in which a person is loved. The rewards are 'to share with people where they are on their journey of life'. For the chaplain, these have included a large number of 'very meaningful, deep, shared experiences'. His hope for the future is that the health service recognises that spiritual care has a profound effect upon healing.

In relation to the chaplaincy styles itemised in Figure 1 (see Chapter 1 above), evidence suggests that the chaplain's style falls within Quadrant 2: institutionally detached with a membership view of praxis. Consequently, the chaplain expresses sympathy for the workforce, caught up in numerous changes and innovations. Such changes, where 'the goal posts seem to have moved every two years' has resulted in discontent and dissatisfaction. 'Severe cutbacks' have resulted in nurses becoming 'overloaded'. 'More and more patients and responsibility' are piled upon them with less and less satisfaction, leading to a general feeling amongst nurses of being undervalued. Within this scenario, the chaplain stands over against the institution to comment upon the quality of care he perceives is being received by patients:

I need to see whether the patients are getting the right quality of service and treatment...so I have a list of those qualities which I consider to be important, like: is this patient getting unqualified,



unconditional regard? Is this patient being treated with the utmost privacy and dignity? Is this person being treated with gentleness and kindness and sympathy and empathy and compassion? Is the patient gaining anything that might enhance the life process that they're going through?

With regard to praxis, the chaplain is unequivocal about the primary focus of his ministry:

I see myself as first and foremost determining the religious need of the patient if there is one, the contact with the Church, the contact with a prayerful community, the contact with a sacramental ministry. After that are these other essential qualities of life.

Of the 5 nurses who completed the questionnaire, none had more than 20 years' experience and 4 had less than 10. Two nurses felt they were occasionally involved in spiritual care; 3 thought they were rarely involved. Pre-registration, spiritual care training had featured hardly at all for 3 nurses and not at all for 2. A similar situation related to post registration training. Yet 3/5 nurses felt either very comfortable or quite comfortable in the spiritual domain. Only 1 nurse felt very uncomfortable. All the respondents thought patients required someone to listen to them, someone to 'be there' for them and someone to provide information. Four nurses thought patients most frequently wished to address spiritual issues around concern for relatives, pain and suffering.

The nurses who were interviewed considered that holistic care includes physical, social, psychological and spiritual care. That said, the acute ward is a busy place, where physical care sometimes assumes a priority. Consequently, spiritual care is seen to rest with the chaplaincy department or within the interests of particular nurses. Night-time, however, may be less pressured, and generally provides more opportunities to listen to individual patients. Spiritual care, however, is regarded as a complex issue

that relates to a number of variables. It may range from ward services to personal reassurance, symptom control to the provision of pat dogs - or just treating a patient as 'normal'.

There were few opportunities for spiritual care training outside of the programmes of study for palliative care, care of the dying, or bereavement care. However, on this acute medical ward for the elderly, several members of staff showed an interest in spiritual care. As a result, the chaplain provided training and helped with the development of a strategy. This strategy considered the implications of what was termed 'patient journeys' and their impact upon resources and personnel. Amongst other developments, plans were devised to enhance patient dignity by upgrading facilities for private discussions. As the ward accommodates patients who are also elderly and confused, this complemented other initiatives such as the development of reminiscence groups and the provision of a reminiscence room:

they bring bars of soap and things from the olden days that sparks off things, motivates them and just instigates a little bit of conversation – so a person who's sat there and doesn't interact suddenly talks about when she used to 'lead the steps'. That to me addressed the spiritual needs because they're looking at the holistic things for that patient.

Acute wards present particular challenges, not least concerning time and resources. Mixed wards and the demands of working with the elderly provide added pressures. So do changes in the way that nurses are trained and practise. Whilst 'high tech' care has its place, patients also need 'some empathy – somebody to talk to and somebody to sit and listen'. Sometimes relatives feel guilty about a family member dying in hospital rather than dying at home, and frequently regret that more time cannot be spent at the bedside. Patients worry too - about family and finance, entering a residential

home and having a faith that has lapsed. In such circumstances the concept of team, particularly of an extended palliative care team, comes into sharper focus. Though working with the elderly described as 'a lovely field of nursing', hopes for the future centre around better practice, more clinical training and more holistic nursing.

Patient G – 'Gwen' – is 79 years old and has lived locally all her life. As a young woman, she 'worked in t' mill' and continued to work long after she married. Gwen now lives in sheltered accommodation. She has a seat near the window and likes to sit and watch people coming and going. She experiences some dementia and has metastatic cancer.

Although Gwen was widowed in the 1940s, she still has strong feelings about the unhappy relationship she experienced with her husband:

I wun't get wed no more. Not for t' fella I 'ad. Oh no. He'd no thoughts, no feelings, no nothing. It wa' like talking to a bloody brick wall. And he bloody wun't work. If I stopped at home he'd sulk – didn't want none (children). Frightened o' me being at home, that's why. He liked money in his pocket t' much. I wouldn't get wed. Not what I know now.

Gwen grew up within the Methodist tradition. As a child, she remembers being 'taken to t' Wesleyan chapel' by her mother. 'They used to come and talk to you', she says, 'they were very nice'. Though Gwen no longer attends, she maintains she is 'just as good as them what goes'. She still says her prayers and has retained her belief in God. 'I think about him. I think he helps me a lot – just wi' me faith'.

Gwen has no living relatives and receives no visitors. She was known, however, to the chaplain and to the chaplaincy volunteer – both of whom included her in their rounds. The patient notes record Gwen's religion as 'Church of England'. She died 8 days after the interview.

Patient H – ‘Hettie’ is 73 years old. She was born in a small town some 10 miles from the hospital. Her husband, Bill, was born in a neighbouring street. As a young man, Bill joined the army, served in Burma, and then returned to marry Hettie. After they were married, they settled in the town of their birth and raised two daughters. Both daughters subsequently moved away, one of them to America. After 50 years of marriage, Bill became seriously ill and died in the hospital where Hettie is now a patient. Hettie has been in hospital for more than 6 months and is being treated for metastatic cancer.

Hettie is pleased with the way she is being cared for. She regards the ward as the best place she has been and describes the staff as ‘lovely, lovely girls’. It’s an ‘easy life’ and she is able to have ‘some good laughs and jokes’. She would love to go home, however, but it has not yet happened. Something always seems to prevent it: ‘every time they say I can go home I finish up with an infection. I dread them bloody words!’ she says. Consequently, she gets ‘fed up’ and then her spirits fall. When that happens, she acknowledges a sharper side to her nature. ‘If I feel like I’ve felt today, they try and keep away if they can, ‘cos I tell ‘em to piss off’.

At times, Hettie feels she has only herself to talk to. She also feels isolated and alone; feelings exacerbated by the physical distance between herself and her daughters. Yet Hettie found an unexpected source of strength when she was moved to the ward where Bill had died. ‘It sort of lifted me through them months’, she says. ‘I know I can’t get better. I’ve said to him many times - ne’er mind, lad, I’ll be seeing you before long’. Although claiming not to be religious, Hettie has also found strength in prayer and in her belief in God.

The patient notes record that Hettie is a non-practising member of the Church of England. A subsequent note by a member of the hospital-based palliative care team stated that Hettie had been anxious and 'found it helpful to talk'. It also transpired that the chaplain knew her and included her in his ward rounds.

On my last visit, Hettie was sat by her bed - with a smile on her face - as she waited for the transport to take her home. 'I came in to die', she said, 'but I'm going home - and Bill will have to wait a bit longer for me'.

*Reflection: 'empathy with the elderly'*. I found the defining characteristic of this case to be its focus on the elderly. Both interviews were conducted with elderly patients. The practices and ethos of the ward were shaped by the needs of the elderly. The palliative care link-nurse was trained in the care of the elderly.

Within this scenario, spiritual care related to the patient's situation in life. Reminiscence played an important part. The husbands of both patients interviewed for this study had died. One patient had no surviving family and received no visits; the children of the other lived a great distance away. Companionship, 'being there' and spending time with the patient were seen as important. Although the days could be busy, night-time provided opportunities to talk. Both patients were known to the chaplaincy department and both were visited by its staff.

### *Hospital 2*

This university hospital contains 1,135 beds and is part of a multi-site trust that contains 3,200 beds. The study focussed on a surgical ward. Originally,

a school stood on the site, built in 1848 to house and educate 500 pauper children from the neighbouring workhouse. Anxious about the spiritual welfare of the children, the Board of Guardians for the Poor appointed a cleric to be the first head teacher, granting him responsibility for the children's physical, mental and spiritual welfare. Subsequent developments included an infirmary and a detached chapel. The infirmary developed into a general hospital that was converted to a military hospital during World War 1. New extensions were added in 1940 and the hospital was granted university status in 1970. It became a NHS trust in 1998

The chapel was opened in 1861 and is used to this day. The nave was built to accommodate 784 paupers, with 499 children in the galleries. The chaplain, appointed in 1861 served for 25 years. A full list of chaplains, in date order, is inscribed on a plaque mounted on the chapel wall. The gallery now contains an organ, dedicated by the bishop in 1976. The chapel is traditionally furnished, including a stone pulpit, brass eagle and bishop's chair. Part of the chapel has been converted to house the chaplains' office accommodation. No multifaith room is available for faiths other than Christian, but part of a room in the chapel has been set-aside for Muslim prayers. Staff include whole-time Anglican, Free Church and Roman Catholic chaplains, a chaplaincy secretary and around 30 volunteers. A Jewish chaplain and Muslim chaplain are available on a sessional basis.

According to the chaplains, the size of the hospital and the throughput of patients present management problems that require a focussed, co-ordinated approach to spiritual care delivery. Consequently, the department aims to enlist the help of volunteers, train them and then allocate them to wards - ensuring that the same volunteer visits the same ward on the same day each week to preserve continuity. Within the chaplaincy team, each chaplain seeks to offer a shared, 'core element' of spiritual care that can be delivered

inter-changeably by any team member. Additional religious or denominational care is then available - to all who require it - from ministers of different traditions. In addition, chaplains may specialise in particular areas of work such as the Renal Unit or the Palliative Care Team. Spiritual care relates specifically to the love of Christ:

As a Christian minister my role is to bring the presence and the love of Christ into the situation where I am, and that could mean a whole variety of different things, because the situation and the people are always so different. But that is the bottom line, and if I was unable to do that - or not allowed to do that - then I wouldn't be here.

Communication is related to the issue of size. Consequently, a clear strategy is employed to bring the work of the chaplaincy department to the notice of patients. A current issue of the trust's newsletter contains a half page article from the chaplains. Posters are displayed around the hospital that show photographs of chaplaincy staff. In public areas, TV monitors run a videotape that advertises the broadcast Sunday Service - found on the hospital radio channel. A chaplaincy leaflet with a tear-off slip requesting a visit can be found in bedside lockers. The leaflet explains the chaplaincy rationale:

The name 'chaplaincy' derives from the Latin word *cappella* which means 'cloak'. As human beings we are called to serve one another, to bring a touch of comfort, healing and strength. The symbol of Chaplaincy in this Hospital Trust is of one person holding another by the hand, while both are enfolded, or cloaked, within the love and protection of God.

In relation to the chaplaincy styles itemised in Figure 1 (see Chapter 1), the chaplain's style falls within Quadrant 3: institutionally detached with an incarnational view of praxis. The view was expressed that with regard to the institution, chaplaincy was a 'Cinderella department' - with small numbers and a small budget - that for years had been managerially 'kept in the dark'.

It was the exception for chaplains to feel part of a team and in certain places, 'you feel they wonder what you're there for, wishing you'd go away'. Chaplains were 'often not consulted' and such perceptions coloured the relationship between the department and the NHS trust. As a result, chaplains sought to exercise an 'alongside role', bringing items of importance to the attention of the trust and suggesting areas where improvements might be made.

With regard to praxis, the chaplain's vision was of a core spiritual care service that was available from any member of the department, irrespective of religious affiliation. He was frustrated, therefore, that admission forms sought information regarding a patient's Church, rather than a patient's religion. All people of all faiths were welcome. Where a patient needed to talk but had no personal faith, the chaplain offered support by focussing on that which the patient valued within his or her background or community.

On the wards, booklets were available giving guidance on how to respect people's faith and beliefs. These itemised the major faiths but also included the beliefs of humanists and pagans. Telephone numbers of local and national leaders were listed. Guidance was given on how to demonstrate equity and respect to same-sex partners. On the ward featured in this study, papers were available that focussed on the dying patient in an acute hospital, on terminal care and on bereavement support. A protocol of bereavement care was in place and a collection of resources - such as sympathy cards - were to hand. The resources and protocol were established after consultation with the local hospice.

A dedicated cancer centre offers other forms of support. Recently opened, the centre attempts to meet a variety of expressed needs: how to live with uncertainty, how to deal with the effects of bad news, how to tell family



members. Alongside an information service and complementary therapies is a service of spiritual healing that operates independently of chaplaincy. A leaflet explains that healing aims to re-energise and relax patients to enable their own natural resources to deal with their illness. For relatives and carers, it is suggested that healing enables them to cope with the stresses and strains associated with caring for a person with cancer. According to the centre manager, the provision of spiritual healing is a response to the large demand:

People kept coming in saying 'do you have healers here?' It's so popular, and we get men - an equal number of men and women, young and old - coming for it. Yeah, and it does make such a difference to the patients. Most people who come for healing, the prognosis is not that good - and you'll see that they're extremely anxious, they're extremely isolated because they don't want to talk about their cancer to anyone - they come in and they're hunched up, and when they go out they're just so tall, and they'll sit and have a cup of tea and they're so relaxed, and they become much more positive about their illness in a way that's really quite hard to describe. We get the same effect sometimes with aromatherapy and reflexology, but the most dramatic changes in people that I've seen have come through the healing service.

The spiritual healer in this study is a trained nurse with a background in the Christian tradition. She is a member of the National Federation of Spiritual Healers (NFSH) and has undertaken a training course approved by that body. She has also completed a two-year probationary period. She believes that spiritual healing crosses cultures and traditions. 'It doesn't have any particular 'isms or 'ologies but respects the tradition of the person who's receiving the healing'. Based on love and the energy of God, she considers that spiritual healing should not be seen as a miraculous cure: it should be viewed alongside traditional medicine as a means to help people cope with their illness as well as possible:

It's just about being lovingly alongside a person and helping them into whatever phase is happening to them - through their illness

and into death as well – and I would also apply that to all the carers that are involved.

Of the 5 nurses who completed the questionnaire, 4 had between 10 and 20 years' experience; 1 had less than 10 years' experience. One nurse thought she was frequently involved in spiritual care; 4 nurses thought they were occasionally involved. Pre-registration, spiritual care training had featured hardly at all, or not at all, for all respondents. Post registration, 3 nurses thought spiritual care training had figured quite prominently. Four nurses felt quite comfortable in the spiritual domain; 1 nurse felt quite uncomfortable. Spiritual assessments were conducted around the admission of patients and also during the patients' stay. Only nurses were involved in such assessments. For all nurses, assessments included religious affiliation, a wish to worship and special diets. All the nurses thought patients required someone to listen to them. Four nurses thought patients required someone to be there for them, and someone to provide information for them. All nurses thought patients most frequently wished to address spiritual issues around pain; 3 nurses thought concern for relatives and death and dying occurred most frequently after that.

The nurses aim to see that patients are supported during their stay in hospital and on their return to the community. On a busy surgical ward, a lot of time is focussed on physical, post-operative care. Consequently, spiritual caregiving may be left to others. Some nurses feel acutely uncomfortable in the spiritual domain. Others – particularly those with palliative care training - feel both comfortable and competent. A spiritual assessment, undertaken around the time of admission, helps determine the spiritual priorities of the patient. Frequently, patients need information. They mis-hear what has been said and have anxieties about what is going to happen. In these circumstances, it is usual for a nurse to return to a patient and say 'you had

some bad news this morning, would you like to talk about it, now you've had a bit of time to think?'

A return home may not always be possible, whereupon the aims may change to help the patient achieve a peaceful death. An acute ward – with people 'bustling around' all the time - is not the ideal place to die, and attempts are made to support both the patient and family during the dying process. A side room is made available for increased privacy; someone is designated to 'be there' for the patient and to ensure s/he is not left alone. In such circumstances, time is essential and patients are given the time they need. 'We consider that as well', said one of the sisters who had previously worked at Hospice 2. 'For me it's as much a priority as the patient who's just come out of theatre'.

Links with the local hospice had given some nurses insights into the workings of a multidisciplinary team. Whilst teamwork on the ward was different, it was nevertheless being nurtured and developed. One nurse had returned to work on the ward because 'there was more to work than money' and she wanted 'to make a difference as a team'. There was a sense of privilege about doing the job and a sense of satisfaction in doing the job well. A view of teamwork was exemplified in a poster pinned to the wall in the nurses' office:

When geese fly in formation, they travel about 70% faster than when they do alone. Geese share leadership. When the lead goose tires he (or she) rotates back into the 'V' and another flies forward to become the leader. Geese keep company with the fallen. When a sick or weak goose drops out of flight formation at least one other goose joins in to help and protect. By being part of a team, we too can accomplish and support (honking from behind) help inspire and energise those on the front lines by helping them to keep pace in spite of the day-to-day pressures.

Patient I – ‘Ivy’ - is 61 years old. She was born in the north but after marrying a university lecturer has lived locally for over 30 years, bringing up two children. She made plans to take early retirement at the same time as her husband, but as the date approached she became ill and was diagnosed as having cancer of the bowel. She is currently awaiting surgery to remove ‘a blockage’.

Ivy’s view of hospitals is coloured by the fact that her cancer pain has been difficult to control. ‘I was in tremendous pain, just living on morphine’, she says. Yet nothing could be done about it ‘until the surgeons had done something’. She found it hard to be denied painkillers between her regular medication. ‘Some of the nurses were sticklers for every four hours’ she says. ‘That’s no good to you is it?’ It was not always so. For a long time, Ivy suffered few ill effects and recently had ‘a lovely summer playing golf’. Yet she vividly remembers waking from the anaesthetic and hearing that her condition was serious. She recalls that during the next clinic ‘they just said “no treatment, you’ve probably got 6 months”. I thought it was rather brutal’, she explained. That was 2 years ago.

Ivy was a practising Roman Catholic for over 50 years, going regularly to Mass and praying every day. All that has changed. Though she would wish to experience faith again, ‘for some reason it seems to be dead’. As a result, Ivy feels she ‘must be wicked for it to just fly away’. The Catholic Chaplain still visits, but Ivy says she is not interested in maintaining links. She professes to ‘believe in something’, but she no longer knows what and confesses to being ‘really confused about it’. Though ‘nothing happens’ when Ivy remembers her faith, she feels that golf has been her lifeline – or rather the friends associated with the game. ‘Everyone’s been so supportive’, she says, ‘that was the biggest help, there’s always been

someone there'. Ivy recognises that eventually she will have to face some major issues:

Everybody says, you know, you're marvellous for just getting on with your life. But I don't know whether I've got this ability just to shut things out. Some people have haven't they? Try to forget about things and not – it's actually, probably, not facing them. But I probably have come to terms with it in a way, because I just blot it out. I just pretend things are normal.

Patient J – 'Jasmine' is 58 years old. She was born in the West Indies and came to England with other members of her family in 1961. She married in England and has raised three girls and a boy. Jasmine worked as a health care assistant but took early retirement two years ago when she damaged her back lifting a patient. Last year, she decided that after suffering from a hiatus hernia for over 20 years, she would have it checked out. An investigation revealed she had cancer of the stomach.

Jasmine was shocked by the diagnosis and suffered panic attacks. 'I wasn't taking it in', she says. 'I was just crying because of shock'. She was admitted to hospital that weekend and underwent surgery the following week. 'It just went like a conveyor belt – so quickly – that sometimes I keep looking back and thinking, did this really happen?' She now awaits another endoscopy. She worries about both the pain and the outcome. Last year, two of her family died of cancer within 8 weeks of each other. For a while, she thought she would be the third. Afraid of the impact the news would have on her family, Jasmine kept quiet. 'I couldn't even tell me dad - who is an old man of 87, in the West Indies - otherwise the shock would kill him as well'.

Jasmine is a Jehovah's Witness and has practised her faith for over 30 years. Her family and friends are also Jehovah's Witnesses. They send her

religious texts and visit to read the bible with her every day. She is adamant she will 'never give up on God no matter what', and strongly believes that 'God will protect you if you have faith'. She prays 'all the time', and despite her troubles, Jasmine has never blamed God nor found her faith to weaken:

God don't put his children on earth and then destroy them. We know that death and sickness enter this world because of Adam and Eve's sin. So I cannot blame God for something that they done.

Jasmine now hopes that 'everything goes alright'. She also hopes to 'do things' with her family and 'to continue serving Jehovah'. As a result of her illness, she has adopted a different outlook and takes fewer things for granted. Instead of returning to the West Indies, she now wishes to stay in England with her children and her grandchildren. The most important thing, however is to 'pray to Jehovah that the cancer won't return'. In her uncertain situation, God remains the primary source of Jasmine's comfort and strength. Significantly, she describes how 'God was there' in her time of need:

When I were praying to him, I put my hand over the trolley when I were going to theatre, and in my mind - because my faith was so strong - he was holding my hand.

*Reflection: 'activity amidst uncertainty'*. My overriding impression of this case is the high level of activity on the surgical ward - and the feelings of apprehension and uncertainty on the part of patients, interviewed for the present study. One patient had lost her faith; the other was afraid that a recurrence of her cancer would have to be kept secret from her bereaved father.

These features of ward life were well known to the staff. In such circumstances, spiritual care frequently took the form of listening, clarifying, explaining and discussing. For the dying, more time was made available. Expertise in the care of the dying was gained through special training and links with the neighbouring hospice. In the context of this large institution, information about spiritual care has become a high priority. Use is made, therefore, of chaplaincy leaflets, posters, videotapes and cassettes. Spiritual care is a joint enterprise that includes members of staff, visiting ministers and chaplaincy volunteers: more activity in the midst of uncertainty.

### **Case studies compared**

*The spiritual needs of patients.* Using Kellehear's (2000) model of spiritual needs, patient interviews were analysed to find indications of what he calls 'the building blocks of spiritual meaning' (2000:149). These building blocks relate to three sources of transcendence: the situational, the moral and biographical, and the religious.

Within the category of situational transcendence, indicators of hope and connectedness were found amongst all 10 patients (Table 18). Some hopes related to the patient's condition: for the cancer to go away/ not to get worse; a return to normality - by going home; or for a peaceful death,

without pain. Connectedness focussed mainly on friends and family. Social presence featured prominently for 7 patients, with nurses playing a key role. The opportunity to talk was seen to be advantageous.

Within the moral and biographical category, a belief in God or 'a larger being' was present amongst all patients. Seven patients sought transcendence through prayer, 3 patients admitting to daily prayer and 1 patient to 'praying all the time'. Five patients had come to a sense of closure: 2 patients recognising 'it's over', 1 patient having instructed and paid the undertaker, another having left her body to science.

Of the 10 patients interviewed in this study, only one of them - a Jehovah's Witness - considered herself to be religious. Yet 8 patients displayed evidence of religious needs. Indications of divine support were found amongst 3 patients. Two patients focussed upon an afterlife. One patient felt wicked after losing her faith. Religious leaders played a significant role for 3 patients.



**Table 18** The spiritual needs of patients identified by their discourses (after Kellehear).

Unit	Patient	Religion	Situational transcendence	Moral and biographical transcendence	Religious transcendence
Hospice 1	A	C/E	Purpose – I've tried to be a friend to people Meaning - my life has been useful Hope – to die in a peaceful way	Peace – I feel happy and contented Moral / social analysis – belief in a larger being Closure – I've had good times but that's over	
	B	Non Practising	Connectedness – I know people are there Social presence – talking something through helps Purpose – the hospice gives you a reason to live Hope – to enjoy the rest of me life Affirmation – chaplain to do funeral, he knows me Connectedness – next door neighbour Social presence – nurses sit and talk	Peace – I've found a sense of peacefulness Moral/social analysis – believe in God Closure – I've even paid the undertaker	
Hospice 2	C	C/E	Hope – to go home: live longer Connectedness – my daughter comes every night Social presence – nurses sit and listen to you	Moral and social analysis – I believe in God Reconciliation – come to accept a wonderful daughter Reunion – one or two children now come to see me Prayer – I pray every morning and evening Closure – I'm leaving my body to science.	Divine support – he's there at the end for you Afterlife – I believe in afterlife
	D	C/E	Meaning – life will just go on Hope – to help my wife more Connectedness – I've been married 65 years	Moral/social analysis – I believe in God very much Prayer – I pray each night	Religious rites – the ritual keeps you in touch
	E	Non Practising Jew	Purpose – I try to be a good Jew Affirmation – I want to be loved Hope – to go out of here on my two feet Connectedness – wherever love comes from is OK Social presence – nurses are there for you all the time	Moral and social analysis – I believe in God Prayer – I pray Peace - feel I've been born again, I'm a born-again Jew.	Visits by Rabbi – such a good man; kind, thoughtful
	F	C/E	Hope – for a peaceful death, no pain Connectedness – the love from people has helped	Moral and social analysis – I have a belief in God Prayer – I do pray Peace – I'm actually at peace Reconciliation – I've accepted what's going to happen Closure – I'm glad it's over because this is hell anyway	Afterlife – I had a tap on my shoulder from my dad (deceased)
Hospital 1	G	C/E	Hope - for a peaceful night and to get up better Connectedness - felt lifted being where husband died Social presence – family visits	Reunion – with my dead husband Prayer – give thanks every night Moral / social analysis – belief in God	Afterlife – sometimes I wish it could be today
	H	C/E	Affirmation – I'm as good as those who go to chapel Hope – to go home Connectedness – I looked after my friends m other Social presence – nice to have somebody to talk to	Moral/ social analysis –I believe in God Prayer Closure – wouldn't get married again	Divine support – He helps me a lot
Hospital 2	I	Non Practising RC	Purpose – to maintain a quality of life Hope – not to get worse Connectedness – my husband's so supportive Social presence – always been someone there	Moral/ social analysis – I possibly believe in God	Religious reconciliation – I'd like to feel something Divine forgiveness – I feel wicked to lose my faith Visits by chaplain – he still comes
	J	Jehovah Witness Practising	Meaning – if it's God's will, let it be so Hope – for the cancer to go away Connectedness – I have supportive friends and family	Moral/ social analysis – I believe in God. Prayer – I pray all the time	Divine support – God guide and protect me Religious literature – I read the bible every day Visits by faith leaders – they come and pray Discussions about God – we talk for hours Hope - to carry on serving Jehovah

Self complete questionnaires were used to elicit from nurses their opinions about how frequently patients required aspects of religious and non-religious spiritual care. Responses were recorded on a scale of 'frequently', 'occasionally' and 'rarely'. Table 19 shows the responses in the 'frequently' category. All nurses in all four institutions thought that patients 'frequently' required someone to listen to them. Someone to 'be there' for them – 9/10 in both groups – followed closely behind. About 11 categories of spiritual issues, both hospice and hospital nurses indicated that patients most frequently wished to address spiritual issues around concern for relatives,

**Table 19** Nurses' perceptions of the 'frequent' spiritual requirements of patients

	Hospice 1 <i>n</i>	Hospice 2 <i>n</i>	Hospital 1 <i>n</i>	Hospital 2 <i>n</i>	Total Hospice <i>n</i>	Total Hospital <i>n</i>
<b>Non religious requirements</b>						
Someone to listen	5	5	5	5	10	10
Someone to 'be there,	5	4	5	4	9	9
<b>Opportunities to discuss</b>						
why me?	3	3	2	2	6	4
pain	5	4	4	5	9	9
meaning of life	1	0	1	0	1	1
value of one's own life	4	1	2	1	5	3
suffering	5	2	4	2	7	6
forgiveness	1	0	1	0	1	1
transcendence	0	0	0	0	0	0
the nature of God	1	1	0	0	1	1
concern for relatives	5	5	4	3	10	7
death and dying	5	3	3	3	8	6
afterlife	0	0	1	0	0	1
<b>Religious requirements</b>						
Prayer	2	0	0	1	2	1
Texts	0	0	0	1	0	1
Worship	3	1	0	1	4	1
Special rituals	1	0	0	0	1	0
Baptism	0	0	0	0	0	0
Confession	2	1	0	1	3	1
Communion	3	3	0	1	6	1
Anointing	1	1	0	0	2	0
Last rites	2	2	0	2	4	2

pain, and death and dying. Of 9 religious requirements, holy communion (6/10) featured most prominently amongst hospice nurses, last rites (2/10) amongst hospital nurses. In total, hospice nurses made 48 responses relating to spiritual issues compared to 39 responses amongst hospital nurses. With regard to religious requirements, hospice nurses made 22 responses, hospital nurses 7. Within hospital 2, nurses did not make a single response.

*Raising awareness.* All services made efforts to raise awareness of their spiritual care provision (Table 20), using a number of common methods. These ranged from the publication of newsletters and information packs to the distribution of leaflets and posters. One site used a videotape played on strategically placed hospital monitors.

**Table 20** Methods used to raise awareness of spiritual care provision

	Hospice 1	Hospice 2	Hospital 1	Hospital 2
<b>Advertisements</b>				
posters	•	•	•	•
hospital video: broadcast service				•
leaflets				•
<b>Documentary information for patients</b>				
site information service	•	•	•	•
site funeral information	•	•	•	•
site newsletters	•	•	•	•
site information pack	•	•	•	
day unit/ ward information pack	•	•	•	
chaplaincy leaflet(s)	•	•	•	•
special projects		•	•	

*Identification of spiritual needs.* A variety of formal and informal methods were used to identify the spiritual needs of patients (Table 21). Common to all was a formal checklist, used to gather initial information that related to religious affiliation, a desire to worship or to see a chaplain. All units encouraged patients to make their specific needs known. Informal means included a receptiveness to patient questions and conversations.

**Table 21** Methods used to identify the spiritual needs of patients

	Hospice 1	Hospice 2	Hospital 1	Hospital 2
<b>Formal methods</b>				
Encouraging patient disclosure	•	•	•	•
Initial assessment - checklist	•	•	•	•
Supplementary assessment – prompt questions	•	•		
Reflection on conversations	•		•	
Patient review (eg MDT/ spirituality forum)	•	•	•	
<b>Informal methods</b>				
Patient questions	•	•	•	•
General conversations	•	•	•	•
Observation of patient demeanour	•	•	•	
Obtaining family perceptions	•	•	•	

*Delivery of spiritual care.* All units employed a variety of methods to deliver spiritual care (Table 22). Some strategies – such as the appointment of a multifaith link worker (hospice 2) or a spiritual healer (hospital 2) - related to individual sites. Others were common across all sites. These included the provision of physical resources - such as chapels and quiet spaces, and human resources - such as chaplains and chaplaincy visitors. Measures were also in place to create a spiritual ethos, to ‘share the patient’s journey’ and to care for family members.

**Table 22**

**Strategies used in the delivery of spiritual care**

	Hospice 1	Hospice 2	Hospital 1	Hospital 2
<b>Institutional</b>				
<b>Provision of physical resources</b>				
chapel	•	•	•	•
Muslim prayer room/ Interfaith quiet room		•	•	
cancer centre reminiscence room			•	•
chaplains offices	•	•	•	•
wheelchair/ bed access to chapel	•	•	•	•
religious objects	•	•	•	•
religious literature	•	•	•	•
<b>Provision of specialist human resources</b>				
service manager/ chaplain	•	•	•	•
assistant chaplains (Christian)			•	•
multifaith link worker		•		
access to multifaith expertise	•	•	•	•
visiting Christian ministers	•	•	•	•
visiting leaders of major faiths		•	•	•
chaplains volunteers		•	•	•
spiritual healer				•
<b>Provision of worship/ sacraments</b>				
Christian worship: different traditions	•	•	•	•
guided reflection/ meditation/ prayer	•	•	•	•
special rituals: baptism, marriage		•		•
creating special moments		•		
memorial services	•	•	•	•
bedside ministry	•	•	•	•
ward services			•	
celebration of festivals: world faiths		•		
broadcast services (hospital radio)				•
spiritual healing				•
<b>Professional</b>				
<b>Provision of education/ documentation</b>				
on site seminars, training courses	•	•	•	•
offsite courses	•	•	•	•
forum for reflection		•		
induction: new staff	•	•	•	•
philosophy/ mission statement	•	•	•	•
multifaith guidelines	•	•	•	•
caring for the dying and bereaved	•	•	•	•
<b>Practice development</b>				
creating a spiritual ethos	•	•	•	•
using the chaplain as a resource	•	•	•	•
meeting religious needs		•	•	•
being available/ bringing love of Christ				•
forging good relationships with churches				•
valuing the person	•	•	•	•
advocacy		•		
encouraging honesty		•	•	
creating an open relationship	•	•	•	•
good communication	•	•	•	•
celebrating diversity		•		
sharing the patients journey	•	•	•	•
acknowledging hope	•		•	
giving/ finding time	•	•	•	•
listening	•	•	•	•
being there	•	•	•	•
caring for the family	•	•	•	•
self disclosure	•	•		•
respecting the dead	•		•	
help a person find meaning/ peace	•	•	•	•

*Role of the nurse.* Amongst the nurses, only 1 hospice nurse had less than 10 years' experience as opposed to 5 hospital nurses (Table 23). Four hospice nurses had more than 20 years' experience as opposed to none within the hospital group. In pre-registration training, spiritual care featured 'hardly at all' or 'not at all' amongst 9/10 of the hospice group and all 10 of the hospital group. Since registration, spiritual care training featured 'very prominently' or 'quite prominently' for 9 hospice nurses as opposed to 3 hospital nurses. Eight hospice nurses as opposed to 1 hospital nurse

**Table 23** Nurses' spiritual care training and involvement

N=5 each site	Hospice 1 <i>n</i>	Hospice 2 <i>n</i>	Hospital 1 <i>n</i>	Hospital 2 <i>n</i>	Total Hospice <i>n</i>	Total Hospital <i>n</i>
<b>Length of service</b>						
0-9 years	0	1	4	1	1	5
10-19 years	2	3	1	4	5	5
20-29 years	1	0	0	0	1	0
30+ years	2	1	0	0	3	0
<b>Spiritual care in initial training, featured</b>						
very prominently	0	0	0	0	0	0
quite prominently	0	1	0	0	1	0
hardly at all	4	2	3	3	6	6
not at all	1	2	2	2	3	4
<b>Spiritual care in post reg. training, featured</b>						
very prominently	1	0	0	0	1	0
quite prominently	4	4	0	3	8	3
hardly at all	0	0	2	1	0	3
not at all	0	1	3	1	1	4
<b>Involvement in the spiritual domain</b>						
frequently	5	3	0	1	8	1
occasionally	0	1	2	4	1	6
rarely	0	1	3	0	1	3
never	0	0	0	0	0	0
<b>Comfort in the spiritual domain</b>						
very comfortable	2	0	1	0	2	1
quite comfortable	2	4	2	4	6	6
quite uncomfortable	1	1	1	1	2	2
very uncomfortable	0	0	1	0	0	1
<b>Spiritual assessment: personnel</b>						
clerk	1	0	0	0	1	0
nurse	0	2	5	5	2	1
						0
chaplain	0	0	0	0	0	0
Nurse + other (eg doctor)	0	1	0	0	1	0
nurse+ chaplain	3	0	0	0	3	0
nurse + chaplain + other	1	2	0	0	3	0

thought they were 'frequently' involved in the spiritual domain of patients. Eight hospice nurses and 7 hospital nurses felt either 'quite comfortable' or 'very comfortable' in the spiritual domain. All 10 hospital nurses as opposed to 2 hospice nurses made spiritual assessments unassisted.

*Spiritually aware personnel.* All patients in all units had encounters with spiritually aware personnel (Table 24). In this study, 'spiritually aware personnel' is taken to mean those members of staff or volunteers who have undertaken some form of professional training in the spiritual dimension of health care. This training may have been be at an advanced level – as in the case of chaplains; or at a basic level - as in the case of support staff. This latter form is amplified by the following comment from the spiritual care director of hospice 2:

Part of my role with staff in the non-clinical areas is around helping people to understand that they actually do contribute to the well-being of patients by how they receive them in reception, by how they present the food - the spiritual aspects of all that – and people need to be helped sometimes to see the connections

For some, training may have been undertaken as a module or integrated theme within courses on the care of the dying or palliative care (as in those offered by the Universities of Manchester and Sheffield). For the purposes of this study, I regarded health professionals with a strong religious faith as being spiritually aware.

In all cases, encounters with spiritually aware personnel included a Christian chaplain or a chaplaincy volunteer, whether or not patients professed the Christian faith or regarded themselves as religious. Personnel also included those trained in the care of the dying. In addition, Patient E received visits from the Rabbi and members of the synagogue; patient J

received visits from the congregation of Jehovah's Witnesses; and patient I received visits from her Roman Catholic parish priest.

**Table 24** Patient encounters with spiritually aware personnel.

	Patients									
	Hospice 1		C	Hospice 2			Hospital 1		Hospital 2	
	A	B		D	E	F	G	H	I	J
Recorded religion	C/E	None	C/E	C/E	J	C/E	C/E	C/E	RC	JW
Practising/ Non-practising	NP	NP	NP	NP	NP	NP	NP	NP	NP	P
Chaplain (Free Church)	•	•						•		
Chaplain (Roman Catholic)			•	•	•	•			•	
Chaplain (Church of England)							•		•	•
Chaplain (student)		•								
Chaplaincy volunteer			•	•	•	•	•	•	•	•
Visiting minister/ elder						•			•	•
Visiting believers						•				•
Palliative care physician	•	•	•	•	•	•	•	•		
Nurse: (pall care specialist)	•	•	•	•	•	•	•	•		
Nurse: (trained care of dying)	•	•	•	•	•	•	•	•	•	•
Nurse: (unit trained)	•	•	•	•	•	•		•		
Health Care Assistant (unit trained)	•	•	•	•	•	•	•			
Social worker	•	•	•	•	•	•				
Support staff (receptionists, domestics)	•	•	•	•	•	•				
Care staff (personal faith)	•	•	•	•	•	•	•	•		

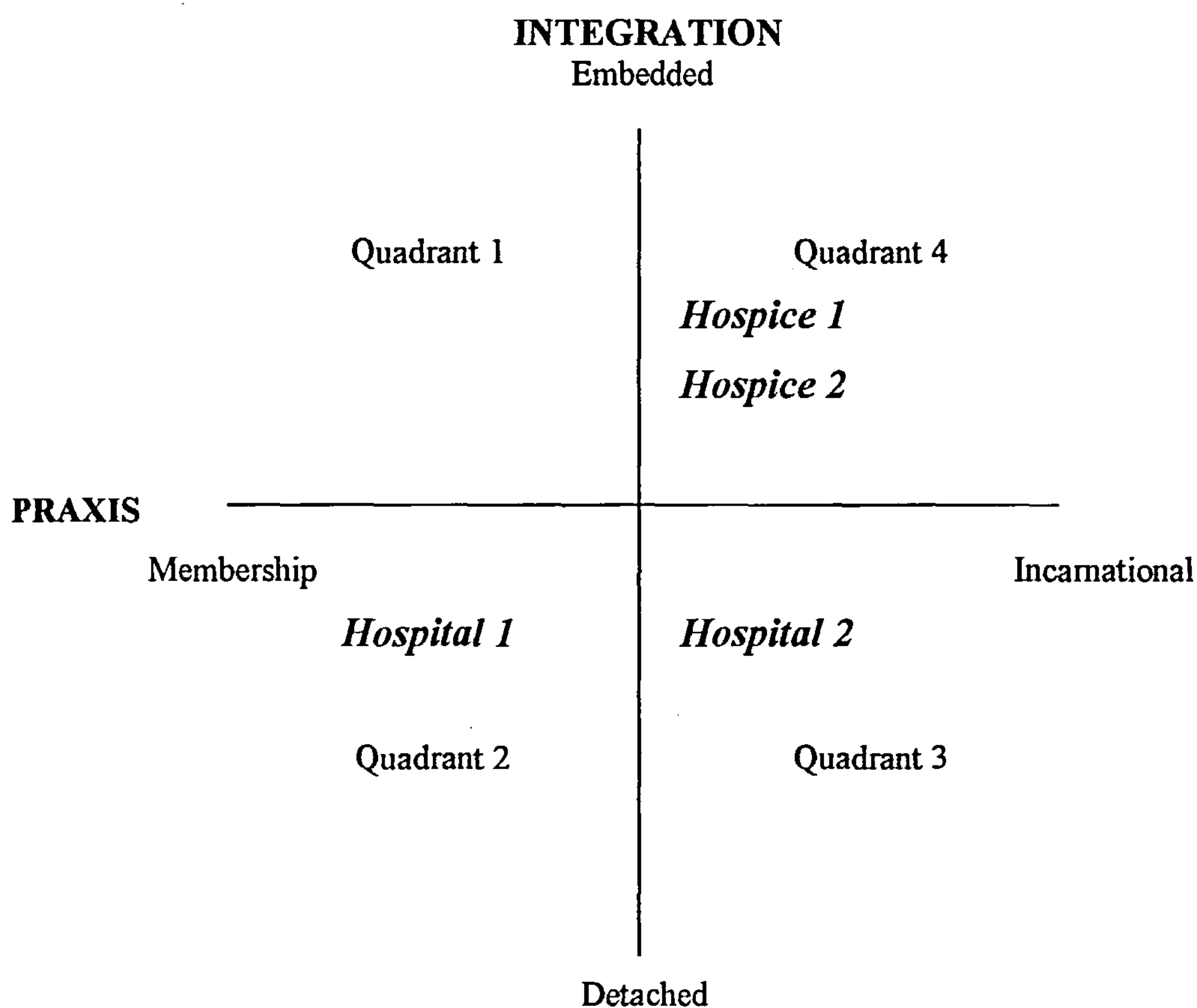
C/E = Church of England, J = Jew, RC = Roman Catholic, JW = Jehovah's Witness

*Chaplaincy styles.* A clear divide was evident between hospitals and hospices along the continuum of integration (Figure 6). The hospice chaplains were firmly embedded in the structures and organisation of their institutions. They regarded themselves as being part of a team. Their contribution was valued. The hospice itself appeared to be a 'spiritual institution'. By contrast the hospital chaplains regarded themselves as being detached from their institution. In hospital 1, the chaplain regretted cutbacks to services. He associated himself strongly with an 'overloaded' workforce and adopted the role of commentator to the NHS trust on the quality of patient care. In hospital 2, the chaplains saw themselves associated with a 'cinderella department' - routinely kept in the dark and infrequently consulted. Consequently, they adopted an 'alongside role' in relation to the trust that identified areas for improvement.



With regard to praxis, three of the four institutions adopted an incarnational approach to ministry. The chaplain of hospital 1 however, saw his primary role in terms of meeting the religious needs of patients and forging links between the hospital and their local church communities.

**Figure 6** Chaplaincy styles within each setting



### Discussion

A striking feature of this study is the context within which spiritual care is delivered. In a hospice with 16 inpatient beds, the chapel – prominently situated within a few metres of each part of the hospice - has a visible impact upon the physical landscape. A chaplain is employed on a whole time basis. Staff consider they have adequate time to listen to patients. By contrast is the acute university hospital with over 1100 beds, served by the

equivalent of 3 whole time chaplains. Patients stay for an average of 3 to 4 days. The surgical unit is a busy place, where physical care assumes a high priority, particularly post-operatively. Staff consider time to be at a premium.

Within such extremes, the management of spiritual care takes different forms. Communication is important. In the smaller hospice, the chaplain may find many opportunities to talk with patients, and spiritual needs may be routinely discussed at meetings of the multidisciplinary team. In the larger hospital, some reliance is placed on patients knowing the services that are available to them and how they may be accessed to meet individual needs. Chaplaincy visitors fulfil important roles, frequently operating as both chaplaincy representatives and frontline caregivers - factors also noted in Orchard's (2000) London study. Significantly, although the chaplains did not know which patients were to be included, nor the wards where they were to be found, enquiries revealed that all 4 patients interviewed in the acute hospitals were known to chaplaincy personnel.

The range of styles identified amongst chaplains fall within three of the four quadrants of the chaplaincy styles model (Figure 4). With regard to praxis, it is perhaps unsurprising that in an institution that attempts to cater for everyone, the majority of ministers adopted an incarnational approach, espousing inclusiveness and availability to all. In view of the established nature of the Church of England, it may have been assumed that the Anglican chaplain would be amongst those who displayed an incarnational perspective. In this case, however, the chaplain who focussed upon church members belonged to the Anglican Church; those who ministered equally to all belonged to the Roman Catholic, Methodist and Baptist Churches.

Also interesting is the clear divide along the continuum of integration: hospice chaplaincies embedded in their institution, hospital chaplaincies detached. Questions arise as to whether smaller institutions - where management is closer to the workforce - have opportunities to create a greater feeling of belonging than larger institutions. This may especially be the case in a small health care unit that has a single focus to its work, values teamwork, and creates space for chaplains to make a distinctive contribution. Both chaplains speak thus of their own institution. As a result, their institutional relationship is characterised by ownership and alignment.

Within the hospitals, chaplains clearly felt themselves to be distanced from the discussion and decision-making forums of their institution. Questions arise as to why this has happened. Is size a factor? Diversity? Changing values? Line management? Or does it relate to tensions generated at the interface between religious bodies and secular institutions? In view of this distance - and the lack of a voice at the managerial level of the institution - the chaplains have come to emphasise that which they think management *should* hear from them, rather than what management may *wish* to hear. Consequently, in the absence of any formative influence upon the institution's philosophy and direction, ownership and alignment have attenuated in the face of judgement and prophecy.

The data provide strong evidence of the central role played by nurses, particularly in relation to spiritual assessments (Table 22). A striking feature of this enquiry is that within both hospitals, nurses are solely responsible for such assessments. This is interesting in light of the fact that spiritual care training featured 'hardly at all' or 'not all' in the initial training of all 10 hospital nurses - and that similar findings were evident in the post registration training of 7 of the nurses. This lack of training suggests that nurses may be reticent to enter the spiritual domain of patients

(Narayanasami, 1993; Dyson et al, 1998) - a point underlined by Ross (1998) who, in her study of the perceptions of nurses conducted in 1990, found only 18% of nurses were willing to help patients meet their spiritual needs. This resonates with Hockley's (1989) finding: that nurses in the acute hospital experience difficulty just 'being with' a patient and spending time with them.

In this study, however, it is interesting that 7 out of 10 hospital nurses feel 'quite comfortable' or 'very comfortable' in the spiritual domain, even though they are not involved in it as frequently as hospice nurses. Speculation may arise about the source of this comfort. Could it be found in the fact that initial spiritual assessments often utilise a checklist – safe to administer - designed to gather factual information about a patient's religious affiliation or wish for a special diet? Perhaps – though consideration may also be given to another possibility: that nurses are beginning to feel more secure within the spiritual domain now that religious interpretations are less frequently expected. Seen in this light, the finding that nurses from hospital 1 did not think any religious requirements arose frequently amongst patients, assumes greater proportions.

## **Concluding comments**

In this chapter, I detail the research undertaken during Phase 3 of the project: a multiple case study that sought to determine how the spiritual requirements of patients with cancer are identified and met within the hospice and the acute hospital.

The separation of religion from spirituality has become a marked feature of current thought. Consequently, although the caregiving of chaplains may include a unique denominational role, a broader role that relates to the spiritual activities of transcending, finding meaning and connecting has come to attract a wider ownership: an ownership that includes the psychologist (Johnston, 1998) the physician (Whipp, 1998), the complementary therapist (Workgroup on the Arts and Humanities, 2000) and the nurse (Ronaldson, 2000). For a striking example of this wider ownership see Walter's (1997:29) account of the nurse tutor who excluded the chaplain from her seminars on spiritual care.

A consequence of this wider ownership has led to a patchwork of spiritually aware personnel. Some - such as the chaplaincy volunteers or the nurses found in hospital 1 - have a strong religious faith. Others have no religious faith, yet may relate easily to the spiritual personhood of the confused - or may routinely create time, privacy, and accompaniment for those dying on a busy ward. They include those whose spiritual awareness has been raised through education alongside those who have spent just a little time reflecting upon how their role contributes to the spiritual ethos of the institution. All these in addition to chaplains: all found in this study.

This variable spiritual awareness bears a relationship to the diverse nature of patient spiritualities. Amongst this group of 10 patients, 9 described

themselves as 'not religious' – yet all 10 believed in God, 7 prayed daily and all sought connectedness with other human beings. Although one person claimed to have lost her faith, another found her faith had been strengthened by illness. Significantly, although most of these patients were not churchgoers, they nevertheless returned to the language and imagery of the Church, previously learnt during their childhood. In a sense, familiar landscapes re-appeared as the patients moved towards the end of their lives. This re-emergence – or *pentimento* (Denzin, 1989:81) – has been likened to that within a painting, where shadows of previously drawn lines return and become visible again with the passage of time.

Recognising these re-emerging spiritual patterns is clearly important, particularly at the end of life. In this study, all 6 hospice patients and 1 hospital patient died within 3 months of the interview. Amongst the 6 hospice patients, 5 had a background in the Church of England. A common practice for patients who die in institutions – particularly if they are 'not religious' - is for the local (Anglican) incumbent to visit the bereaved family and subsequently conduct the funeral service. That did not happen in this study. Two patients from hospice 2 had their funeral service conducted by the hospice's spiritual care director (a Roman Catholic). Within hospice 1, one patient had his service taken by the chaplain (a Methodist), the other by myself (an Anglican). In each instance this was due to the relationship that had been established during the patient's stay in the hospice; in particular, because the patient wanted the affirmation of someone to whom s/he was known. As a result, such considerations overrode factors such as common practice or denomination.

This phase of the research clearly indicates i) a spiritual dimension amongst patients who describe themselves as 'not-religious', together with ii) a greater awareness of spirituality iii) a broader ownership of spiritual care,

and iv) a higher level of spiritual activity than is generally acknowledged within health care literature.

## CHAPTER 6

### SUMMARY AND CONCLUSIONS

This chapter is in two parts. In part 1, I summarise the content of the preceding five chapters. I refer to three of the study's major influences that I addressed in chapter 1: concepts associated with illness; health care chaplaincy; and contemporary spirituality - before turning to the major methodological issues that I addressed in chapter 2. I then summarise the three phases of the research: a cross-sectional descriptive survey of the views of hospital and hospice chaplains; a phenomenological enquiry into the perceptions of stakeholders regarding spiritual care; and a multiple case study in four health settings. In part 2, I give an annotated list of the conclusions, making a comment upon each conclusion and a statement about its implications.



## Summary

I began this thesis by identifying three of the major influences upon the study: concepts associated with illness; health care chaplaincy; and contemporary spirituality. In the first section of chapter 1, I addressed the theoretical content of loss, suffering, pain, hope and woundedness - concepts that impact upon the meaning of illness in the experience of both patients and caregivers.

In the second section, I traced the origins and development of health care chaplaincy from 1948 to present, acknowledging the influence of Norman Autton's formative concept of the chaplain-hero and the subsequent emergence of alternative views. I proposed a theoretical framework that combines ways of relating (to the institution) with ways of ministering (to patients). The resulting quadrants represent four paradigmatic chaplaincy styles that locate these variables within theoretical boundaries. As such it provided an additional tool for use during the case study analysis of Phase 3.

In the third section of chapter 1, I detailed some of the wider influences that impact upon contemporary spirituality - such as perspectives on postmodernity and secularity - and set them against the back-drop of philosophical and practical developments in palliative care. I presented an inclusive theoretical model that acknowledges multiple articulations of spirituality and suggests that amongst patients drawn from pluralistic societies, there is no single world view or spiritual source.

In the second chapter I addressed the study's major methodological issues. I stated the overarching question, together with the main aim and objectives, then showed how these impact upon the question of design. I articulated the rationale underpinning the selection of a mixed method design, explored the

notion of triangulation, and showed the appropriateness of the concept of crystallisation. Whist conceding that some depth may have been lost by the adoption of such a design, I argued that it resonates with the multifaceted nature of contemporary spirituality and reflects the breadth of its individual and collective interpretations.

In chapter 3, I went on to outline Phase 1 of the research: a cross sectional descriptive survey of the perceptions of senior chaplains in 151 hospices and 194 hospital trusts throughout England and Wales that was undertaken in the summer of 1999. Data were collected by means of a postal questionnaire, revised in the light of a pilot study. The questionnaires sought information about a) the infrastructure to support spiritual care and b) patient requirements of religious and non-religious spiritual care. The overall response rate was 76%.

The findings indicate

- i) a trend away from establishing chapels as the spiritual focal point within hospitals and hospices
- ii) the development of broader roles for chaplains
- iii) a different level of service provision between hospices with funded chaplaincies and hospices with voluntary chaplaincies
- iv) a wide range of non-religious spiritual care requirements on the part of patients
- v) a more frequent requirement for religious care in hospitals rather than hospices.

In chapter 4, I outlined Phase 2 of the research - a phenomenological enquiry into the essence of spiritual care. Based on the Husserlian tradition, the study sought to discover the essence of spiritual care in the lived experience of stakeholders. Semi-structured, recorded interviews were conducted with 16 participants identified by purposive and snowball sampling. These participants held a variety of roles linked to palliative care and were of different religions and none. The tapes were transcribed, producing around 140,000 words of text - then analysed using NUD\*IST software. Significant statements were identified and clusters of themes compiled. The essence of spiritual care was drawn from the analysis.

In this set of interviews, the data suggest the following:

*Spirituality.* All people are spiritual beings. Spirituality may be expressed religiously or humanistically. Within both contexts, what may be termed 'personhood' (including values and beliefs) and relationships (with self, others, and God) figure prominently. Spirituality transcends the here and now by reaching both beyond and within the self, and has the capacity to search for meaning by addressing the big questions of life and death.

*Prompts to spirituality.* Spiritual activity is prompted by dissatisfaction with materialism and science, by personal experience of life, and by the decline in organised forms of religion. Other prompts relate to the recognition of something spiritual at the centre of life, and a sense of calling or commitment to God. Illness and the prospect of death have the capacity to touch something profoundly spiritual, pulling on the soul and creating opportunities for re-assessment, forgiveness and reconciliation.

*Spiritual care.* Spiritual care affirms the value of each and every individual. It acknowledges the place of cultural traditions and personal relationships. It is based on empathy and non-judgemental love, affirming the worth of each person in the eyes of God. It responds to religious and non-religious spiritual

needs by meeting both the requirements of faith and the humanistic desire for another person to 'be there', to listen, and to love. It acknowledges the dignity and nobility of life, respecting each person as themselves up until the point of death. A wide range of people can deliver spiritual care - although within health care, chaplains are frequently seen as representing both religion and the spiritual domain.

*Difficulties associated with spiritual care.* Difficulties arise due to the varied meanings of spiritual care and the absence of a generally accepted definition. These difficulties are compounded by the close association between spiritual care and the Church, and by the growth of a spiritual care industry. Also problematic is the speed with which patients pass through the health care system, together with the high number of patients involved. These factors contribute to a service that is crisis driven. The presence of cultural or religious inappropriateness is a further inhibitor. In addition, spiritual care incorporates intangible, immeasurable features that contrast sharply with the contemporary focus on high-tech, physical care that has lost the human touch. Running parallel is an increasing lack of confidence on the part of health professionals to enter the spiritual domain of patients, seeking instead what are deemed to be a safe pair of hands. Chaplains are generally seen in this light, but low staffing levels, under-funding, and the demands of spiritual caregiving are sources of tension. Within this scenario, spiritual care frequently becomes substituted by religious care.

*Hopes for the future.* Hopes for the future of spiritual care relate to a desire to do better. Key to improvement is a broader recognition of the spiritual domain and less confusion between the spiritual and the religious. Training staff to recognise both spiritual issues and the needs of religious groups is seen to be crucial. So is the restoration of the human touch and opportunities for staff to take time to listen. For the dying, this involves the adoption of different values and a different perspective. Fundamentally, a more

consistent approach towards spiritual assessment is hoped for, together with an increase in research. While acknowledging that many people give spiritual care, recognition of the chaplain's central, often co-ordinating role is thought to be important. Hopes abound for increased resources, more personnel, the establishment of better networks and a regional office to support chaplaincy.

*Essence.* In this study, the essence of spiritual care is founded on the assumption that all people are spiritual beings. It recognises the relationship between illness and the spiritual domain and acknowledges the possibility of a search for meaning in the big questions of life and death. It responds to religious and humanistic needs by meeting both the requirements of faith and the desire for another human being to 'be there'. Within the context of health care constraints and hopes for service improvements, spiritual care seeks to affirm the value of each and every person based on non-judgemental love.

In chapter 5, I detailed the research that was undertaken during Phase 3 of the project. A multiple case study sought to determine how the spiritual requirements of patients with cancer are identified and met within the hospice and the acute hospital. Purposive sampling techniques were used to identify two hospices and their neighbouring acute hospitals. On each site, semi-structured, recorded interviews were conducted with the senior chaplain and a focus group of nurses. Interviews were also conducted with patients and, where possible, a matched relative. A questionnaire sought the views of five nurses on each site. Other data were gathered from unit documents, policy statements and newsletters.

The 26 interviews were transcribed, producing more than 173,000 words of text. NUD\*IST software was used to analyse the interviews of chaplains and nurses. Biographical techniques were used to analyse the interviews of

patients and relatives, along with Kellehear's (2000) theoretical framework for identifying spiritual needs. Documentary analysis procedures were used for the texts. Data from the nurses' questionnaires were summarised in frequency tables.

The institutions identified spiritual needs using a number of formal and informal means. These included checklists, prompt questions, patient observations and reflection upon conversations. Patient narratives indicated the impact of diagnosis upon self and relationships: the rediscovery of spiritual imagery (pentimento), personal re-assessment and new beginnings. Only 1/10 patient described herself as religious; yet all believed in God, 7 prayed and all sought connectedness. Each service attempted to make patients aware of their spiritual care provision and how that provision may be accessed.

Attempts were made to meet spiritual needs by providing physical resources (such as a chapel or multifaith room), and human resources (such as a chaplain, chaplaincy volunteers or spiritual healers). Within all institutions patients in the study came into contact with spiritually aware personnel: staff and volunteers who had undertaken training in the spiritual dimension of health care. Worship, sacraments, prayer and rituals were routinely available. Each institution attempted to create a spiritual ethos through notions such as 'valuing the individual' and 'helping the patient to find meaning'. In each case, support was available to staff through education and training. Documentary support included multifaith guidelines and caring for the dying and the bereaved.

These findings signify the presence of i) a spiritual dimension amongst non-religious patients, and ii) a greater awareness of spirituality iii) a broader

ownership of spiritual care iv) a higher level of spiritual activity than is generally acknowledged within health care literature.

## **Conclusions**

*1 All people have the potential to become spiritual beings.*

A recurring theme throughout the research attributed spirituality with an element of mystery that rendered definitions either flawed or meaningless. A consensus emerged in Phase 2, however, to the effect that all humans have the potential to become spiritual beings - thereby confirming a viewpoint that was frequently stated in the literature (Burnard, 1998; Stoll, 1989; Stoter, 1991; Ross, 1994; Hall, 1997; Speck 1998). This does not mean that people are spiritual all the time, nor that all people achieve the same degree of spiritual growth. Rather that human beings have the potential to become spiritual, and that spiritual growth may be recognised and nurtured.

Significantly, a shared understanding of spirituality was prevalent amongst all stakeholders interviewed during Phase 2. In essence, it was regarded as a phenomenon that relates to both personhood and relationships, that may be religiously or humanistically expressed, that seeks meaning in the big questions of life and death, and achieves transcendence by either 'going beyond' or 'going within'. This represents a synthesis of the elements of spirituality widely found in western literature (Autton, 1968; Twycross et al, 1991; Wakefield, 1993; Harrison, 1993; Burkhardt, 1994; Speck, 1995; Wilson, 1999; Reed, 1998; Kellehear, 2000; Cobb, 2001).

*Implications.* Spirituality has common features that cross the boundaries of culture and faith, enabling dialogue between those who subscribe to different faiths or none.

2 *Contemporary publications promote a broad view of spirituality.*

During the course of this research, a wide range of historical and contemporary documents were identified that influenced the shape and development of spiritual care within health settings. Amongst the historical documents, the following were of particular influence were: The Lunatics Act, 1828 (promoting the posts of chaplains in institutions for the insane); Hospital Building note 20: Mortuaries and Post Mortem Rooms, 1933/66 (making chaplains responsible for the oversight of mortuaries); HM (48) 62 (establishing the posts of chaplains in the National Health Service); HM (63) 80 (recommending secretarial facilities for chaplaincy, a room set apart for interviews, recording the religious affiliation of patients); PM (86) 15 (ruling on confidentiality with regard to patient information and local clergy).

Significant contemporary publications include the Patients Charter, 1991 (promoting respect for religious and cultural traditions); and HSG (92) 2 (providing for the spiritual needs of both Christians and non-Christians). Guidelines have also been published by: the International Workgroup on Death, Dying and Bereavement, 1990 (outlining a spiritual context for the dying); Andrews and McIntosh, 1993 (concerning the needs of members of other faiths); NHSE, 1995 (suggesting a framework for spiritual care); NAHAT, 1996 (outlining a vision of spiritual care in the NHS). In addition, Health Care Chaplaincy Standards were published in 1993. The most recent



handbook for chaplains -published by The Hospital Chaplaincies Council – appeared in 1987 after earlier publications in 1951 and 1978.

Although earlier documents equated the spiritual with the religious, a clear shift in emphasis became discernible in the later documents – 1990 onwards. Whilst stressing that patients should always have access to a minister of their faith, writers have taken the view that spiritual care transcends the boundaries of religion. Within this broader perspective, recommendations have focussed upon the wider role of chaplaincy. In particular: should it re-invent as a department of spiritual care? Some chaplaincy departments (see The Queen's Medical Centre, Nottingham), have already followed this guidance, changing both their name and emphasis. Others are currently re-structuring (see St Christopher's Hospice newly formed Department of Psychosocial and Spiritual Care). By appointing a director of spiritual care, rather than a chaplain, hospice 2 of the case study has also followed this trend.

*Implications.* Although the literature extols the advantages of a broader spiritual view, the precise relationship between chaplaincy and spiritual care remains to be fully debated and still lacks clarity. Whilst many chaplains appear to favour the broader spiritual role, a change of name and emphasis is not insignificant. Questions are raised about purpose, recruitment, training and accountability, especially in cases where chaplaincy becomes subsumed under another name or discipline.

- 3 *The publication of information regarding spiritual care provision by hospices and hospitals is sporadic.*

Within Phase 3, the hospices and hospitals went to some lengths to raise the general awareness of their spiritual care provision. Both the hospices and hospitals gave spiritual care information on admission and each of the four institutions had devised a chaplaincy statement on spiritual care. In addition, hospices 1 and 2 and hospital 1 had produced a unit statement on spiritual care.

This was not the case nationally, however. Within England and Wales (Phase 1), the frequently stated claim that palliative and holistic models of care are spiritually inclusive, was not universally reflected in an institution's literature. Although 68% of hospices purported to give spiritual care information on admission, the finding that only 57% of hospice units and 45% of hospice chaplaincies issued statements about spiritual care is significant. In view of the rhetoric surrounding the spiritual dimension of palliative care, these latter figures are surprising and compare unfavourably with acute NHS trusts. Within the hospitals, 75% purported to give spiritual care information to patients on their admission - and although only 40% of hospitals issued a unit statement, 78% of hospital chaplaincies had drawn up a departmental statement.

*Implications.* In that spiritual care is a widely publicised component of palliative and holistic models of care, patients may make assumptions about the ability of an institution to articulate its standpoint and policy on spiritual care. This is especially the case for those patients who regard spirituality as being personally significant.

4 *Multifaith guidelines are not universally available.*

Although each of the hospices and hospitals in the case study (Phase 3) had guidelines on multifaith issues readily available, this was not the case nationally (Phase 1). In that 14% of hospitals and 40% of hospices had no multifaith guidelines, questions inevitably arise about the ability of those institutions to respond quickly and appropriately to a broader range of spiritual and cultural requirements, should the need arise.

*Implications.* The hospital figure suggests that some trusts did not perceive the need to meet the requirements of the Patients Charter - and the hospice figure adds weight to the view that such institutions are driven by a basically Christian perspective of human spirituality.

#### 5 *Spiritual assessments lack coherence.*

The case study (Phase 3) revealed that each hospice and hospital had procedures in place to make an assessment of the spiritual requirements of patients. These included formal methods – such as the use of checklists, discussions at multidisciplinary team meetings, and structured reflections upon patient conversations; and informal methods - such as the awareness of a patient's demeanour, obtaining the perceptions of family members, and listening to the questions of patients.

Nationally however, the picture showed a lack of coherence. The finding that 12% of hospices and 29 % of trusts within England and Wales do not assess the patients' spiritual, religious or cultural requirements suggests a general discomfort amongst some sections of the service regarding the spiritual domain. Although the figure is lower for hospices than for hospitals, it is surprising in view of the

professed inclusiveness of palliative care. Where assessments are undertaken, around three quarters of hospices include items about worship, sacraments and a preference for the patient's own minister; less than half of the hospitals include these items. This suggests a lack of consistency about the practice of spiritual assessment, and the absence of a consensus about what spiritual assessments should include.

*Implications.* Deficiencies are evident in the area of spiritual assessment. Services would benefit from guidelines that encourage confidence and consistency.

6 *Nurses are involved with around 90% of spiritual assessments and make around 50% of such assessments unassisted.*

Nurses had a particularly prominent role to play in the area of spiritual assessment. Amongst the 20 nurses who completed questionnaires during the case study (Phase 3), spiritual care education had featured 'hardly at all' or 'not at all' for 9/10 hospice nurses and for all 10 hospital nurses. Post registration, however, spiritual care training had featured 'prominently' or 'very prominently' for 9/10 hospice nurses as opposed to 3/10 hospital nurses. Yet 19/20 nurses considered they were involved with spiritual assessments - and 2 hospice nurses and all 10 hospital nurses claimed to undertake spiritual assessments unassisted.

The national survey (Phase 1) revealed similar figures. Within England and Wales, the nurse was involved in around 90% of spiritual assessment. Significantly, around 50% of nurses in both hospital and hospice undertook spiritual assessments unassisted.

*Implications.* As spiritual assessments depend heavily on nurses, questions arise as to nurse education and training, lending further weight to the argument for a consistent, user-friendly approach to such assessments.

- 7 *The 1990s has seen a developing trend within both hospitals and hospices away from the establishment of chapels.*

Although chapels have traditionally been regarded as a spiritual focal point within hospitals and hospices (Hospital Chaplaincies Commission, 1951), the recent growth of multifaith rooms has become indicative of changing perceptions. These were evident during Phase 2 when stakeholders suggested that the time had come to recognise different traditions - that chapels were insufficient to meet the needs of a changing population, and that Christians must learn to share their sacred space.

This shift in emphasis is not insignificant. Within hospitals, the 73 hospital chapels opened during the 1990s were outnumbered by the establishment of 86 multifaith rooms – 91% of the total. Within hospice, the data suggesting that 17 hospices with chapels had recently opened multifaith rooms, and that 9 hospices had opened multifaith rooms instead of chapels, shows that the change in emphasis is not confined to the NHS.

*Implications.* These developments indicate a significant shift in the physical resources designed to support spiritual care within both hospital and hospice. Questions arise, however, about the location of

an institution's spiritual focus, and about the place of religious objects in spaces set aside for the use of faith traditions.

8 *Illness may become a prompt for spiritual re-assessment and new beginnings.*

Previous evidence – largely anecdotal - indicates that illness has the capacity to become a catalyst for spiritual growth (Ainsworth-Smith and Speck, 1999; Singh, 1999; Elsdon 1995; Kearney, 2000); it is a view confirmed by this study.

As patients told their stories during Phase 3, they did not hide their shock on hearing they had cancer. The impact of their diagnosis - on themselves and on their families - was vividly portrayed. Feelings of outrage, sadness and loss were graphically acknowledged. Yet almost paradoxically, the patients also disclosed that having cancer had brought them some 'benefits': finding a reason to live, having time to think, arranging new priorities. As one patient confessed to being born again and another embarked upon a closer relationship with her estranged daughter, the tacit awareness of new beginnings was overtly expressed. New shoots had appeared amongst the wreckage.

*Implications.* As patients assess the impact of their diagnosis - on their lives, their priorities, their assumptions and behaviours - the spiritual domain is not excluded and should not therefore be underestimated.

9 *Patients articulate their spiritual (re-) awakening through religious imagery that stretches back to childhood (pentimento).*

A feature of this study is the easy manner whereby non-religious patients told of their previous association with the Church. Sunday school, confirmation classes, choir membership and youth activities were vividly recounted. In many cases, once-forgotten prayers had been re-discovered - brought forward and incorporated into newly established routines. Some patients favoured set times for prayer; others had a conversation with God throughout the day. This may be considered remarkable for patients who generally eschewed contact with the Church during all of their adult lives. It may also be thought remarkable that this re-awakening was informed by the religious values, imagery and language encountered during childhood – a gap of over 80 years for one patient.

This is a striking case of *pentimento* - a term used to describe an image that has been painted over and obscured, but which becomes visible again with the passage of time (Denzin, 1989: 81). In the case of patients, that which has newly appeared – an interest in the spiritual - is something that had previously been hidden: a spiritual memory left to one side until it assumed irresistible proportions in the biography of the individual. In a sense, the patient's narrative has twisted and turned - exploring each and every resource - in an attempt to find meaning in the unique experience of illness she has come to call her own. In such circumstances, the re-discovery of a spiritual memory may be regarded as a resource.

*Implications.* It should not be surprising that patients who describe themselves as not religious, appear to discover an interest in the spiritual domain and a desire for prayer. The language and imagery of childhood, however, may not always be appropriate to the adult

situation. Guidance towards a meaningful language may be appreciated in these circumstances.

10 *Patients have a strong desire for transcendence.*

The 'need' for transcendence features prominently within health care and related literature (Travelbee, 1971; Colliton, 1975; Stoll, 1979, 1989; Ellis, 1980; O'Brien, 1982; Carson, 1989; Gill, 1989; McFadyen 1990; Harrison, 1993; Reed, 1998; Kellehear, 2000). Although chaplains surveyed during Phase 1 did not consider transcendence to be a high priority amongst patients, evidence from the patients revealed otherwise. Kellehear's (2000) theoretical framework indicates the ways in which patients may achieve transcendence. In that these include: situational transcendence (achieved through affirmation, social presence and connectedness); moral and biographical transcendence (achieved through prayer, the discovery of peace, and a sense of closure); and religious transcendence (achieved through divine support, belief in an afterlife, and the support of faith leaders) - recognition was given to a more coherent range of vehicles than has previously been identified. In practical terms, this study confirmed the relevance of Kellehear's theoretical model.

*Implications.* A greater awareness of the vehicles through which transcendence may be achieved would be likely to enhance the sensitivity of health professionals towards the patient's search for meaning.



- 11 *Spiritual care seeks to affirm the value of each and every person, based on non-judgemental love.*

During the past 10 years, the term 'spiritual care' has come to occupy an increasingly prominent position within health care literature (International Workgroup on Death, Dying and Bereavement, 1990; Department of Health, 1991, 1992; Andrews and McIntosh, 1993; Speck, 1995; NHSE, 1995; NAHAT, 1996, Speck 1995; Cobb 2001). Its use is not unproblematic, however. Related to 'spirituality' it is beset by similar problems of definition and parameters.

In an unequivocal consensus, the stakeholders interviewed during Phase 2 of this research considered that spiritual care seeks primarily to affirm the value of each and every individual, acknowledging the place of cultural traditions and personal relationships, and based upon non-judgemental love. Believers also wished to acknowledge the worth of every person in the eyes of God. This confirms previous thinking that regards spiritual care as being concerned with a partnership relationship (Speck, 1995:36) based on equality, respect and commitment (Stoter, 1995:155) that makes a contribution to the patient's sense of well-being (Cobb 2001:86).

*Implications.* By both including and transcending the realm of the religious, contemporary notions of spiritual care impact upon a broad range of religious and non-religious dimensions of care.

- 12 *Spiritual care is currently seen in the light of a broader ownership and a more integrated approach.*

A striking feature of this research is the number of spiritually aware personnel who came into contact with the patients interviewed during Phase 3. It is perhaps unsurprising that during Phase 2, chaplains and ministers of other faiths were regarded as spiritual caregivers. However, doctors, nurses, members of the multidisciplinary team and – significantly - all empathetic staff were also identified as caregivers. This resonates with the view of the chaplain of hospital 1 (Phase 3), who stated that spiritual care and quality care were synonymous. It further echoes the view of Patient E (a non-practising Jew) who identified love as the key ingredient of spiritual care - and that love was always acceptable, whatever its source.

*Implications.* These new data suggest that since spiritual care has assumed a broader ownership, the number of spiritual encounters within health care has been under-estimated.

- 13 *Someone to listen and someone to 'be there' are the most frequent non-religious requirements of patients.*

Human companionship from compassionate people is seen as the key ingredient of non-religious spiritual care. Eighty-nine percent of both hospital and hospice chaplains, and all 20 nurses across 4 health settings who completed questionnaires during Phase 3, thought that patients most frequently needed someone to listen to them. Someone to 'be there' – in the sense of sharing the patient's space and being with the patient in a supportive way (Speck, 1995:24) - followed closely behind across all measures. It is in this context that illness has come to be seen as a call for stories amid metaphors of journey and accompanying (Sontag, 1979; Kleinman, 1988; Frank, 1991, 1995; Stoter, 1995; Hawkins, 1999).

*Implications.* In view of the confusion surrounding the spiritual domain, a clearer understanding of the place and value of non-religious spiritual care would be advantageous to practitioners.

- 14 *Concern for relatives, suffering, and death and dying are the most frequently addressed non-religious issues.*

The commonality of perceptions amongst chaplains during Phase 1 and nurses during Phase 3 in relation to patients' frequent desire to address spiritual issues is striking. Amongst 11 items, concern for relatives and issues around the patient's own death and dying, were two of the most frequent concerns amongst all respondents in both hospice and hospital. The third most frequent response was split between pain and suffering. These concerns were also reflected in the patient narratives, for example: Patient D expressed anxiety about not being able to support his wife as his own condition deteriorated; Patient A hoped for a peaceful death; and Patient F was anxious to know how medical staff would realise she was in pain when she could no longer speak. Significantly, these issues raised practical questions for the patients and appeared to be of a higher priority than issues such as why me? the afterlife, and the nature of God.

*Implications.* Patient requirements for someone to listen, someone to 'be there' and someone to facilitate the exploration of spiritual issues do not of themselves necessitate the presence of a chaplain, so long as an empathetic person is available.

- 15 *Holy communion, prayer and worship are the most frequent religious requirements of Christian patients.*

Amongst 9 religious items, chaplains within both hospices and hospitals were of a common mind: that holy communion, prayer and worship are the most frequent religious requirements amongst Christian patients in England and Wales. A different perspective was evident amongst nurses in Phase 3: six out of ten hospice nurses thought holy communion was most frequently required, followed equally by prayer and the last rites. Hospital 1 did not recognise any frequent religious requirements; two out five nurses from hospital 2, however, thought that last rites were most frequently required.

Although findings from the larger sample of chaplains clearly carry more weight, data from the nurses is interesting in two respects: i) last rites feature prominently amongst nurses in the three institutions that recognise frequent religious requirements, and ii) nurses who were solely responsible for undertaking spiritual assessments in hospital 1 did not recognise any frequent religious requirements amongst their patients – raising questions about their spiritual awareness and training.

#### *Implications.*

Within the broad patient base covered by hospices and hospitals, both non-religious and religious spiritual requirements will inevitably be found amongst individual patients. In the event of religious requirements being identified, patients will need access to a minister of their tradition.

16 *Difficulties arise within spiritual care due to the absence of a generally accepted definition, the close association between spiritual*

*care and the Church, and the speed with which patients pass through the health care system.*

Problems posed by confusion between the spiritual and the religious cannot be over-emphasised (Speck, 1988, 1998; Narayanasami, 1993; Harrison, 1993; Elsdon, 1995; Oldnall, 1996; Ross, 1997; Dyson et al, 1997; Hilliard, 1998; Golberg, 1998; McSherry, 1998). A burgeoning literature bears witness to the difficulties still encountered in this area. These difficulties were underlined by stakeholders during Phase 2, who considered that in the light of current misunderstandings, nurses were becoming increasingly reluctant to enter the spiritual domain of patients.

*Implications.* Training programmes that assist health professionals to recognise distinctions between the spiritual and the religious would help minimise confusion and bring a sharper focus to what may be required by patients.

17 *Chaplains are coming to adopt a broader role within health care.*

A comparison of the chaplain's duties reported by the first Commission of the Hospital Chaplaincies Council (1951) and the findings reported in this study, shows how the role of the chaplain has changed over the years. Some things remain constant: the spiritual care of patients and staff; the conducting of services; the administration of the sacraments; and the care of the dying. These functions are currently recognised as part of the chaplain's role by other health professionals (NHSE, 1995; Fraser, 1996; NAHAT, 1996). Gone however, are any assumptions that patients will be visited by a chaplain on the day of their admission (Hospital

Chaplaincies Council Commission, 1951: 5), or that the chaplain will commend every newly-born child and her mother to their local parish priest (1951:6). Both the context and behaviours of chaplaincy have moved on since then.

In the context of changing spiritual perceptions and continuing pressures within health care, these are uncertain days for chaplains. Consequently, chaplains are learning to become managers: of time, finance, resources and personnel. Increasingly, they are being asked to manage a spiritual care service, to monitor activity, contribute to education, undertake audits, liaise with leaders of other faiths, and manage - rather than be involved with - a bereavement service.

The data here confirm that some chaplains have embraced this more professionalised role: others, however, are adopting a more theoretical stance – re-examining the nature of practical theology, questioning the core business of chaplains and re-considering their contribution to the work of the institution (see Sutherland, 2000). This questioning and re-articulation assumes greater significance in view of the Church's increasing involvement in Chaplaincy and the likelihood that this will continue (Gilliat-Ray, 2001).

*Implications.* Within a changing service, a reflective, negotiated articulation of the core and extended responsibilities of chaplains may be seen as a priority if a dislocation of expectations between management and chaplaincy is to be avoided.

18 *Hospice chaplains are more integrated into their institution than hospital chaplains.*

Although the proposed framework for analysing chaplaincy styles was only utilised in the four 4 settings of Phase 3, the results are both interesting and encouraging. Within the chaplains' interviews, data that allowed their professional styles to be recorded along the two continuums of praxis and integration could be clearly identified. As these data originated in statements of belief or perceptions of reality, I argue that they are indicative of how individual chaplains have come to resolve the tensions of ministering to everyone or prioritising the needs of the faithful; of being immersed in the institution or standing prophetically detached from it.

It was surprising however, that from such a small number, the individual styles of the 4 chaplains were spread across 3 quadrants. Also surprising was the finding that the 2 hospice chaplains were embedded in their institutions while the 2 hospital chaplains were detached. Attempts may be made to discover the reasons for this difference by undertaking comparisons between the two types of institution. Whilst this may be helpful, the element of personal conviction should not be overlooked.

*Implications.* The framework has provided some initial indications of its usefulness – a factor that would be illuminated by further research.

19 *Chaplaincy is almost exclusively Christian and dominated by the Church of England.*

Although 18% of voluntary hospital ministers represent faiths other than Christian, this is not reflected in chaplaincy funding within either hospitals or hospices. The finding that 98% of funded hours were allocated to Christians in hospital chaplaincies (60% to

Anglicans) and 99.5 % of funded hours were allocated to Christians in hospice chaplaincies (70% to Anglicans) suggests that within England and Wales, spiritual care is largely operationalised within a Christian context and tradition.

*Implications.* Unless NHS trusts and hospices review current policies governing the recruitment of ministers, both the under-funding and under-representation of those belonging to faiths other than Christian are likely to continue.

20 *A higher level of service provision is evident in hospices with funded chaplaincies.*

A striking feature of this study is the positive association between hospices with funded chaplaincies and other variables relating to responsibilities and resources. In particular, hospices that funded chaplaincy were also likely to provide chaplaincy accommodation, access to a patient database and a dedicated budget – together with a role description that included spiritual care education, liaison with religious leaders, and the management of bereavement care.

*Implications.* Commitment to funding appears to be the catalyst for an articulation of the chaplain's role expectations and resource needs.

21 *There is a higher demand for religious care in hospitals than in hospices.*

This is surprising and raises questions about why it is so. Perhaps a clue may be found amongst the Phase 2 data, where stakeholders pointed to the difficulties of a scenario in which a small number of



chaplains ministered to a large number of patients who passed through the acute hospitals with some speed. Given the nature of the service and the number of patients requesting religious care, it may be that religious functions play a larger part of the chaplain's total ministry than in the smaller hospices. Chaplains in Phase 2 hinted at this point when they said that spiritual care frequently focussed upon religious care.

*Implications.* This conclusion appears to confirm the view that within the smaller environment and gentler pace of the hospice, more time can be spent on activities that have come to be known as 'finding meaning' or 'sharing the patient's journey'.

## END NOTE

In contemporary health care, the metaphor of the 'journey' is frequently mentioned. Some find it meaningful and helpful. I usually find it limiting and constraining. To me it conjures up notions of purpose and intent, landscape and perspective, vision and movement where in reality, none may exist. And how does the concept of distance transfer from the temporal to the ethereal? So I frequently find that the term raises more problems than it solves.

That said, I consider the metaphor of 'journey' to be appropriate to this present study. With a clear beginning and end, a purpose and a structure and guided by probing and stimulating supervisors, it became the framework for both academic discovery and personal growth. The iterative, mixed method design incorporated reflexivity and encouraged a personal engagement with the data. As such, the study incorporated the capacity to become genuinely developmental - seen at its clearest in the move from Phase 2 to Phase 3.

With the benefit of hindsight, the mixed method design presented a number of challenges. It meant coming to terms with different world views, handling a variety of methodological concepts, learning the skills of questionnaire design and selecting between transcendental and existential phenomenological approaches. After the first two phases were completed, it then meant using the findings to inform the construction of a multiple case study that addressed key questions with patients, relatives and health professionals, all the while ensuring that the three distinct phases remained part of a unified whole. Notwithstanding these challenges, I consider that this design has been a major success of the study and a vehicle through which large quantities of new data could be placed in the public domain.

Another landmark was the ability to place the perceptions of patients and their carers 'on the record' – a gift, graciously offered, that I do not underestimate. Most of these patients were coming to the end of their lives. For some, death was very close. The interview was a physical struggle and rest periods were essential. Yet the patients were willing – determined even - to share their thoughts and feelings around this personal and sensitive area.

For me, a hospital chaplain who was not unfamiliar with patient conversations held close to death, the process of gaining informed consent and the management of equipment needed to undertake the recordings were new experiences. In such circumstances, ethical issues were inescapable. Such issues also influenced how the data, once collected, was handled: hopefully with care and respect, a sense of responsibility and a desire to keep the life stories of patients 'intact'. For these were the recordings of people I knew; who allowed me to share their time that was so precious; who had not recoiled from the difficult areas, and in one case - who decided at our first meeting that I should conduct his funeral service: a growth point in my personal journey.

As the study moved into its final year, other, surprising things happened. Professor David Clark (who supervised this project), invited me to undertake a one year project with him designed to gather information about the development of palliative care services in Eastern Europe and Central Asia: twenty nine countries in all, from Albania to Mongolia and Latvia to Uzbekistan. Part of that project has involved case studies of five 'beacon' sites that are setting a lead in palliative care in their countries and regions.

As a result, I have gathered data in Slovenia and Poland, undertaken case studies in Warsaw and Poznan, St Petersburg and Budapest. These case studies have involved interviews with health professionals; discussions with

patients; the gathering of documentary records, the collection of information about fund-raising and educational provision. In short, employing a similar methodology to that used during Phase 3.

Significantly, the project in Eastern Europe draws very much on the skills learnt in this present study: how to adopt a broad perspective, an accepting approach, a recognition of the commonality and differences of human experience and an acknowledgement of the variety of religious traditions – all of equal value. A prominent feature has been the perceived level of personal commitment - often in testing circumstances - by people of compassion, determined to alleviate the suffering of others. Another feature has been the overt level of international collaboration that exists at many levels, national and municipal, civic, religious and personal.

Finally, I wish to make reference to the shocking events of September 11<sup>th</sup>: events that have changed the perspectives of human beings world wide and which took place as this study was nearing completion. In themselves, those events contradict everything encompassed by the notion of holistic care. They also make light of that common bond of humanity that transcends nationality, religion and culture.

Amongst the words that flowed afterwards were these that follow, written by a 14-year girl living in New York. For me, writing about the care of the dying against the backdrop of those events, I considered her final words to resonate with my own, broader feelings of unity and hope that are implicit both in the present study and also in the Eastern European study. To me, they provide a forward-looking vantage point from which to end this particular journey.

## **One**

As the soot and dirt and ash rained down,

We became one colour.

As we carried each other down the stairs of the

Burning building,

We became one class.

As we lit candles of waiting and hope,

We became one generation.

As the firefighters and the police officers fought their

Way into the inferno,

We became one gender.

As we fell to our knees in a prayer for strength,

We became one faith.

As we whispered words of encouragement,

We spoke one language.

As we gave our blood standing in lines a mile long,

We became one body.

As we mourned together,

We became one family.

As we cried tears of loss,

We became one soul.

As we retell the stories of sacrifice,

We became one people.

Now we are

One colour

One class

One generation

One gender

One faith

One family

One soul

One people

We are the Power of One.

And now we are united.

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**PHASE 3: INFORMATION SHEET FOR PATIENTS AND RELATIVES**

**1 What is the project about?**

It is a 3-year study investigating the spiritual care of patients.

**2 Why is the project being carried out?**

Because little research has been carried out into spiritual care. The findings will be important for the development of spiritual care in the future.

**3 Who is leading it?**

Rev. Michael Wright. Michael is the chaplain at Doncaster Royal Infirmary. He has been granted study leave to carry out the research and has become a research student at the University of Sheffield. Professor David Clark, from the Department of Palliative Medicine is supervising the research.

**4 What is spiritual care?**

Spiritual care is broadly defined. For some, it might mean making sure there are opportunities to carry out religious practices. It might also mean paying attention to diet, to clothing or to objects the patient considers important.

In particular, spiritual care is about making sure the whole person is cared for. While religious considerations are important, therefore, they are only one part of spiritual care. The other parts are about those things we have in common as human beings: 'being there' for each other, offering support, or being prepared to just listen.

**5 How would I be involved?**

With your permission, I would like to speak with you. I am interested in your 'story' - that is, hearing about the things that are important to you, what it's like to be a patient and where you find your help and support. I would like to record our discussions so that I don't have to make notes or rely solely on my memory.

**6 Is the discussion confidential?**

Yes. Only my supervisor and myself will have access to the tapes. All the tapes will be destroyed when the study ends, and care will be taken to ensure that no person or institution will be able to be identified in any report or presentation.

**7 Who else would you like to interview?**

In addition to yourself, I would like to speak with a member of your family or a close friend. I also intend to speak with some staff. The discussions with staff will be about their own views and experiences, and will not be about you or your care.

**8 How long will the interview last?**

That depends on you. The interview could be quite short or, if you speak for longer, it will be a bit more lengthy. You are in control, however, and you can stop whenever you wish - no questions asked.

**9 Am I expected to take part?**

No. The choice is entirely yours.

**10 Will you want any more information?**

If you agree to take part, I would ask your permission to see if any matters relating to your spiritual care were recorded at the time of your admission, or are recorded in your care plan.

**11 Can I think about it?**

Yes, and please discuss it with your family, if you wish. You will have at least 24 hours after seeing this information before being asked whether you would allow me to speak with you about the project and the interview.

If you decide to meet me, you and/or your relatives can ask any further questions about what is involved. After all your questions have been answered, you will then be asked to consider giving your consent for the interview. If you agree, your consent would be indicated by signing a form, allowing me to visit you and interview you **on another day.**

**12 What happens next?**

This sheet will be collected from you after 24 hours. If you are willing to speak with me, please sign below. Please note that you are only being asked to consider speaking with me about the project. Formal consent to participate is gained on a second form and is not being sought here.

**I am willing to speak with Rev Michael Wright about the spiritual care project and interview.**

Signed.....Date.....  
Name (Capital letters, please)

.....

**PHASE 3: PATIENT/ RELATIVES CONSENT FORMS**

Please tick the boxes which apply:

		Yes	No
1	Have you read the information sheet?	<input type="checkbox"/>	<input type="checkbox"/>
2	Have you had the opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
3	Are you satisfied with the answers to your questions?	<input type="checkbox"/>	<input type="checkbox"/>
4	Who have you spoken to?.....		
5	Do you understand that:		
	(i) you can stop the interview at any time?	<input type="checkbox"/>	<input type="checkbox"/>
	(ii) without having to give a reason?	<input type="checkbox"/>	<input type="checkbox"/>
	(iii) you may have some-one else present?	<input type="checkbox"/>	<input type="checkbox"/>
6	Do you agree to an informal, recorded interview with the researcher, Rev Michael Wright?	<input type="checkbox"/>	<input type="checkbox"/>
7	Do you agree to the researcher consulting your Admission Form and care plan for references to spiritual care?	<input type="checkbox"/>	<input type="checkbox"/>

SIGNED.....DATE.....

NAME (in capital letters, please)

.....

WITNESS.....DATE.....

NAME (in capitals letters, please)

.....DESIGNATION.....

**PHASE 3: SUBMISSION TO ETHICS COMMITTEE**

**HEALTH AUTHORITY  
DISTRICT RESEARCH ETHICS COMMITTEE**

**APPLICATION FOR APPROVAL OF A RESEARCH PROJECT**

**N.B.** All Applicants should answer all questions in Part I.  
Investigators intending to administer Drugs, or use invasive procedures should also complete Part II.

**PLEASE SUBMIT:** 15 COPIES of the APPLICATION, plus  
15 COPIES of the PATIENT INFORMATION SHEET and  
15 COPIES of the PATIENT CONSENT FORM, plus  
15 COPIES of any QUESTIONNAIRE TO BE USED, plus  
3 COPIES of the COMPLETE PROTOCOL and  
1 COPY of the RELEVANT LETTER OF INDEMNITY

1. **NAMES**

Responsible Investigators

Rev Michael Wright

Supervised by

Prof David Clark

Organisation - (Tick as appropriate)

Appointment

Hospital Chaplain/ PhD student

Professor of Medical Sociology

Health Authority	Hospitals Trust
Community Trust	GP Fundholder
Others ( <i>Please specify</i> ) #	University of Sheffield

Does your organisation know of this application? **YES**

2. a) **FULL TITLE OF PROJECT**

b) **Abbreviated Title, if appropriate**

Spiritual health care: An enquiry into the spiritual care of cancer patients.

3. a) Has your protocol been considered by any other LREC **NO**

b) Were any adverse comments made?

c) If yes, what were they?

- 
4. a) Has it been initiated by Investigator? **YES**  
*or* is it part of a multi-centre trial? **NO**  
*or* both?
- b) Please give the Name of Sponsoring Company, and  
Name of Contract Research Company (if different.)
- c) How is the project to be funded?  
Doncaster Royal Infirmary is funding the salary of the researcher  
  
Who will receive any payment to be made in respect of this study?  
No-one
- 

5. **OBJECTIVE**

- a) What is the hypothesis which it is intended to test?

This is a 3 year qualitative study enquiring into the nature of spiritual care within health services. Holistic and palliative care both claim to be spiritually inclusive, yet little is known about how the spiritual needs of cancer patients are identified and met. The main objective of this phase (Phase III) is to explore the perceptions of patients, relatives and health professionals on spiritual care issues.

- b) What practical benefits do you envisage from a successful completion of this project?

A contribution to knowledge and service delivery by gaining a greater understanding of

- The nature of spiritual needs within healthcare settings
  - The process by which spiritual needs are assessed
  - The ingredients and delivery of spiritual care
  - The perceptions of patients and relatives
  - The role of health professionals within the spiritual domain
- 

6. **TIMING**

- a) When do you propose to start recruiting?  
April. 2000
- b) When do you expect to have completed the study?  
May 31<sup>st</sup> 2000
-

## **7. SCIENTIFIC BACKGROUND**

**Spiritual care and chaplaincy.** The National Health Act of 1946 (para 61) prompted guidance (HMC (48) 62) advising hospital authorities that they should provide for the spiritual care of patients and staff: they might also establish hospital chapels and appoint paid chaplains from different traditions. Chaplains, therefore, were seen as key personnel within spiritual care delivery and have remained so during subsequent decades. The Patients' Charter (1991) set a national standard relating to respect for religious beliefs, and HSG (92) 2 offered updated guidance on meeting spiritual needs.

**Spiritual needs within healthcare settings.** A body of literature focuses upon spirituality and the role it plays as a patient confronts illness and death. Spirituality has been traditionally associated with religion, (Butler & Butler, 1996; Narayanasami, 1993) which, in its institutionalised form has the power to address spiritual needs (Harrison, 1997), and bring about a sense of peace and well-being. (Jourard, 1971; Clark et al 1991). Increasingly, however, spirituality is being described as a generic human attribute, unfettered by religious constraints (Renault & Freke 1996; Brussat & Brussat 1996). In essence, it focuses upon the ontological significance of life and the ultimate search for meaning (Martsolf, 1998; Frankl, 1959). Within the spiritual domain, evidence emerges of a strong pattern of relationships between self, others, and 'God' (Dyson et al, 1998); and a unique engagement with the universe (Danvers, 1998). Serious illness confronts and challenges these relationships, giving rise - on occasion - to spiritual distress (Burnard, 1987), or spiritual need (Stoll, 1979).

**The methods by which spiritual needs are identified.** Stoll (1979) published a spiritual history guide based on patient interviews. Other models within health care settings rely heavily on interview techniques, together with the skills of discernment when 'being with', observing, or listening to a patient (Hay, 1989; NAHAT, 1996; NHS (E) 1995; Clark and Heidenreich, 1995).

**The delivery of spiritual care: the role of the nurse.** The nurse is in a prime position to deliver spiritual care. Historically, there are strong links between caring for the sick, and the religious orders (Porter, 1999), and even after Nightingale's secularization of nursing, perceptions of the spiritual dimension of care remained within the nursing tradition (Bradshaw, 1994). Evidence suggests, however, that the concept of spirituality is not generally meaningful to nurses (Goldberg, 1998) and that many approach the spiritual domain with misgivings (Ellis, 1980). Colliton (1975) notes that, since the 1950's, spiritual considerations diminished within the nursing curricula as emphasis on medical technology increased. Narayansami (1993) found that some nurses feel inadequately prepared to deal with spiritual issues and either send for the chaplain or ignore them.

**The patient perspective.** Drawing on the previous work of Van Gennep (1909/1960) and Turner (1977), Froggatt (1997) applied concepts associated with rites of passage to the structures surrounding death and bereavement within hospice culture. She notes that the dying person becomes separated into liminality – a transitional, sacred space – and enters into the experience of 'communitas'. Prior (1999) quotes Arbuckle (1987) who suggests the model of separation, transformation and incorporation is articulated within the planning and structure of retreats, enabling subjects to cross spiritual thresholds. This link between liminality and the possibility of spiritual encounters is significant, and confirms the view of Murray and Zentner (1987) that spiritual issues come to the fore during times of illness.



Briefly describe the results of previous trials, or studies e.g. efficacy, safety, patient numbers etc..

Please include the pharmacological properties of any drugs used.

8. a) Has an investigation of this sort been done previously? **NO**  
b) If YES, why repeat it?

---

9. **DESIGN OF THE STUDY**

- a) Is this a Clinical Trial? **NO**  
If YES, is it:-

<b>PHASE I</b> Study on healthy Human subjects	<b>PHASE II</b> Clinical study on limited patients
<b>PHASE III</b> Comparative study large number of patients	<b>PHASE IV</b> Further comparative study on efficacy and/or use

- b) Describe briefly the design of the study, making sure that you answer each of the following questions:-

**Research Design:**

The research uses a multiphase, multimethod design in three discrete phases. Phases 1 and 2 are now complete. Approval is being sought here for research within Phase III - to be carried out in a district general hospital and a hospice under the jurisdiction of this ethics committee. Each location will be the focus of research for one month.

In each setting, it is proposed

- to collect data from 3 patients and 3 (matched) relatives by means of semi-structured, recorded interviews - 1 interview per subject. The length of the interview will be at the discretion of the subjects: they can stop whenever they wish. The shape of the interview will be based loosely on Stoll's (1979) model. Interviews will take place within the unit in a suitable, mutually convenient location, after consultation with staff
- to conduct interviews with 1 nurse and 1 chaplain
- to administer questionnaires to 5 nurses
- to examine the admission forms and care plans of the patients interviewed for references to spiritual care
- to examine published documents for references to spiritual care

- i) **TYPE OF INVESTIGATION** What type of an investigation is it?

An ethnographic study focusing on the spiritual domain of patients

- ii) **SUBJECT INVOLVEMENT** How long is the trial, and what will a subject's participation in the trial involve?

The researcher will be intermittently involved with the unit for a period of one month. The subject will be met by the researcher after indicating a willingness to find out about the project, and will meet the researcher a second time for the interview to be conducted

iii) **PLACE** Where will the work be undertaken?

Inpatient hospice and hospital. The hospital patients would be drawn from a medical ward. Venue at the discretion of staff

iv) **ASSESSMENT** What are the key assessment measurements to be used? N/A

v) **END-POINTS** What are the Primary and Secondary end-points?

As this is an ethnographic study, the interviews will be transcribed and the contents categorised, coded and analysed with the assistance of NUD\*IST software. These are the endpoints of the study.

vi) **RECRUITMENT** How will subjects be recruited, and how many in the jurisdiction of this committee? Distinguish between patients, patient volunteers, and healthy volunteers.

Staff will be asked to give an information sheet to included subjects which invite them to consider speaking with the researcher about the project. After 24 hours, staff would collect the information sheets. Meetings would subsequently be arranged between the researcher and the patients/ relatives who expressed an interest. At that meeting, details of the research and the interview would be fully explained and the subjects invited to consent. Consent forms will remind prospective interviewees that they may be accompanied, and that if they begin to feel uncomfortable during the interview, the interview will cease immediately.

vii) **SELECTION CRITERIA** What are the main **INCLUSION** and **EXCLUSION** criteria?

Inclusion: inpatients over the age of 18, diagnosed with cancer, who are well enough and willing to be interviewed. Exclusion: young people under the age of 18; non-cancer patients; patients who are not well enough to be interviewed. Health professionals will be fully informed about the research and advice sought from them on these matters regarding patients.

viii) **STATISTICS** What are the statistical grounds for believing that the trial as designed will provide a valid answer to the question posed? N/A

State what statistical advice has been obtained

- a) in preparing the project,
- b) in deciding the number of subjects needed.

ix) **FOLLOW-UP** What follow-up care has been arranged for subjects at the end of the trial, should it prove necessary?

Care will be taken to avoid any distress to patients. However, if a patient begins to show signs of distress, permission will be asked to inform - and seek support from - the patients' key nurse and/or the chaplain.

Will trial drugs be available on a compassionate basis? **NO**

10. **CONSENT OF OTHERS INVOLVED**

a) Will the subjects' GPs be informed? **NO**  
(Please enclose a copy of letter to GPs)

b) Will the consent of others clinically  
involved be obtained? **NO**  
  
(If YES, who, and how will this be achieved?)

c) Do the subjects have parents/guardians/carers  
who should be informed? **YES**

If YES, who are they?  
how will they be informed?

Relatives or friends. Informed by information sheet.

d) Will your research have resource  
consequences for the NHS? **NO**

If YES, please specify briefly. For Clinical trials, please also complete  
section 18 in Part II.

e) Have you discussed the extra workload and/or financial consequences of  
your project with the department(s) and budget holder concerned?

An approach to each of the relevant departments has been made.

f) Has your Organisation's Research and Development Committee given its  
approval? **YES**

If YES, give date and reference.  
Through Professor Clark, research supervisor

11. **INFORMED CONSENT**

- a) Will informed consent be written? **YES**

If **YES**, please state exactly

- i) How the subject will be invited to participate

By signing an information sheet agreeing to discuss participation with the researcher.

- ii) How long they will have to consider the invitation, and consult relatives, before giving consent

At least 2 days. Please see 9 b above

- iii) What the subject will be told about the project and what it is intended to show

The interview guide will be discussed

- iv) What the subject will be told about what the investigation actually entails, including possible side effects.

The subject will be told about the possibility of spiritual distress.

*(REMINDER: Patient Consent Forms, and Patient Information sheets must be submitted along with this proforma.)*

---

12. **CONFIDENTIALITY**

- i) What steps will be taken to safeguard confidentiality of patient records?

No observations from patient records will be linked to a name.

The interview tapes will remain anonymous, labelled only with a number and date; access to the tapes will be limited to the researcher and supervisor; the tapes will be destroyed at the end of the study; no person or unit will be identifiable in any report or presentation.

- ii) If you plan to enter the results of your researches on computer, are you registered under the Data Protection Act? **YES**

If **NO**, what alternative arrangements have you made?

---

13. INDEMNITY

Please outline the Insurance, or Indemnity arrangements pertaining to this trial, and produce evidence of cover, or a letter of indemnity.

N/A

INVESTIGATORS

The information supplied is to the best of my knowledge and belief accurate. I have read the notes to investigators, and clearly understand my obligations and the rights of the patients, subjects and volunteers, particularly as to obtaining freely-given and informed consent.

Signature of Investigator(s)..... *Michael Wipfl.* .....

**Investigator's Supervisor (where appropriate)**  
I hereby endorse this application with my approval:

Signature..... *David Clark* .....

Name (Capitals)..... *PROF. DAVID CLARK* ..... Date..... *31 Jan 2000* .....

**TO BE COUNTERSIGNED (where appropriate) BY CHIEF EXECUTIVE**

This research proposals has been evaluated and I agree to the project being undertaken in the Trust.

Signature..... *[Signature]* ..... Date..... *10/4/00* .....

Name (Capitals)..... *D. COLLINS* ..... Status..... *Director of R&D* .....

**PHASE 3: LETTER FROM ETHICS COMMITTEE (1) REQUESTING  
CLARIFICATION**

15 March 2000

Dear Rev Wright

**TITLE OF PROJECT: Spiritual health care: An enquiry into the spiritual care of cancer patients**

Thank you for attending the District Research Ethics Committee held on 15 February 2000 and presenting the above study.

We are writing to confirm that the following items were requested:-

- i) letter giving R & D approval
- ii) to clarify the contents of page 5 of the application form (i.e. inclusion/exclusion and patient recruitment paragraphs in particular);
- iii) to confirm the tapes used will be destroyed at the end of three years;
- iv) to reproduce the patient information sheet and patient consent form on the appropriate Trust letterheaded paper;
- v) to provide space for the witness signature and date on the patient consent form.

If you could forward these items as soon as possible then final approval for you to conduct your study may be confirmed. If, in the meantime, you have any queries please contact Cynthia when every assistance will be given.

We await hearing from you in due course.

Yours sincerely,

*J. A. Barden*

Judith A Barden (Mrs)  
Chairman  
District Research Ethics Committee  
(Signed for and on behalf of)

**PHASE 3: REPLY TO ETHICS COMMITTEE (1)**

**Your ref: LREC/00/02/083**

Dear Mrs Barden,

**TITLE OF PROJECT: Spiritual health care: An enquiry into the spiritual care of cancer patients**

Further to your letter of 15<sup>th</sup> March 2000, I should be grateful if you would find the enclosed documents:

- 1 letter giving R & D approval
- 2 a revised page 5 to clarify the points about patient recruitment and inclusion/exclusion criteria
- 3 patient information sheets and consent forms on Trust and hospice letterhead paper

Please note that on the revised patient consent form space is included for witness signature and date, as requested

Finally, I confirm that the tapes used will be destroyed after 3 years.

I should be grateful if consideration could be given to finally approving the research as soon as is convenient.

Thank you for your consideration.

Yours sincerely,



M C Wright (Rev) 

**PHASE 3: LETTER FROM ETHICS COMMITTEE (2) REQUESTING  
CLARIFICATION**

Dear Rev Wright

**Project No. 00/70: Spiritual health care: An enquiry into the spiritual care of cancer patients within the acute hospital and specialist inpatient palliative care unit**

Your study was discussed at a recent meeting of the Ethics Committee and there are a number of points we would like you to address:

- 1 How will you select the subjects to be interviewed from those people who express an interest in taking part in the research?
- 2 Do you propose to produce separate information sheets for the other groups to be interviewed?
- 3 The requirement for patients to sign a form even if they are not interested in taking part in the research is felt to be unacceptable. It would be more appropriate to ask people for a signature only if they would be willing to become involved.
- 4 Could you clarify whether you have obtained the approval of the Trust or the consultants responsible for the patients to undertake the study.

Yours sincerely

*Ann Prothero*

✓ Dr P R F Dear  
Chairman



**PHASE 3: REPLY TO ETHICS COMMITTEE (2)**

As requested, I address the points itemised in your letter, as follows

10 June 2000

- 1 **Selection of subjects.** Only 3 patients (and 3 matched carers) are required from each site - [REDACTED] In view of the very small numbers, there will not be any general distribution of information.

The process - successfully followed elsewhere in this study - will be to liaise with ward staff about the purpose of the research and then trust to their discretion about the identification of patients who fall within the inclusion criteria. Only such patients will be given the information sheet and, and if interested, invited to consent. Crucially, however, each patient will be identified individually and approached singly; when 3 patients have consented, the process will cease.

- 2 **Information sheets for other groups.** I do not propose to produce separate information sheets for other groups to be interviewed, since these groups are made up of only 1 chaplain and 1 nurse. Experience has shown that any extra information can be provided personally.

- 3 **Patient signature.** I have amended the Patient Information Sheet to comply with your view that only patients interested in the research should be asked for a signature. (Copy enclosed)

- 4 **Trust approval.** Similar research is currently being undertaken at another hospice and another hospital with the approval of the appropriate ethics committee. The process after approval has been as follows:

- Preliminary contact between myself and the Trust/ hospice to discuss how best to proceed
- A presentation to ward manager(s)/ and interested staff
- Setting up a communication system for information re suitable subjects and timing of information to them
- Consultation re timing of patient/ carer interviews

Regarding this application:

- a) I have met with Dr [REDACTED] to discuss the implications of the research and to identify appropriate strategies
- b) I have written to [REDACTED] Manager, asking if I might liaise with her and elicit her advice about how to proceed once approval has been given. She has a full copy of the protocol and interview guides.
- c) I knew the Trust's previous chaplain, [REDACTED], and intended to contact the Chaplaincy Department to seek supplementary advice - and arrange an interview. As he has left the Trust, I decided to approach the Department once approval has been granted.

My intention, therefore, is to consult fully with appropriate managers and ward staff - securing their trust and approval about the process of the research - and then to proceed carefully, in line with any specific requirements of either the hospice or the ward, in order to avoid any inconvenience to patients, carers or staff.

**PHASE 3: APPROVAL - ETHICS COMMITTEE (1)**

11 May 2000

Dear Rev Wright

**TITLE OF PROJECT: Spiritual health care: An enquiry into the spiritual care of cancer patients**

We would like to acknowledge receipt of your letter dated 20 April 2000 together with the enclosed documents forwarded to us in response to the queries raised at the District Research Ethics Committee meeting in February when you presented the above study.

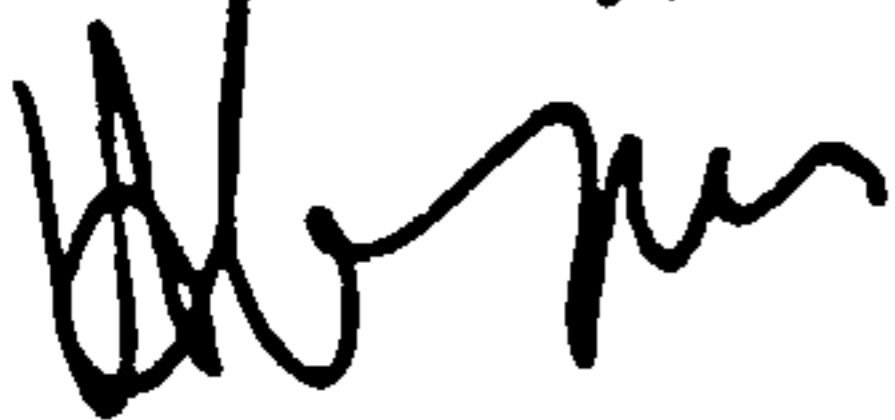
These items were approved at the meeting held on 18 April 2000 and we are pleased therefore, to confirm that you may now commence this study in line with the pro forma presented and the additional items referred to above.

In giving you final approval we would ask you to provide regular progress reports but taking into account the length of this study one complete progress and final report combined will be sufficient for our needs.

We wish you every success with your study and you should not hesitate to contact us for either advice or assistance if and when required.

Kind regards

Yours sincerely,



Dr L A Loizou  
Acting Chairman  
District Research Ethics Committee

**PHASE 3: APPROVAL - ETHICS COMMITTEE (2)**

Dear Rev Wright

**Project No. 00/70: Spiritual health care: An enquiry into the spiritual care of cancer patients within the acute hospital and specialist inpatient palliative care unit**

Thank you for your letter of 10 June responding to queries raised by members of the Ethics Committee on the above study and enclosing a revised information sheet. I am pleased to confirm that your study has now been approved by the Committee.

We would be very interested to receive a copy of your findings at some future date.

Yours sincerely

*Ann Prothero*

✓ **Dr P R F Dear**  
**Chairman**

**PHASE 1: LETTER TO QUESTIONNAIRE RECIPIENTS**

**THE UNIVERSITY OF SHEFFIELD**  
*Department of Palliative Medicine/ Lincoln Theological Institute*

Dear Colleague  
1999

11 June

**Spiritual Care within Health Services: National Survey**

I am currently the hospital chaplain at Doncaster Royal Infirmary, seconded to Sheffield University to carry out a doctoral study of spiritual care within health services. The study's main objective is to discover what constitutes 'spiritual care'— identifying its characteristic features, its methods of delivery and the roles of key stakeholders.

Since much is written about the spiritually inclusive nature of holistic and palliative care, the study focuses upon the spiritual care of cancer patients.

The research will take place in three phases. Phase I is to gain information by means of a national survey. Questionnaires are being sent senior chaplains in around 180 Trusts offering acute services, and to a similar number of chaplains working in specialist palliative care inpatient units. This is to elicit the views of people working within health services who have a specific responsibility for spiritual care and are likely to meet cancer patients during their working hours.

Could I please enlist your help? The questionnaire takes around 10 minutes to complete, and although I realise that all time is precious within today's busy schedules, your contribution – regarding a form of care to which we are both committed – would be of the utmost value.

Confidentiality is guaranteed and no individual or unit will be identified in any report.

If you have questions or comments you would like to make to me in person, please don't hesitate to contact me on one of the numbers below. If you are willing to help, returning the questionnaire within two weeks – in the pre-paid envelope - would be very helpful.

Thank you for your help.

Yours sincerely,

Rev Michael Wright

*Contact address:*

*Trent Palliative Care Centre, Sykes House, Little Common Lane, Sheffield S11 9NE  
TPCC 0114 2620174 Home Tel/Fax*

**PHASE 1: FOLLOW UP LETTER TO NON-RESPONDERS**

**THE UNIVERSITY OF SHEFFIELD**  
**Department of Palliative Medicine/ Lincoln Theological Institute**

Dear Colleague

11 June 1999

**Spiritual Care within Health Services: National Survey**

I recently wrote to you asking if you would be kind enough to assist me in my research by completing a Pilot Questionnaire on spiritual care. As of today I have not received a reply, but would still very much appreciate your help.

If you intend to return the questionnaire, it would be helpful to receive it in the near future. If you are not able to assist just now, then please accept my apologies for putting more paper on your desk at such a busy time.

Best wishes,

Yours sincerely,

Rev Michael Wright

*Contact address:*

*Trent Palliative Care Centre, Sykes House, Little Common Lane, Sheffield S11 9NE*  
*TPCC 0114 2620174 Home Tel/Fax*

**PHASE 2: LETTER TO INTERVIEWEE**

**THE UNIVERSITY OF SHEFFIELD**  
**Department of Palliative Medicine/ Lincoln Theological Institute**

**Rabbi Dr**

**21 December 1999**

**Research Project: Spiritual Health Care**

I write to confirm our meeting at 2.00pm on Jan 6<sup>th</sup> and thank you for allowing me to interview you.

You might remember that I am currently seconded to Sheffield University to carry out a doctoral research project investigating spiritual care within health services - and that we met at Warwick last September.

The research is being undertaken in three phases. Phase I involved a survey of the views of chaplains in around 190 Hospital Trusts and 150 specialist palliative care inpatient units. Phase II consists of interviews with key stakeholders within the spiritual care domain; people of influence whose decisions could affect the scope and characteristics of spiritual care - from managers to volunteers, chaplains to therapists, Christians to members of other faiths, and those of no faith at all. Phase III will collect will be a case study within different care settings.

This interview is part of the Phase II research - recording the views of stakeholders who are able to influence the shape of spiritual care. The interviews are confidential and no individual or institution will be named in any report - though with your permission, your words will be used in an unattributed form.

I look forward to meeting you. If you have any queries or observations please don't hesitate to contact me at my home address:

Yours sincerely,

Rev Michael Wright

## APPENDIX 13

### PHASE 2: INTERVIEW NUMBER 6

*6 September 1999*

MW Well Bishop (N), thank you for seeing me.

I It's a pleasure Mike (laughter)

MW I much appreciate your time and the thoughts that you're going to share with me today.

I Yeah.

MW As you know, I'm interested in this whole area of spirituality - and someone once said that spirituality was rather easy to understand until you try to define it, and then it became more difficult.

I Yeah.

Q1 Can I ask you what you understand by this word spirituality?

I Yeah. I mean, I remember trying to define it some, some while back - and I tried an Alice in Wonderland kind of definition which is something like: spirituality is that - refers to that part of human nature which cannot be defined (laughter). Now that's the kind of logical Alice in Wonderland logic, but I mean - I actually believe that, because I think it's, it's virtually impossible to define. And there was a time back in the '60's when I actually thought that psychology and psychiatry were going to provide the language to help us totally understand our humanity; and now, now we're in the '90's that language, beautiful as it is, isn't quite enough - which is why we have to use words about spirituality. So if push came to shove, I

think it's about our relationship with Mystery, capital M. It's our relationship with the mystery of our understanding of ourselves and it's how we try to give voice to the purpose of our lives - drawing on all those things which matter to us, like - well for me it would be poetry and prayer and the scriptures and the church and all of that - but recognising for a lot of people it will draw on many, many other things. So I can't define it is the answer. I can't define it, except in that Alice in Wonderland-ish way; but I know that it's very, very important. But I can't define it.

**Q2** Thank you. How did you personally become interested in this thing-that's-difficult-to define called spirituality?

**I** Well I have to be a bit personal; but it began when I was about 6 or 7 and my father used to go to church and I went with him, or with my step-mother. And my father I have to describe - because that, that was the impact on me. He was a - actually looking back he was only about 5 foot 8 or 9 - but he was a very big, chunky man, well-built. He was a lorry driver; had his own small business with his brothers. But I just remember him as a very big, physically very, very strong man; which was true, very strong. And one day - when we went to church one Sunday he, as always, he just knelt down and said his prayers at the beginning of the service. And there was something about the way he sank to his knees that I shall never, ever forget - because for me he was a giant of a man; and suddenly I saw him as kneeling in front of God. So that was one very powerful influence to start off with, which I can't - I can hardly now put into words. The second was again in church; but a particular Sunday School Teacher who was just lovely, who wore a grey felt hat and was hopeless in keeping order - but just loved us kids to bits really: the mining community I grew up in. And there was - she talked about God in such a way that I caught something of her, her love of God. And the third person was a curate who had a terrible, terrible stammer but who was a brilliant story teller - and I could see that it was important for him. And then, I think the fourth thing for me was - oh 4 or 5 - fourth thing, was being in a community where,



when, when people worshipped at Harvest Festival or whatever, there was something about the beauty of the language and the way people used the language of - and in those days - the prayer book, which I don't know just affected me very, very deeply. And the fifth thing was the landscape in which I grew up - because I grew up in the Forest of Dean; so I was incredibly lucky in terms of a beautiful landscape in which to grow up - but I wasn't romantic because it was a mining community, so you saw silicosis and poverty and all of that. But all those things combined - as I look back - made me aware that there was something about the centre, I don't know, the centre of our lives - and the way - the beauty of the world which only now as I, I reflect now many years later, only the word spiritual would do. At the time I couldn't begin to use a word like spiritual; didn't know what it was about. And then I suppose I would have to go on and be again autobiographical; but it was people at school who influenced me - and it was then music, and then actually at Wells Theological College with Tom Baker and Compline in the Undercroft - and all those sorts of things which you just can't put into words. And then, several years later, I was doing some research in Shropshire in Religious Education and we were tape recording children talking about the nature of God; and we stumbled across this research - it was in the sort of golden age of Teacher Centres back in the early '70's - and I learnt a huge amount from the way that primary school children talked about God, about how important spirituality was. And from then on, well, I, I pray every day - and then at holiday times I give up praying so I can have a break (laughter); and, and then I come back to it so refreshed, so refreshed that I can't wait to get back to praying. It's ever so strange. I cannot do without saying my prayers; it's like a kind of - I suppose it like a sort of addiction really. And I think it can be addictive in a bad way, I don't deny that - but I just, I just don't know how to give up praying really, because it still matters to me very much, - although my prayers have become quieter and quieter and I say less and less and less. So that's where I am Mike. I don't know whether that's - I can't remember, even remember my answer now (laughter) - that was so much biographical. What was the

question? What was the question?

MW The question was about how you became interested yourself.

I Oh right. Yeah right. Well that's - all of that's absolutely true. Absolutely true.

Q3 There is a lot of interest just now.

I Yeah.

MW Why do you think that is?

I Well I think the more - the more pessimistic side of me thinks people are interested in it in a kind of self-fulfilment; it's all part of huge, huge self interest and self awareness amongst people; and I think of newspapers now which run not just a paragraph about health and healing but actually pages about health and healing. So part of me think it's part narcissistic - but part of me thinks it's also an inevitable part of being human, that you have to try to discover what makes us tick and not least in relation to dying and death. And I, I get - I personally get very tired of people, journalists in particular, talking about death as the last taboo. I've never - I've never found that to be true; wherever I've been as a parish priest people have wanted to talk about death, it wasn't taboo. What we didn't have was a very -we no longer have a kind of corporate language or corporate rituals - so again the autobiography. When I grew up - mining community - anybody died - windows were closed, curtains were drawn, the men wore black This wasn't just the immediate family, you know - when the funeral set off at my aunt's and my uncle's from the village street - all the curtains were drawn. People stopped walking in the street. Men worn black arm bands. You knew which order you had to walk in procession and all of that. So there were rituals around people dying which helped you make sense, but that doesn't happen any more. And certainly when I was a vicar

people, would ask me what they had to do - and it was, they were lost; and I just realised how lucky I was growing up in a community which still had some rituals. Those rituals don't exist; so I think it's part of that as well that we - we don't any longer much have confidence in rituals and desperately yearn for them. So I think it's all of that really and partly, I suppose - the third bit - is that actually life is unbelievably confusing and difficult now and it would be nice if we could all find this kind of still centre to make sense of it all. There's just too much I think for many people. I include myself in that sometimes. It's just all too much; and so you have to try and find a still centre where you can make sense of it. And I think it may be a bit psychological. I'm not a psychologist, but I do know enough of psychology to know that if you stop people dreaming they become very ill mentally. And I don't think we have much time in our lives now to dream - in a day-dreaming kind of way - and spirituality provides time to kind of let the brain or the soul sift out what's important, yeah.

**Q4** Within healthcare there's a study that's been done that identified nurses as having a specific responsibility for assessment of spiritual need and delivering spiritual care...

**I** Yeah.

**MW** ...and found that they were quite distressed to work in this area - and concluded that before people took on responsibilities and roles in the spiritual domain that they should have already begun to have addressed their own spirituality. Would you agree with that?

**I** Absolutely. I don't - absolutely - I don't think it's possible for anybody to care for anybody else spiritually, whatever that means, without themselves either being prayerful - and we're not just talking about Christianity here, I'm talking about right across religion - or deeply thoughtful; or even themselves having been through a lot of suffering. And, and then you

need a language in which to express that; and in, in Christianity that language used to be common, and I don't think it's common any more to society. And so I can see why nurses struggle with that if they've not grown up in a, in a common language kind of culture like the church. But even if they have, it's now incredibly difficult because most of the people on the ward haven't. They're still hugely sympathetic aren't they...?

MW Yes.

I ...hugely sympathetic to spiritual things; but it's trying to find the right words and there isn't a common language for spirituality any more - not in national terms as far as I can see. I wish there were but there isn't. So I can see why nurses get really, really confused. Partly because if you start talking about spirituality you're making yourself pretty vulnerable as well - and as a nurse there's a limit to how much you can and should do that, I think.

MW Have you reflected on the relationship between spirituality and religion?

I I have Mike - but not too, not - I haven't sorted it. (Silence) I have, as you know - I mean you and I are of the generation which were quite influenced by Bonhoeffer's religionless Christianity..

MW Yes.

I ...and there's a bit of me that understands what he was trying to drive at there. And I find it ironic that as a bishop (laughter) I'm so, I'm so - kind of looked at in religious ways that can be quite a burden. But I, I haven't yet discovered a society that can be religion-less. It's almost as though every society needs at least part of it to be religious, to be thinking about these things vicariously so that the rest can, sort of, hang onto the coat-tails - and that's fair enough. So I see religion, I think, defined in terms of

activities which have a specific base - like a church or temple or whatever, with an organisation and a structure and a theology and within that religion a sense of history. And although spirituality can be part of a religious set of beliefs, I, I believe it's perfectly possible to be spiritual without being a member of a religious faith community; obviously I think that. But in the end, you've still got to find a language to deal with whatever it is you're experiencing - which I think is why lots of people are sort of, investigating Celtic spirituality and all that sort of stuff; because it seems to provide a sort of language that makes sense of creation and make sense of their feelings. I'll put a P.S. to that because I think some of it's very phoney - but there we are (laughter). So I think that's where I'd make a distinction - and it's possible to be religious without being spiritual and it's possible to be spiritual without being religious. And if I had to make a choice I'd rather be spiritual without being religious because I think religion without spirituality is fatal, absolutely fatal.

MW If we just move to health care now?

I Yeah.

Q4 Why do you think patients with conditions such as cancer often bring forward spiritual or religious needs when they come into hospital or hospice?

I Well I think it's to do with their sudden awareness of their own mortality, you know, 'Was that it?' as it were. In other words they look back over their lives and say, 'Well was that all it was about,' really. I have a feeling it's even deeper than that though, because my experience of being with people who are dying is that there is a communication between them and their friends or sometimes the chaplain, whatever, which is at a level much deeper than words. And I think either spiritually or psychologically - and I can't make a distinction in those two words there - there is something

going on very, very, very deep inside the core of their personality, which is also surprising to them. And I can't find a word to this, Mike, but it's, it's something to do with becoming aware of the - of their own core of individuality and, in my terms, I believe the awareness that they are loved. But that will be happening I think at levels which are well below our understanding, beyond our understanding. And even in their dreams there will be lots of sorting out going on. And of course there's denial and all of that but I - my experience when I was - I was only briefly a hospice chaplain as part of being a vicar - but, but the level at which we communicated - I didn't have to say anything and they didn't have to say anything - was, I just can't, I just can't describe really. And there were some people who were frightened and some who were totally calm and, and most - all of them in fact - I found I was - more of a privilege for me to be there than, than the other way round - and it was more like being in a delivery ward than it was being in a place of death. It was all paradoxical, I couldn't make sense of it. That was - that was my, my experience. Well I suppose everything gets into perspective doesn't it? You don't worry too much about the movement of the pound in relation to the euro or whatever when you know you've only got a few hours left, or a few days.

**Q5** Do you think spiritual needs can actually be assessed?

**I** Yes-ish, but I'm pausing Mike because I, I think the assessment is to do, to do with the intuition of the person who is sitting next to the person who seems to have spiritual needs, as it were. Because it's two ways; it's more discovered in conversation and intuition I think, than by anything measurable. Though you know and I know people - when you're in their presence you feel in the presence of somebody, and you have to use a word like 'deeply' about them - which is a way of measurement; people who are deeply spiritual. But it's an intuitive measurement. I couldn't say, this is person is only 10% spiritual and this person 100%. I don't know how to measure it because I think it is trying to measure the immeasurable. And in, in theological terms I think the

spirituality of people is in, is held within the grace of God anyway; and He then becomes more like a mid-wife - pick up the analogy - and helps to deliver people into eternity really.

Q6 So what do you think are the main ingredients of spiritual healthcare?

I One, without an absolutely shadow of doubt is love, both objectively and pastorally and emotionally, and all of that. I don't know, we haven't got a better word than love so it will have to do. It has to be based on love for each single human being. So if whoever the spiritual care-givers are don't love their people then they might as well pack up and go home. So I think it's based profoundly on love and therefore based profoundly on respect for the dignity and nobility of human life and the importance of human life. And if, as I say - if those people can't, can't offer love then, then they, they shouldn't be involved in thinking about spiritual care because that love has to be utterly, utterly objective in the sense of being self-effacing; and it's not for the spiritual care-giver to be involved in loving someone for their own soul-sake, if you see what I mean. So it's not - I don't love people, or I shouldn't love people for the sake of my ego. I should love them because they are loveable in themselves; and again in Christian terms, because they're the children of God. And I mustn't love them for anything except that they are to be loved - because otherwise they get into manipulation and voyeurism. So I think that's the number one; and that needs a lot of thought and care. And I think anybody who offers spiritual care is going to be exhausted; and therefore they themselves need to go away into quite places or rooms or retreats or a walk on mountains or whatever - where they themselves can recharge their spiritual batteries, because it is based on utter self giving love. And I suppose the next thing it's based on - and everything flows from that - it's based on the worth of the other person, and for me the worth of everybody in the eyes of God. I realise that wouldn't be true for all spiritual care-givers - they won't believe in God; but for me that's, that's where it is, yeah.

Q7 There was a Ministry of Health circular in 1948 that asked hospital boards to provide for the spiritual needs of patients and staff. And then there was another circular in 1992, 44 years later, which also states that the National Health Service should make every effort to provide for the spiritual needs of patients and staff. Do you think the authors meant the same thing? And they were talking about spiritual health care... (laughter)

I That's an easy question...(laughter). Well I've no idea. I've no idea. But it's a fascinating bit of research to see if they did. I suspect - here's a guess and it can only be a guess. I've no evidence what I'm gonna say at all, but in the first of those - it's '47 wasn't it; 1947 did you say?

MW 1948, yes.

I '48. Just post war, Britain was still a - institutionally was a Christian country; so there was no multi-faith stuff around much. So I suspect what they meant by spiritual care was something sort of Christian, religious - whereas now, I think it's probably a much broader definition which is about other faiths, other religions, other lifestyles, integrity. But is it? If that was true - if one was partly to do with, kind of, society and culture, and the most recent definition is to do with what my private belief systems are - and I think that's probably the difference - then it indicates a huge shift in our understanding both of spirituality - and even more, what the word 'national' means in a national health service. A massive shift. I'm very, very glad it's in both cases but I suspect it represents a massive shift in understanding, yeah. I've no evidence for any of that Mike, it's just surmised. Have you, have you got evidence for what, the difference between the two?

MW I think in some of the documents that have come out recently that rely on this '92 circular: it has a broad base, a multi-faith - a religious observance across a range of outcomes.



I Sure, sure, all of that.

MW All of that. And looking at the things that happened quite quickly after '48, I suspect that everything that you've said just now is absolutely on target.

I Right, right. Sorry Mike you should.... (laughter)

MW Yes we won't regress and change the roles. (laughter). So talking about roles then (N)...talking about roles...

I Yeah.

MW Talking about roles, I read your recent report for the College of...

I ...Health care Chaplains.

MW ...Health care Chaplains and you have a very specific role.

I Yeah.

Q8 Would you like to say just something about that, how your role impacts upon the work of the chaplains.

I Yeah, I mean the vast - I mean 99.9% of the work is actually done by Robert Clarke and Malcolm Masterman and Liz and Elspeth; that's where all the actual day to day, hard, informative, educational, professional, political work is done. And my job is to chair the health chaplaincy's council, health care chaplaincy's council; and so I operate at two levels there. The first is just to chair the meeting, just to turn up and do it; but the second is to try to make a contribution as I think about health. So in those meetings to raise questions -both in the meetings and beyond - which are do to with the nature of chaplaincy. And then thirdly - and this is only

just starting - beginning to reflect on what the role of the church is in general in relation to the NHS, and more particularly what are the areas of discourse in the NHS and health care that the church ought - through a bishop or through somebody else - ought to have a voice in. Not because we have a voice as a right, we don't, but because our theology ought to be enabling us to make contributions which I hope will be helpful to the development of the service. So it's those three levels really and the last one is only just beginning to emerge. Up to now it's been played as a, a fairly low key task to keep a synodical function operating - and all the work has been done by the officers and they do it brilliantly. But I think now I've got to - I am starting to think, right what, what public voice should the church have in the NHS? But that raises a huge number of questions; I mean, not least of which I believe is - if the church is to have a voice in it, it's got to earn that voice; and it will only earn it by doing things thoughtfully and not in a knee-jerk, instant reaction way. And the question then is whether we can be thoughtful enough in co-operating with lots of other people from the health service to make a useful contribution. And if we can't be, I don't think we should do anything knee-jerk; that doesn't do any good.

**Q9** I was intrigued to read in your report that sometimes when you use the word 'chaplains' there's then a hyphen spiritual caregivers.

**I** Yeah.

**MW** Two questions related to that. A). Are they interchangeable? and B) Do you see anyone else in the territory, any other players?

**I** They are, they are now almost inter-changeable and this has been a very, very recent development. Chaplains, I think, up until very, very, very recently have been observed as - and have been perceived as - somehow representing religion and spirituality. And so an Anglican chaplain, for instance, would wear a dog-collar - not all the time but most of the time

round the hospital - and would be perceived as quote, say 'vicar', end quotes. I think spiritual care-givers: that phrase is in for 2 reasons: one to try to embrace all those other communities who have the equivalent of a vicar - and therefore this is an attempt to be inclusive of all leaders of spiritual communities in this country, religions, communities - but it's also an acknowledgement that there are many, many people for whom their spirituality matters a lot, but who have no overt or explicit religious allegiance. My hope is that those two words will remain; those two sort of phrases - chaplain on one side and spiritual caregiver on the other, will actually be held together.

MW Right.

I I hope very, very much because if, if chaplains just go round representing religion I think, again, that would be awful - because religion can be so destructive as well as liberating; and usually when it's called religion it's pretty destructive. But spiritual care-givers: if that's just left of it's own it could just become kind of fluffy and pink and not at all challenging and not at all rooted in, in human history, in human thinking. So I hope very much it will be held together. Was there a second question?

MW There was.

I What was the second one?

Q10 Who might the other players be?

I As spiritual care givers you mean?

MW Yes.

CH Well I think some nursing staff, some counsellors - though they might not

want that work, but actually they are involved in that - some therapists, some physiotherapists, some O.T. Can be anybody in a hospital who enables the patient to become more whole.

MW Right.

I And usually it's people with a bit of time.

Q11 So how would you see the special contribution of chaplaincy then? What's distinctive about chaplaincy?

I As opposed to spiritual caregivers you mean or chaplaincy in general?

MW No, as a department within the hospital.

I Oh I think it's hugely important. I hardly know where to start. Well I think firstly they represent the possibility of God; secondly they represent the possibility of meaning beyond the walls of the hospital; thirdly they represent the profound truths on which hospitals are based - the values which hospitals can't make explicit but actually are based on love and faith; and I think because they also try to represent something about truth and eternity. So that's the kind of philosophical kind of level. At a practical level they're the only people in a hospital who have the freedom to go to every level of the hospital, from the basement to the penthouse suite, from the mortuary through to ITU or wherever. And because hospitals are inevitably very, very complex institutions, it's almost like a kind of - my experience of hospitals: they're almost like a kind of nation in themselves with all sorts of little counties around, and each county develops its own speak and, and dialect and all of that. So I think chaplains are free to go around from place to place and act as interpreters and, and reconcilers and a more difficult task, sometimes to speak truths that are very difficult for people to hear, but that's very, very difficult.

Q12 Would you like to comment on the interface with other faiths within

healthcare?

I Yeah I wish I understood more about this, Mike. It's not an area which I know very much about - but I believe it absolutely right that every human being that goes into hospital has the right to have their faith recognised and acknowledged, provided that it is a faith which is recognised and acknowledged nationally. And so I think chaplaincy should enable that to happen. So what was the next bit of the question, sorry Mike?

MW About the interface.

I The interface, yeah. So, so that means then that whoever is a senior chaplain has to be very sensitive to whatever the make up of the local community is; very, very sensitive - I mean theological and politically. Where, I think, the next stage of the development is gonna be is how far those chaplains can sit down and discuss not only what their faiths have in common but also what separates them and what - how they overcome separation without losing their own beliefs and integrity in the process. And that's, that's gonna be a massive task but I think that's one that's gonna be very important. And I think, because chaplaincy is right at the cutting edge of all this, both, well certainly in inter-faith terms and especially in ethical terms, they're gonna have a lot to teach the wider community.

Q13 There's been a move recently towards the creation of multi-faith rooms within hospitals.

I Yeah.

MW Some say that as multi-faith rooms are established for everybody they actually serve nobody and that that isn't necessarily the best way forward.

I Right.

MW Where do you stand on this issue?

I Oh I, (silence) I mean, it's impossible to get, for me anyway, religion away from its architecture and its artefacts. And so I think architecture, whether we like it or not, reflects what we believe; and a multi-faith room therefore is bound to be sending out mixed messages and very confused messages - bound to by its nature. I'm sort of thinking aloud here, Mike, I don't know. And so I don't quite see - because I also come in as a patient with a whole set of baggage about what my beliefs are and how they're expressed - I think I look around for a few landmarks really. I mixed my metaphors horribly there - but, I do look around for landmarks which are gonna help me. And I think if I was in a multi-faith room I wouldn't know where to look; and therefore wouldn't know where to focus and therefore would be more confused rather than less confused. So as a Christian going to hospital I would actually hope that I would have a room which, through its architecture, recognised the importance of my faith and Christianity and the life of the nation. I suspect if I was Muslim I would want something similar to be provided for me - that by its architecture would say, 'Yes. We take your faith seriously'. But that has all sorts of implications and it - I haven't thought it through really.

Q14 We've just slightly touched on this issue already: what do you think are the main difficulties in the area of spiritual care?

I One is finding a language; and that, that would go on being the case - because I think in that respect chaplains are gonna be more like poets than anything else. I think it's going to be finding people who not only think spiritually and deeply, but also have a sense in history - of where their spirituality has come from - and that requires quite a lot of disciplined thinking. So I think it's those two areas really. And the - while the third, which is, how - in a multi-faith society, how does religion find a public space in which it can operate? And I, I think the jury's out on that. We haven't found that. We've lost that. Cathedrals provided it for Christians

and indeed for the wider community - but hospitals I think are well beyond cathedrals in trying to find - or are - the places where public faith and private faith, and public truth and private truth meet. And I think hospitals - I hope and pray they're going to be the places which do thinking which enable the rest of the community to make sense of that. So for the spiritual care-givers in a hospital that is going to be a very demanding philosophical and intellectual task.

**Q15** So what do you think the future actually holds for spiritual health care?

I Well I pray that it's importance will go on being realised by those who control finance and by those who control resources because there's a lot of power and wealth in hospitals. There was - has to be - there has to be a lot of power. People have got to make very difficult decisions and that is an exercise in power; and there's a lot of wealth around. So, I think it's gonna be difficult but without it then hospitals will just become mechanistic and that holistic understanding of human, human beings will be lost. So I would hope that, I would hope that chaplaincy would provide the place where people of all faiths within a hospital can meet to set - to make explicit - the values on which the hospital is based. That doesn't happen much, but I think those values are shared. But that will take a lot of doing, and it's difficult then to put into words. It sounds sentimental to say this hospital is based on love, but it would be actually a tremendous breakthrough if, as well as, you know, the words 'patients' charters' and all of those - if just occasionally you would see something that wasn't sentimental but which made explicit what the values were on which the hospital was based.

**MW** And one last question to finish with then.

I Yeah.

**Q16** If you could select one thing that could come true in your wish list for

spiritual care within the next 12 months, what would it be?

I That chaplains would have the confidence and the time to work with other professionals in their hospital to make explicit the values the system of that hospital. But it would take much longer than a year to do (laughter).

MW It certainly would. Is there anything else that you'd like to add that we haven't touched on?

I No - one other point - you're a brilliant interviewer (laughter). No. Thank you. I don't think I've got anything else to say Mike, no.

End of Interview

5, 957 words



## APPENDIX 14

### PHASE 2: PROFILE OF INTERVIEW 6 (APPENDIX 13)

(Numbers refer to categories of responses across all interviews)

<b>1</b>	<b>Definition of spirituality</b>	<b>10.</b>	<b>Difficulties within spiritual care</b>
1.2	Religious/ non-religious spirituality	10. 27	Finding a language
1.15	Spirituality beyond definition	10.28	Finding chaplains with 'history'
1.17	Mystery - understanding ourselves	10.29	Finding a public space
<b>2.</b>	<b>Personal interest in spirituality</b>	<b>11.</b>	<b>Spiritual self awareness on the part of the caregivers</b>
2.7	Example of others	11.8.1	Spiritual awareness crucial
2.2	Beauty of the world	11.9	Need for a language
<b>3</b>	<b>Reasons for general interest</b>	<b>12</b>	<b>Spiritual care and non-Christian faiths</b>
3.8.5	Own mortality	12.8	Right of recognition
3.8.6	awareness of being loved	12.9	Sensitivity
3.10	Current narcissism	<b>13</b>	<b>Chapels and faith rooms</b>
3.11	Human characteristic	13.8	Message of architecture
3.12	Loss of rituals	13.9	Confusion without landmarks
3.13	Vehicle for dreams	<b>14</b>	<b>Personal priorities</b>
<b>4</b>	<b>Ingredients of spiritual care</b>	15.7	Articulation of value system
4.8	Love	<b>16</b>	<b>Future for spiritual care</b>
4.9	Respect for life	16.7	A role for the Church
4.10	Space for care-giver	16.8	Needs support of managers
4.11	Worth of individual	16.9	Requires articulation of values
<b>4</b>	<b>NHS Circulars - 1948 / 1992</b>	<b>17</b>	<b>Contribution of chaplaincy</b>
5.1	Meanings 1948 / 1992	17.14	Care for the unchurched
<b>6</b>	<b>The main players</b>	17.15	To articulate truths and values
6.1	Chaplains	17.16	Interpreters and reconcilers
6.5	Ministers of other faiths		
6.6	Empathetic staff		
<b>8</b>	<b>Spiritual assessment</b>		
8.1	Intuition		

**STAKEHOLDER THEMES:  
ALL INTERVIEWS**

**APPENDIX 15**

<b>1</b>	<b>Definition of Spirituality</b>		
1.1	A life orientation	1.8	The Holy Spirit
1.2	Religious/non religious spirituality	1.9	Search for meaning
1.2.1	less commitment to religion	1.10	Development of inner self
1.2.2	completeness when together	1.11	Commitment, sacrifice, dying
1.2.3	folk religion	1.12	Stewardship
1.3	Spirituality - aspect of humanity	1.13	Centrality of 'big questions'
1.3.1	being at ease with oneself	1.14	Focus on individual
1.3.2	being 'in balance'	1.15	Spirituality beyond definition
1.3.3	a depth of peacefulness	1.16	Relates to inner self
1.3.4	awareness	1.17	Mystery - understanding ourselves
1.4	Transcendence	1.18	Jesus' command to love one another
1.4.1	going deeper	1.19	Difficult to define
1.5	Spirituality and the focus on God		
1.5.1	Christian spirituality		
1.5.2	Muslim spirituality		
1.5.3	Jewish spirituality		
1.6	Spirituality shaped by culture		
1.6.1	spirituality shaped by ritual		
1.7	Spirituality and personal space		
		2.1	Personal journey
		2.1.1	becoming a Rabbi
		2.2	Life experience
		2.2.1	near death experience
		2.3	Influence of others
		2.3.1	openness to others
		2.4	Themes of life
		2.5	Witness of illness
		2.6	Why some cope better
		2.7	Example of others
		2.8	Sense of calling
		2.9	Interest in people
		2.10	Beauty of world
		2.11	Personal search

2.11.1	need to make sense of things	3.3	Realisation - science not everything	3.8.11	fear
2.12	Answering God's call	3.3.1	scientists don't hold all answers	3.8.12	need for security
2.13	Knowing Jesus	3.3.2	Search for answers	3.8.13	unfinished business
2.14	Delivering the sacrament	3.4	Feminist influence	3.8.14	feelings of hopelessness
2.15	Delivering spiritual care	3.5	'Green' influence	3.8.15	feeling shaken
2.16	Spirituality & pain	3.6	Influence of Modern Hospice	3.9	Cyclical interest
2.17	Search for language	3.6.1	palliative Care	3.10	Current narcissism
2.18	Experience of loss	3.6.2	holistic care	3.11	Human characteristic
2.19	Beliefs/ behaviour	3.6.3	increased nursing awareness	3.12	Loss of rituals
3	<b>Reasons for general interest</b>	3.7	Re-gaining of confidence	3.13	Vehicle for dreams
3.1	Loss of organised religion	3.8	Interest when sick	3.14	Search for values
3.1.1	loss of spiritual direction	3.8.1	relationship between physical, spiritual and emotional	4	<b>Ingredients of Spiritual Care</b>
3.1.2	disillusionment	3.8.2	pull on the soul	4.1	Sacramental provision
3.2	Dissatisfaction with the materialistic	3.8.3	cancer a spiritual disease	4.1.1	meeting religious needs
		3.8.4	cancer silent and disruptive	4.2	A spiritual care leader
		3.8.5	own mortality	4.2.1	chaplaincy
		3.8.6	awareness of being loved	4.3	Spirituality of caregiver
		3.8.7	interest always been there		
		3.8.8	sickness as punishment		
		3.8.9	reconciliation		
		3.8.10	death		

4.4	Assessment model	4.18	Seeking to understand	6.6	Empathetic staff
4.5	Acknowledging individuality	4.19	Caring for the person	7	<b>Features of Spirituality within Hospice</b>
4.5.1	recognising the family			7.1	Multidisciplinary approach
4.6	Personal prayer	<b>5</b>	<b>NHS Circulars - 1948 / 1992</b>	7.2	Timing of referral
4.7	Giving time	5.1	Meanings 1948 / 1992	7.3	Pain management
4.8	Love	5.2	Influence of societal changes	7.4	Holistic care
4.9	Respect for life	5.3	Commonality of suffering	7.5	Return people home
4.10	Space for care-giver	5.4	Responding to patient needs	7.6	Link to Christian faith
4.11	Worth of individual	5.5	Responding to change	7.7	Expansion to palliative care
4.12	Care for the family	<b>6</b>	<b>The Main Players</b>	7.8	Demands on staff
4.13	Provision for all faiths	6.1	Chaplains	7.9	Micocosm of life
4.14	Care for staff	6.2	Nurses	7.10	Patient journeys
4.15	Listen to stories	6.3	Doctors	7.11	Application to life
4.16	Positive relationships	6.4	Team	7.12	Commitment
4.17	Recognising need	6.5	Ministers of Other Faiths		

7.13	Small organisation	8.7	Gaining evidence of benefits	10.3	Lack of ownership
7.14	Honesty	8.8	Identifying growth	10.4	Unchurched generation
7.15	Meaning of patients' lives	8.9	The patient's openness	10.5	Young not confronting spirituality
7.16	Institutional backdrop	8.10	Awareness of staff	10.5.1	no time to reflect
7.17	Opportunities for reflection (carers)	8.11	Intuition	10.6	Lack of chaplains/ funding
7.18	Bereavement care	8.12	Difficulty in assessment	10.7	Lack of education
				10.8	Medical model
<b>8</b>	<b>Spiritual Assessment</b>	<b>9</b>	<b>Assessment Instruments</b>		
8.1	Religious needs	9.1	Check lists	10.9	Reluctance to assess
8.1.2	spiritual needs	9.2	Semi-structured tools	10.10	Insular wards
8.1.3	attitude to diagnosis	9.3	Stoll's model	10.11	Lack of referrals
8.2	Communication skills	9.4	Dialogue - records	10.12	Loss of 'personal touch'
8.3	Relationships - 'being there'	10	<b>Difficulties within Spiritual Health Care</b>	10.13	Resistance to 'spiritual reflection'
8.4	Knowing a patient	10.1	Throughput of patients	10.13.1	resistance of medics
8.5	Seeing the person	10.1.1	increased numbers	10.14	Professionalisation of nursing
8.6	Keeping up with changes	10.2	Potential for damage	10.15	Less time for reflection

10.16	Absence definition of spirituality	10.28	Finding chaplains with 'history'	10.40	Territorial parochial clergy
10.17	Assumption spiritual = religious	10.29	Finding a public space	10.41	Falling church attendance
10.18	Lack of funding	10.30	Lack of volunteers	10.42	Loss of 'community'
10.19	Spiritual needs=multifaith prayer room	10.31	No quality care without spiritual care	10.43	Changing world
10.20	Idiosyncratic chaplains	10.32	Emotional demands	10.44	Deficiency of professionals
10.21	'Multifaith' a political football	10.33	Religiously biased staff	10.45	Church out of touch
10.22	Assumptions about inter-changeability	10.34	Implications of West-centric attitudes	10.46	Hospice links with 'establishment'
10.23	Acquiescence in low staffing levels	10.35	Not knowing influence	10.47	Patients feeling proselytised
10.24	Formula allocation of chaplains	10.36	Chaplaincy threatened by 'spirituality'	10.48	Spiritual certainty
10.25	Chaplains becoming religious functionaries	10.37	Unclear thinking	10.49	Attenuating spiritual care within nursing
10.26	Over-concern with the measurable	10.38	Reliance on religious people	11	<b>Spiritual Self Awareness on the Part of the Care Givers</b>
10.27	Finding a language	10.39	'Spirituality' new buzz word	11.1	Similarities to bereavement care
		10.39.1	synthetic spiritual care	11.2	Self awareness seminars

11.3	Pre-qualification training	12.2	Markham's caution	13.5	Equal provision impractical
11.3.1	education	12.3	Health care serves all faiths	13.6	Other priorities
11.3.2	conferences	12.4	Challenge to theology	13.7	Example of mortuaries
11.3.3	confidence of tutors	12.5	God in everyone	13.8	Message of architecture
11.4	Team	12.6	Difference v religious & cultural needs	13.9	Confusion without landmarks
11.5	Personal Journey	12.7	Importance of dialogue	13.10	Address misunderstandings
11.6	Related to who we are as people	12.8	Right of recognition	13.11	Learn to share
11.7	Being spiritually prepared	12.9	Sensitivity	13.12	recognise different traditions
11.8	Spiritual awareness crucial	13	<b>Chapels and Faith Rooms</b>	14	<b>Green Shoots within Spiritual Domain</b>
11.8.1	pick and mix spirituality	13.1	Multifaith rooms serve nobody	14.1	Growing body of research
11.8.2	shrinking world	13.1.2	Multifaith rooms helpful	14.2	Richness of spirituality
11.9	Need for a language	13.2	Importance of objects	14.3	Professional recognition of spiritual care
11.10	Experience helpful	13.3	Ambassadorial role of chaplaincy	14.4	Increased educational provision
12	<b>Spiritual Care and Non Christian Faiths</b>	13.4	Chapels not sufficient		
12.1	Commonality in definition				
12.1.1	spirituality within other faiths				

14.5	Caution re Dept of Health 'developments'	15.7	Articulation of value system	15.21	Acknowledging the agendas of the dying
14.6	Creative practice	15.8	More ministers	15.22	Clinical supervision
14.7	Growing network	15.9	More dialogue		
14.8	Chaplain exchanges	15.10	More prayer for chaplaincy	<b>16</b>	<b>Future for Spiritual Care</b>
14.9	The internet	15.11	Recognition of spiritual domain	16.1	Optimistic
14.10	New approaches	15.12	Acceptance of revised HSG 92/ 2	16.2	More chaplains
14.11	New set of values	15.13	Non religious retreats	16.3	Evidence of fulfilment
		15.14	A clear philosophy	16.4	Greater role for chaplains
<b>15</b>	<b>Personal Priorities</b>	15.15	A more responsive church	16.5	Opportunities for dialogue
15.1	More consistent assessments	15.16	A new pioneer	16.6	More teamwork
15.2	More quality research	15.17	Staff Accreditation	16.7	A role for the Church
15.3	National leadership	15.18	Co-ordinating role of chaplain	16.8	Need support of managers
15.4	More funding	15.19	Information for patients	16.9	Requires articulation of values
15.5	Regional Chaplaincy Office	15.20	Training for all staff	<b>17</b>	<b>Contribution of Chaplaincy</b>
15.6	Commitment of nurses			17.1	Changes



17.2	Clear purpose	17.15	Articulate truths and values	18.2	Opportunity for retreats/ space
17.3	Can go anywhere	17.16	Act as interpreters and reconcilers	18.3	Spiritual understanding
17.4	spending time			18.3.1	spiritual values
17.5	Being there	17.17	Show love	18.3.2	spiritual reflection
17.6	Prioritising	17.18	Inter-faith co-operation	18.4	Mentoring
17.7	Providing good administration	17.19	Help patients cope	18.5	Respite
17.8	Allowing people to 'be'	17.20	View of personhood	18.6	Recognition
17.9	Accompanying on journey	17.21	Presencing	18.7	Education in death and dying
17.10	Chaplains arrive with a 'blank page'	17.22	Being as the clown	19	<b>Roles of Interviewees</b>
17.11	Volunteers have a faith	17.23	Being professional	19.1	Delivering the sacraments
17.12	Keeping spiritual care on the agenda	17.24	Theology of struggle	19.2	Praying
17.13	Support from people of faith	17.25	Re-ignite relationship with God	19.3	To be inclusive
17.14	Caring for the unchurched	17.26	Highlight another dimension to care	19.4	Training chaplains
		18	<b>Needs of the Carers</b>	19.5	Supporting chaplains
		18.1	Someone to listen	19.6	Dialogue with health professionals

19.7	Providing retreats	21.3	Loss
19.8	Supporting Muslim patients	21.4	Spirituality
19.8.1	advising on what is Islamic		
19.8.2	being a link	21.5	Wholeness
19.9	St Columba's Fellowship	21.6	Meaning
19.9.1	teaching spiritual care	21.6.1	longing
19.9.2	inclusive language		
19.9.3	dislocation from Church	21.7	Process
		21.7.1	product
20	<b>Interviewees' background</b>	21.8	Effect on artist
20.1	Art		
20.1.2	Music	21.9	Gender issues
20.1.3	Medicine		
20.1.4	Nursing	21.10	Dynamics
20.2	Sculpture: a vital occupation	21.11	Music therapy
20.2.1	Music: performance and therapy	21.11.1	status of Music therapy
20.3	The future	21.12	Relationships
		21.12.1	The guest
21	<b>Hospice and the Arts</b>	21.13	Value of the moment
21.1	Time		
21.2	Communication		

**PHASE 2: TOTAL UNITS OF TEXT CODED UNDER THEME 12  
CHAPLAINCY AND NON-CHRISTIAN FAITHS**

**12.1 COMMONALITY IN DEFINITION**

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+++ ON-LINE DOCUMENT: Participant 12

++ Text units 66-66:

Even more fascinating. I find - the spiritual values of other, er  
- well, let's say of - the spiritual needs that are around, go further  
that the religious or particular religious faiths or denominations.  
And that in itself is great. I think you can meet people on those values  
erm, without getting into the realms of religious stuff. If that is  
important to them, then we have contacts with their leaders or their  
church connections or whatever - the Mosque - but spiritual values: I  
think, there's more to share, more in common, which I find helpful and  
fascinating anyway. Erm, I'm talking here not just of pa tients, but of  
staff as well, cos there are quite a number of Moslem medical staff  
and nurses - what have you - and yeah, I have some fascinating  
discussions with them. They start off as religious, often get into this  
area of depth - but patientwise, at (N) Hospital in any case, they're so  
kind of er, ill, if you like, and old, usually that they've embraced  
one another in their own values erm, so that they appreciate that. And  
we do have good contacts with all the other denominations as well. We  
er, have a meeting once a year now with the Sikhs and Moslems, Chinese  
just to now keep everybody happy, you know. We have a quiet room now,  
but the Moslems have demanded that they have their own quiet room, of  
course, because they're not allowed or they don't like anyway sharing -

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+++ ON-LINE DOCUMENT: Participant 7

+++ Retrieval for this document: 1 unit out of 97, = 1.0%

++ Text units 77-77:

Yes, I have, I have studied other faiths and worked with people of other faiths, and it's most interesting. We say other faiths, you know, but we are so like each other, so much like each other that the dividing line is so thin, sometimes it's hard to see. Yet we make that line thicker because we don't acknowledge it, and I think we should, especially in the hospital. I've got a good example - one of my drivers from (N) was in hospital not so long ago, and he's Asian, and he's Muslim, and I came to see another patient across from him. The first patient that I recognised was the driver, who quite readily tried to get out of bed and shake me by the hand. And it was great that he recognised me. I did what I had to do with the Christian patient and then went back to the Muslim patient, who'd listened and had thoroughly enjoyed. Now my failing was, I never asked him to join me. Why - because my hang-up on the two religions stopped and made that line that little bit thicker between us - but it won't happen again. So you've got to learn by these experiences. You see, we all love one God, and again, you see, this love comes back into it - the same God that loves that Asian driver of mine, also loves my Christian patient.

77

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+++ ON-LINE DOCUMENT: Participant 1

+++ Retrieval for this document: 3 units out of 170, = 1.8%

++ Text units 127-129:

Working from my original definition, which is a very broad and what you could amount to a humanistic definition, there are clearly therefore...would capture other faiths and religion um, and expressed in

different cultural forms to sort of, western Anglo-Saxon. So I, I  
don't have any problem with that 127

and, and I mean, my, um understanding of...for example from comparative  
religious studies, er, would recognise that spirituality is very much a  
part, an under-pinning part of, of major religions in the world. 128

And again, some of those are theistic, some are monotheistic, some you  
would recognise in a very similar way to the way, for example,  
Christianity may operate as a religion, in terms that it's got rituals,  
and um, you know, morals, and things like that. And others are very  
different and, and some of the sort of more Eastern, contemplative, er,  
religions, they might not even call themselves religion. And may even be  
non theistic, er they may certainly have different concepts about, for  
example, suffering, illness, 129

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+++ ON-LINE DOCUMENT: Participant 3

+++ Retrieval for this document: 2 units out of 117, = 1.7%

++ Text units 62-62:

Ah, I think the first thing is that we are all religionists, providing  
care from a religious perspective, so that's the first thing that unites  
us as against those who do not see religion as an important element, you  
know, in the care programme. So, first thing, that we are all  
religionists and I think in the - in the second phase, I mean the second  
(hesitation) - well the second level, er, I think what unites us is the  
fact that spirituality is something that's universal, is human,  
spirituality cannot be Islamic in that way, cannot be Christian in that  
way, cannot be Jewish in that way, it's a human phenomena, you see. 62

++ Text units 64-64:

Everyone has a spiritual side, whether he or she accepts it or not. In other words, I say 'we're all humans' and therefore at one level we are all equal, - Islamic teaching is that we're all together - all equal before God, you see. Then, consequent of difference, you know - different ways of expressing that spirituality, different ways of relating us to the ultimate relative God - Allah, we call him. So, that's the second level that actually unites us, and I think in the case of Christianity - as I said, oh yeah, you know, em, everything is same, history is same, prophets the same, scriptures - they take from each other, you see, well you know, Koran, the Muslim scripture being the latest, obviously - no other books preceding the Koran takes from it, but Koran takes from them, you see. If you read the Koran you will see that, you know, so many things are similar - because Islam, the Koran itself and Islam itself says that, you know, Islam isn't anything new, Islam isn't anything that Mohammed invented, Islam is the religion of nature because Islam means 'submission to God' - and then Islam, I mean all, I Mean the Koran says that all - the religion of all the prophets before Mohammed were - it was Islam in a sense that it was submission to God, because all - all is submitted to God, and therefore Islam, the letter - it is the religion of the letter, as the Koran says, you know, because it is submission to God and the whole letter's submitted to God - and the Koran, time and again...the Koran reaffirms what the earlier scriptures say and preached about God, about prophets - all that the Koran claims to have done freshly is - is the, is the purification of, you know, the - of the consent of God, from the sake of politics and from the sake of pronunciation etc., etc. - so all the Koran and Islam claims to have done is this, that is why, you know, the morality, the Islamic religion is so strong ... and this is why we have this big difference about Jesus, and his - whether he has, whether he is the Son of God, or he has any divinity, and all this. Now, so...there's much more that unites the

three than there is that which actually disunites them, keeps them apart. 64

### 12.1.1 Spirituality within other faiths

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+++ ON-LINE DOCUMENT: Participant 13

+++ Retrieval for this document: 3 units out of 86, = 3.5%

++ Text units 5-7:

I think it means many things - exactly as I would say spirituality means different things for Christians and Muslims and whatever. I don't think - I think you would find as many different definitions of spirituality amongst Jews as you would amongst Christians or amongst Muslims - I don't think it's religion specific but the language may well be religion specific. 5

I mean for instance, I think there's something quite interesting about Jews on the whole not having petitionary prayer. Largely, prayer is about acknowledgement and 'thank you' although there is a tradition, a patristic, Hasidic tradition of petitionary prayer, the bulk of the Jewish liturgy is not petitionary - so what, when somebody has a spiritual need or a spiritual quest they're asking? They're asking the sorts of questions that you might well see shaped by petitionary prayer. So how do you deal with that if the tradition isn't about petitionary prayer? So one thing one might look at is - what is the Hasidic tradition? Almost the folk religion within Judaism. Some people might argue that did produce petitionary prayer. Did it produce it as an answer to not having the petitionary prayer for precisely these sorts of moments? Is there a strengthening of the spirit one can get from looking at that? Are there things that one can tease out about belief and asking

and acknowledging and saying 'thank you' that are part of the recognition of spirituality? The recognition of the beyond, the other, the imminent, the um, Martin Buber called it the I-Thou, the conversation. 6

Now the conversation a Jew would recognise is often very different from the conversation a Christian would recognise. You've got the, you know, Hasidic stories of all the arguments, 'Well look God if you behave like that I'm not going to have anything to do with you!' - part of that, the conversation, a lot of that being explored with people who, although they have at the back of their head you know that they perhaps heard this as a child or whatever, they won't know about it, many of them, and exploring with them how they feel about the arguments that they're having - and some of that is about accepting what is going to happen to them - 7

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+++ ON-LINE DOCUMENT: Participant 11

+++ Retrieval for this document: 3 units out of 100, = 3.0%

++ Text units 85-87:

Tagore had a big influence. He was Bengali and he made a big - he had a big influence on Indian literature - but also spiritually - he was - he made a big impact. But perhaps the greatest one that I admired - cos I heard him once, my claim to fame - is Dr Ratha Krishnan, and he was an Oxford don in the Eastern and Western something or other. He had a Chair in it. And he was a wonderful speaker. And he came to Zanzibar where I was born. And I was a little boy, and I wasn't allowed in. So I sat outside. And I remember listening - not understanding a word of what he said, um - but thinking 'Gosh, doesn't he speak well! And when I was older I read this book - and there's a very good book he wrote called 'Eastern Religions and Western Thought' - and I still don't understand it. It was very deep philosophical argument, and I keep going back to it and reading it - and every time I read, I understand a little



bit more, but it's very dry of course - but it is very good. And he was I think a good influence on spiritual aspects of Hinduism. But he never talked about the rituals and the mythology of Hinduism. He took the essence of Hinduism and this is why he's not popular; neither is Tagore in that sense -

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popular mythology plays a big part in everybody's life - and you have Diwali - which is our Christmas - and that's based on mythology. It happens to be the end of the lunar year but it's also to do with Brahm from the Brahman. Yeah, Brahm was a Prince - was exiled - and that day marks the end of his exile. When he came home they lit his path with little lights, hence the name Diwali - which means festival of lights - so we put lights up everywhere in Diwali and so on, but it's steeped in mythology. Essentially, the mythology is good versus evil and it's telling you to be good, and to live a life, and to be obedient to your parents, to look after them, to respect the elders - and all these good values as a good Hindu I should have. And Brahm's thing was that he was exiled by his father cos his father had made a promise to his second wife or something, and she wanted the son to go on the throne. So he abdicated, offered it to Brahm as the eldest son who said, 'I will take it on.' But his wife said you promised my son. At once Brahm said 'Well your promise is more important, so I will go.' And he took voluntary exile. And the wife - stepmother it would be - demanded it should be at least 14 years, and he agreed. But then the, [knock on door] the principles - so the other thing was that his brother - stepbrother - who would have gone on the throne was honourable, and said to his mother 'No, I cannot take his throne cos he's my eldest brother, he's the senior member of the family. If father isn't on the throne he should be.' So he put his sandals on there and ruled in his name for fourteen years. It's all about honour and respect - so when you listen to the story it makes you feel proud and you want to do those things. So that was the

good and the evil - and then there's the adventure side, where he goes, and his wife is abducted by a bad person, and he fights a battle, and the battle is incredible - cos they then talked about flying machines and that's - you know aeroplanes were thought of 5,000 years ago by somebody. So all these things come into it, just a fascinating side to it - and those are the stories that were told to say to people 'You should do this, you should do that.'

86

And a personal one - my father: when I got married, I asked for his permission and wrote a letter to him. He hadn't met my wife then, and he didn't reply for a while, and finally, he wrote and gave his blessings - cos I wanted his permission and his blessing - and my wife said, you know, 'What would you have done if he'd not given it?' I says 'I wouldn't have got married' - 'What!!!' [Laughter] But that was the Indian in me. I couldn't go against my father, and she says what would we have done? I said we would have waited till he died, but I think he will give permission. I have confidence, you know. They wrote back and says of

course you have my blessings, why the hell didn't you introduce her to me when I was there? So he told me off as well - but that's the sort of thing, and those are the values that you talked about in Hindu. Very simple, very simple philosophy - but a lot deeper meaning if you want to look into it. So it's everyman's religion - you know, from the most simple illiterate person to the most intellectual philosophers can find something of value in it. That's why I like it mmm.

87

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+++ ON-LINE DOCUMENT: Participant 12

+++ Retrieval for this document: 3 units out of 101, = 3.0%

++ Text units 46-46:

In particular, I've had a lot to do with developing one the hospices in Taiwan, working with them there, and I've been out and had a lot of people on study programmes here, as it were, and that's been really, really helpful to me - to work out - because their spirituality is exactly like mine, but is expressed in a different world of religion, if you see what I mean?

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++ Text units 48-49:

So that to me very much proves that I'm not saying 'everybody needs to be a Christian to meet their spirituality.' I have to personally answer questions to myself about 'how does my, my God as I understand him, look at the Buddhists on their journey and stuff', but that's a sort of personal problem to me. It's not really - it's not their problem, and it's not, it shouldn't really be, you know, the Church's problem. I see us all on the same journey and I feel 'God can worry about who he's going to have in his - (Laughter) his kingdom' and I'm sure they will be there, so I don't spend much time worrying about how you work that one out. I don't believe all roads lead to Rome, but I actually, I find that whole area one where 'do we have to work it all out, do we have to have an opinion, as such? All I know is that their spirituality leads them into the most compassionate care - and the way that they think first of a person, as their personality and their need for meaning, and they see the rest of it as being a kind of outside-self that needs attention - and there's the means of communication and the means of growing, but the real person is, is what, I think, we call the spirituality - and we're coming from a different way. We've always thought of the outside as so important, and we're trying to pay attention to this inner part of - component, as it were, and so we have much to learn from them, and I think they have become - theirs is natural, whereas ours is an acquired skill. It's like learning another language for us, whereas they are born speaking it. Spirituality is something that they take as read in

everybody and anybody. So I find it very helpful,

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and I think I'm always sending kind of Asian people to different hospices - not for what they learn, but because I think they have so much to teach us in this, this area, and therefore how it's expressed, which is the bit that tends to get taught, you know - what do you do if you're a Muslim? What do you do if you're a Hindu, what have you? I mean, I think that's only like 'when do you use an anti-emetic and when do you use a diuretic, or what have you?' They're things that you have to learn if you're going to look after people in that situation, but that's the absolute end of the line. The spirituality is the bit where we communicate, so of course, it's no wonder that the Chaplain may be asked to help that Muslim family, because they've hit upon a thread of spirituality that makes them know. They're respecting and understanding each other, and it's really then, only with sensitivity and care - but you can actually use each other's language to express it. So I think that explains why I, unknowingly, sort of - student nurse stage or what have you - could say a prayer, a Christian prayer for a Jewish patient - and they'd be very grateful, because in fact there's this underlying understanding of spirituality, but we only offend when we're in fact being disrespectful, and when the other person has no sense of your spirituality, you know. When there's a member of staff who's doing something for a patient who has no spiritual dimension themselves in their practice, and then does something that's careless or ignorant with the religious language of the person, it's actually so offensive because there's not a sense of common spirituality. Anyway that's - that's as far as I've got, it all changes day by day [Laughter] -cos it's an on-going journey.

49

## 12.2 MARKHAM'S CAUTION

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+++ ON-LINE DOCUMENT: Participant 1

+++ Retrieval for this document: 1 unit out of 170, = 0.59%

++ Text units 130-130:

em, and the meaning of, Markham's, sort of, paper which would say that spirituality might not be a helpful word because um, it certainly does come out of a Western model um. 130

## 12.3 HEALTH CARE SERVES ALL FAITHS

+++++

+++ ON-LINE DOCUMENT: Participant 1

+++ Retrieval for this document: 3 units out of 170, = 1.8%

++ Text units 132-134:

I see those strands, those threads, those themes running through them. Um, in terms of health care...I mean, the interface is, in a sense, is a very practical one, which is...we, we, we deal with the people within the hospital and whoever makes up that community are the representatives of the various spiritualities. And if, if we happen... 132

I mean, in this hospital, um, the majority by far, align themselves with Christianity. There are other hospitals, as we know, where half the community may align themselves with Islam, and that would be a very clear expression of spirituality within that group. And we're here to serve that community. We're not here just to er, look out for people of very specific er, forms of spirituality. 133

I think it's been a challenge. I mean, again, this is something that's changed post war with the immigration policy and the active recruitment of people from parts of the Empire into this country, we, we've seen a far greater variety of religious forms, and therefore spirituality as well, and that's been a challenge. A challenge for chaplaincy, which has been dominated by Christianity but to a less...to a very lesser extent, Judaism has been some feature of it, 134

#### 12.4 CHALLENGE TO THEOLOGY

+++++

+++ ON-LINE DOCUMENT: Participant 1

+++ Retrieval for this document: 1 unit out of 170, = 0.59%

++ Text units 135-135:

but now we're having to come to term with a, like I say, a greater variety. Um and I think that challenge, is...it is a challenge. It's a challenge for some people's theology and ecclesiology, for one, er, 135

#### 12.5 FEW BARRIERS AMONGST THE SICK

+++++

+++ ON-LINE DOCUMENT: Participant 10

Patientwise, at (N) Hospital in any case, they're so kind of ill, if you like, and old, usually that they've embraced one another in their own values erm, and they appreciate that.

## 12.6 DIFFERENCE BETWEEN RELIGIOUS AND CULTURAL NEEDS

+++++

+++ ON-LINE DOCUMENT: Participant 5

+++ Retrieval for this document: 2 units out of 167, = 1.2%

++ Text units 111-111:

Now, because I came, I took it under the wing, we were able to - to do it, so that it actually met the religious needs of the Muslim community. The ones that I inherited, they - there would have been problems, so that - but equally, I think we also need to help people to understand the difference between religious needs and cultural needs. Cultural needs are important, but sometimes muddy the issue; and also the, you know, the religious community themselves, are not always aware of the differences, in - it's like here, there's been a big issue here, that there are no facilities here for washing bodies. 111

++ Text units 113-113:

Now, these are important things to tease out, because where there are deep religious needs, you need to perhaps argue more strongly with the - with the hospital - and that it needs to actually do it now; whereas we have these other things which are, which are perhaps ideal and they need to be part of a longer-term programme. 113

+++++

+++ ON-LINE DOCUMENT: Participant 8

+++ Retrieval for this document: 1 unit out of 89, = 1.1%

++ Text units 59-59:

Well I think for us now that's a major issue - in certain parts of the country at least. In some parts of the UK it's hardly a problem, but in larger cities then it's a major issue. It's about trying to help people

understand that other faith groups may have different ways of dealing with - and also help those faith groups to recognise that there is a role in health care for them too, when some may not have recognised that in the past. Traditionally, they may not have had a system of pastoral care. It may have been the family that did it, and they're learning a western culture that often this is done by clergy, pastoral care givers, spiritual car givers. They don't have to follow the same patterns but they may have to recognise that that is something that their own people will expect because they're living in a western society and this is what they're seeing about them. And sometimes it's osmosis. It's absorbed without realising.

59

## 12.7 IMPORTANCE OF DIALOGUE

+++++

+++ ON-LINE DOCUMENT: Participant 5

+++ Retrieval for this document: 3 units out of 167, = 1.8%

++ Text units 122-124:

this was why, you see, when I came they were about to start building a Muslim prayer room and they'd not spoken to anybody from the local Mosques - but that's what I mean by the pressure, to be seen to be doing something, but really not actually meeting, you know, people's religious needs. And yet, by calling them in and doing that, we were able to more than satisfy their needs

122

but it was just little things like, you know, we moved the door slightly, because where the door was going to be was exactly where they needed to be facing, you know; we got a special carpet from Manchester with praying spaces, and just little things, which made all the difference - but you see, you need that,

123



it was like deciding you'd have a Christian chapel - but just asking a member of staff who went to Church to do it, you know, you'd not get - cos they're just not aware of the things, so - but I'm aware where you've got lots of other faiths, you know, it is - it is difficult to meet all of the needs - and compromises, you know, need to be, need to be made. 124

## 12.8 RIGHT OF RECOGNITION

+++++

+++ ON-LINE DOCUMENT: Participant 6

+++ Retrieval for this document: 1 unit out of 147, = 0.68%

++ Text units 114-114:

CH Yeah I wish I understood more about this, Mike. It's not an area which I know very much about - but I believe it absolutely right that every human being that goes into hospital has the right to have their faith recognised and acknowledged, provided that it is a faith which is recognised and acknowledged nationally. And so I think chaplaincy should enable that to happen. So what was the next bit of the question, sorry Mike? 114

+++++

+++ ON-LINE DOCUMENT: Participant 8

+++ Retrieval for this document: 1 unit out of 89, = 1.1%

++ Text units 60-60:

And if you're an Islamic patient and you never see anybody from another tradition, you only see the Christian ministers around, then why are our people not here. And we should make sure that they can be there. They should be there if they want them, and that we encourage them and welcome them and support them and help them to be absorbed into the system, as we

help Christian ministers to be absorbed into the system, to become comfortable with the system. And that's not easy because hospitals are a strange environment for those of us who come into them for the first time. When you've been around them a lot you don't realise just how difficult it is. But when you come in for the first time it's quite frightening and you don't know what that bleeping around you is in ITU,

or why they're running down the corridor because there's a cardiac arrest and they're pushing everyone out of the way. But you learn those sorts of things and we've got to help them learn that, and help them, not in a paternalistic way, but help them find the system which best suits their own faith and communities.

60

+++++

+++ ON-LINE DOCUMENT: Participant 11

+++ Retrieval for this document: 1 unit out of 100, = 1.0%

++ Text units 19-19:

if you look at Maslow's hierarchy we put physical and this, and that - but once those are sorted, if the other bit, the one about the being of the person isn't looked at or addressed, then you're giving incomplete palliative care. And so I've always looked upon it as a whole - to be approached totally. And I think we're quite good at it in palliative care although I think a lot of people play at it. It's a personal hobby of them, like - and I think playing at it. Paying lip-service to it is one way of tackling it, the other is to be involved - and I like being involved but I have to be careful in that I'm dabbling - cos I'm not an expert in that field. So I know my limits. I've come to know them and I will pass it on - and that's how we work. But in the development, I was very keen that we had a chaplain. And when we started the hospice, there wasn't a chaplain appointed but we had a very good multi-denominational

team. I can't say multi-faith cos I was disappointed - we wrote to everybody and only the Christian church replied. I was really sad about that, cos I wanted like an Imam from the Muslim church and we wanted a Rabbi – but having said that in ten years we've had I think two or three Muslim patients, a few Orthodox Christian - but the majority have been Christian So when you think about it, that's about right for the proportion of people we have. And of course we get the agnostics and atheists and so on - and they have spiritual needs - and you have to tackle it in their own way. And they see the chaplain sometimes, as a threat - but often end up thinking of them as friends, and say you know -

19

## 12.9 SENSITIVITY

+++++

+++ ON-LINE DOCUMENT: Participant 6

+++ Retrieval for this document: 1 unit out of 147, = 0.68%

++ Text units 116-116:

The interface, yeah. So, so that means then that whoever is a senior chaplain has to be very sensitive to whatever the make up of the local community is; very, very sensitive - I mean theological and politically. Where, I think, the next stage of the development is gonna be is how far those chaplains can sit down and discuss not only what their faiths have in common but also what separates them and what - how they overcome separation without losing their own beliefs and integrity in the process.

116

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+++ ON-LINE DOCUMENT: Participant 12

+++ Retrieval for this document: 1 unit out of 101, = 0.99%

++ Text units 54-54:

I think the great rebellion about having Chaplains doing spiritual care in nurse training and so on, was about this. It's nothing to do with 'Do you baptise babies when they're not going to live, or what have you? That's easy - you read in the book, and it's only on the level with the same courtesies - Hindus, Muslims or anybody else - and even those, you know, we're sort of being fed the idea that if they're Asian they're going to be that and they're going to want the other, but they're just like everybody else. There is no short-cut to learning to know, to listen to them and asking them what they want - you know - don't come in nice neat categories - maybe an Asian who's got quite a splattering into their Muslim faith and wants a real mixture - so I think you can only know about where people are by asking and listening, and watching - but, but you have to do that to yourself as well, and you have to learn to listen to yourself - and then the bridge over to religion is that these things need expression.

1 **TRANSCRIPT PATIENT A - 'ARTHUR' APPENDIX 17**

2

3 **Q1** Yes, thank you for agreeing to see me and for being  
4 willing to talk with me a little about your life and about things that  
5 are important to you just now. I wondered if you could just begin  
6 by saying a little bit about your background and where you come  
7 from

8

9 M Well sort of going a long time back, I was born in -----  
10 and lived there till I was almost 18 and then I moved to  
11 ----- for a short time and then went down to London to live  
12 for a few years and then me father had the opportunity of  
13 taking over some small retail businesses or business units in  
14 the middle of a new housing estate and he was looking to sort  
15 of open these up as like small grocers and newsagents sort of  
16 establishments - nothing large but you know something that  
17 would provide an income for somebody providing they were  
18 prepared to put effort into it. I decided to come back and live  
19 back in ----- to work in that newsagents and grocers shop.  
20 He was working in what was essentially just a newsagents  
21 shop which is in the middle of a sort of industrial area so the  
22 main need for that was just newspapers, cigarettes and things  
23 and there was like a sandwich shop next door. So that's how  
24 I came to be in ----- It's quite strenuous work . I mean, I  
25 don't know whether you've had experience of that sort of  
26 thing but you know, a newsagents work means getting up  
27 very early in the morning and then you're working through  
28 the day till sort of 6/7 o'clock seven days a week so it's quite  
29 a substantial commitment doing that. It got to a stage really  
30 when I felt that either I didn't want to do that for the rest of  
31 me life or else - I didn't you know dislike doing it, it wasn't  
32 something I could envisage - spending the rest of me days  
33 working in this grocers and newsagents. So I decided to sell  
34 the shop and then for a while - I mean I hadn't sort of any  
35 ideas of what I wanted to do, I just knew what I didn't want  
36 to do. I took the opportunity of doing like an access course  
37 to get back into education so ..... financed that through  
38 running like a light haulage business. You know, with  
39 having had a newsagents and grocer I had a sort of medium  
40 sized van, so I could utilise that to do some small jobs, some  
41 small transport jobs. So I used the income from that to help  
42 subsidise me through doing this access course and a degree  
43 course at university - and I think I was in a more fortunate  
44 position than say students today in that you know we were  
45 given money to study

46

47 **Q2** Would that be ---- University?

48 M No I did it at -----

49

50 MW Oh, -----

51

52 M Yeah it was like a polytechnic at the time so, you  
53 know, you got a grant and you got rebate on your housing  
54 and you didn't have to pay rates - and so it was quite  
55 fortunate I think in that respect - that I chose that time to do it  
56

57 Q3 The subject was?

58

59 M What I did was what they call a humanities course  
60 which was - you combined quite a lot of different subjects.  
61 You were able to choose - you didn't do them all but you had  
62 an option of about 9 to 12 subjects and you had to sort of  
63 choose at least one but you could do 2 or 3. One of those  
64 would perhaps be your major subject and other ones would  
65 be just minor subjects. I chose to do Drama as my main  
66 subject and then I did English - yeah English Language  
67 mostly with a little bit of literature. So yeah, the idea was  
68 you just did - if you wanted to drop one of the subjects after  
69 the first year you could have done or you wanted to take up  
70 another one you could have done as long as you'd sort of  
71 completed the units, sufficient number of units you would get  
72 your degree at the end of it. So I did that, really enjoyed it. I  
73 mean I was obviously younger than a lot of the people on the  
74 course 'cos I would be - let's see we're talking about - I got  
75 my degree in 1983 so that would make me 38 I think when I  
76 graduated. There were some students on the course who  
77 were mature students, most of the ones on my course were a  
78 lot younger I mean some of them had just gone straight from  
79 school to - but we all got on well together. One of the  
80 reasons why I chose drama because it was a group activity  
81 you know after studying literature I could get the books out  
82 the library, I can read through them, write the essays and  
83 apart from the dialogue between me and the tutor nobody  
84 else knows what I'm doing on that course. The drama  
85 course involves physical operation you know if you want to  
86 put plays on you need to do some sort of exercises. You  
87 know we do voice and body exercises well you're going to  
88 need at least one other person so that was a good choice.  
89 You know I think consciously I think that's what I wanted to  
90 do

91

92 Q4 Had you a family at this time?

93

94 No, no, no family - so again I was fortunate . I had no  
95 commitments so I was quite – yeah I suppose like a student,  
96 just slightly older than a student, but I don't have the  
97 commitments and so I'm like a student in that way in that  
98 nobody was relying on me for anything. So yeah I got me  
99 degree in 1983 and then started looking round for things I  
100 could do you know I hadn't had any plans as to what I  
101 wanted to do and that's when I got involved in adult literacy  
102 at the College here in -----. Initially I was just sort of  
103 working as a volunteer you know they have students that  
104 come in wanting to improve their English and reading and  
105 writing and some very basic things and the staff can sort of  
106 give you some work – you know if you do this with this  
107 student today they might find that useful. So they chose the  
108 activities but I was sort of there to sort of help them through  
109 any problems that might arise. So it was done on a voluntary  
110 basis initially although there was always a thing in the back  
111 of your mind that that might lead on to you know something -  
112 paid employment. That's what happened really. I mean I got  
113 involved in the ESOL programme, as it was called, helping  
114 people who'd come over from other countries to settle here

115

116 **Q5** That programme was called again?

117

118 **M** ESOL

119

120 **MW** ESOL? E-S-O-L

121

122 **M** Yes, English Speakers of Other Languages. I mean  
123 there seems to be some problems about how to call this type  
124 of work because it's fairly sensitive. You say, you know,  
125 initially it was for speakers of second languages, well you  
126 know that's a bit patronising because most of these people it  
127 might be the 3<sup>rd</sup>, 4<sup>th</sup> or even 5<sup>th</sup> language. You know in their  
128 own country they might sort of speak 2 or 3 languages you  
129 know - the local language, the national language and they  
130 also probably know English for business so you know it's  
131 always been a problem as to how to call this. I think now it's  
132 called EAL or something like that now. I'm a bit out of it  
133 with being poorly but you know it's Speakers of an  
134 Alternative Language or something like that. Yes so I got –  
135 started doing some paid employment with that just 2, 4, 6  
136 hours a week at the College and then you know I enjoyed  
137 doing that but I felt that I was being a bit fraudulent because  
138 I'd taken on this job of teaching English for the second or  
139 alternative or whatever language, but really I had no teaching  
140 qualifications at all. I had no knowledge about the theory of

141 language and so I went and did a short intensive course at  
142 Sheffield University where you look at things like language  
143 teaching - you know language theories about how we acquire  
144 language, how language operates in society that sort of thing.  
145 So really in a sense I got the job and then got the  
146 qualifications for it afterwards, but yeah I mean that was  
147 useful and from that I was able to then think about working  
148 elsewhere. I was qualified, I'd got experience and I wasn't  
149 restricted to working in ----- . I got a job at -----in-----  
150 doing language support work again, and this was with a  
151 scheme that they were running in ---- to do with people on  
152 vocational access courses. So I were doing something like  
153 you know business administration or warehousing or  
154 construction and I would try and give them some extra help  
155 looking at, you know, reading their assignments and you  
156 know structuring their answers and what they were going to  
157 do. Then that sort of - that was part of the ---- Council  
158 scheme for something called VET programme - Voluntary  
159 Employment Training or something - I can't remember the  
160 full title so this was sort of working with people who were  
161 doing vocational training who needed to brush up on their  
162 language. This was run through a scheme operated by the  
163 council and they got the funding from local government and  
164 national government and then they contracted the work out to  
165 whoever you know. So if it's construction work they would  
166 do it through the building college in ---- where they would  
167 offer short courses on bricklaying, carpentry, painting and  
168 decorating and we would have an input of the literacy  
169 bit. We lost the contract - well we didn't lose it, we gave it  
170 away really. The funding became so low that it tended to  
171 become unviable for us to offer the course so I became  
172 absorbed into the college itself doing support work with  
173 pupils in the college who were doing you know just things  
174 like A levels, O levels or some of those might have been  
175 doing vocational related courses. I worked in what's known  
176 as the Learning Support Centre so it's an area where sort of  
177 resources are made available you know it's like a library so  
178 they have those sorts of resources. There's also staff there  
179 who can you know give them advice if necessary and help  
180 them look for that source of information they want and you  
181 know how to write the essays or reports. That more or less  
182 brings you up to date I think

183  
184 MW Very interesting

185  
186 M Well not really but I mean - it seems to be I sort  
187 drifted into these things a bit, there's been no conscious



188 effort on my part to say ' Well you know by the  
189 year 2000 I hope to be you know doing literacy support work'  
190 you know I just seem to have drifted into things. I mean  
191 somebody has just come over and said 'Oh there's this sort of  
192 work going to be coming up you know how do you fancy  
193 doing something like that?'. I know it's nothing really  
194 ethical you know, it's not equal opportunities offering work  
195 to people who should go through a series of interviews and  
196 such, but you know that's how I drifted into me current  
197 situation. Can I just have a little bit of-

198  
199 MW Of course, of course-

200  
201 (Tape turned off for rest period)

202  
203 Q6 So what brought you to the hospice then -----?

204  
205 M The hospice here? Well I had – I was diagnosed as  
206 having bladder cancer in October of last year - so that was  
207 October 1999 and I had the bladder removed but although the  
208 biopsies indicated that there wasn't any tumour left after the  
209 operation, I mean, there was a bit of uncertainty about it. I  
210 worked out that the surgeons were sort of accurate in their  
211 predictions, there was still traces of cancer – you know it was  
212 in such a position where they couldn't remove it surgically  
213 'cos it was adhering to the wall of me pelvis so I started on a  
214 course of radiotherapy over at ----. As we went through the  
215 course of treatment I was getting more and more where I  
216 could feel pains in me sort of upper abdomen where the  
217 operation had been on the lower abdomen so they were a bit  
218 concerned about that and also I was sort of getting  
219 constipated and not feeling like eating and so they did some  
220 more tests and yes they found that there was residual tumours  
221 there, but it was in such a position that there really was  
222 nothing they could do about operating on it. So you know I  
223 went into ----- to try to sort of clear out the constipation  
224 and do tests and try and see what was feasible - but in the end  
225 they decided that really it was pointless trying to sort of do  
226 anything surgically - and you know it wasn't likely to right  
227 itself so you know they decided well you'd be better being in  
228 the hospice here rather than across at ----or at home because  
229 you know here I would get a bit more supervision and  
230 attention. There will be times when I'll feel very poorly I'm  
231 sure and I don't think it's fair to impose meself on the staff at  
232 ----- any longer. They've got very tight schedules,  
233 always stretched you know under-resourced and so they're  
234 not that really in a position to give you adequate support that

235 I'm sure they feel you should be getting. You know they're  
236 not consciously just saying 'oh well you know there's no  
237 hope, we won't bother looking after him too much' I mean  
238 they'd like to have -they'd like to do as much as they can for  
239 you but they've got limitations you know -lots of other  
240 patients

241

242 **Q7** Were you in and out of ----- then?

243

244 **M** Not really no. I mean I'd been in for biopsies and  
245 operations, so I hadn't been in and out a lot but with this last  
246 time I went in I mean it was obvious that I wasn't really  
247 going to be well enough to come out you know 'cos from  
248 having me bladder removed to 4/6 weeks ago I'd been  
249 alright, reasonably able to look after meself but it's got to a  
250 stage now where I can't do what I'd like to do. I need some  
251 sort of help - well I mean I've got ----- who's my partner and  
252 she's working full - although she has gone on to just part-  
253 time work for now so she can sort of give me some sort of  
254 help - but not the sort of help that you would get in a hospital  
255 or a hospice where they've got facilities on hand and they've  
256 got experience of how to cope with you, now any sort of  
257 medical crisis or things such as that. So the only option  
258 really is to come into the hospice - and although their help  
259 isn't intrusive at least you know it is there if you need it. The  
260 problem with ----- you know, the care there is not  
261 intentionally intrusive but it's not really adequate all-round  
262 supervision. It's no criticism about them in any way. I mean  
263 they do what they can so that's why I've ended up here

264

265 **Q8** Did you suspect that you had something serious in  
266 your condition before it was actually diagnosed?

267

268 **M** No not as serious as it's turned out. I mean you know  
269 I felt there was something wrong with me - you know  
270 intestines or whatever - 'cos originally I was diagnosed as  
271 having prostatitis but subsequent tests showed that it was a  
272 bit more severe than that. But yeah I mean that's a vague  
273 idea - but not that it was as serious as it is because I've  
274 always been very fit and active and I've never really had any  
275 illness in me life - nothing that laid me up for a long time. So  
276 no I mean I didn't imagine that I had got something like  
277 cancer - or if I had it would be only a minor form which  
278 could be dealt with

279

280 **Q9** What impact did that diagnosis make upon you?

281 M Well I suppose initially I was quite shocked by it. As  
282 I say it wasn't something I was expecting but initially I mean  
283 it was a condition which was treatable - and so there was no  
284 sort of problems coming to terms with it 'cos you know I  
285 could have an operation with radiotherapy after it and then it  
286 would settle down again. So you know it wasn't - it didn't  
287 affect me a lot to start with. I suppose it's only this second  
288 round of treatment that, you know, I've realised that it's  
289 much more serious. It's not life threatening or anything now  
290 it's just - but you know they don't give up hope you know,  
291 but you have to be more realistic to what is going to happen  
292 next. It's not going to be something where you take a few  
293 pills and it's going to clean it up, so I mean I can accept that,  
294 the only thing I find difficult to accept is how that impacts on  
295 other people. Initially when the doctor - I mean the doctor  
296 told me one day when I went into hospital the week before,  
297 he said you know how the condition was and how there was  
298 nothing else they could do, and fair enough you know, I  
299 mean I've accepted that you know, we're all going to die  
300 eventually you know, all we hope is that we die in a  
301 satisfactory or peaceful way. Having told me he called -----  
302 in the next day and then spoke to her on her own. She was  
303 obviously devastated by it. And she said you know - I  
304 suppose the usual things maybe - but this sort of thing 'I love  
305 you and you know don't want you to go' and things like that  
306 and I had to really say to her 'well that's not what I want. I  
307 don't want you to be saying how much you're going to miss  
308 me, how much you know you want me to sort of get better,  
309 how much you'd like to do things, because that makes it  
310 worse for me you know, that I - you know, if I know that we  
311 could both accept together that this is inevitable and that we  
312 just try and make the most of whatever else is left for us and  
313 not get so emotional about it and I'm sure that would make it  
314 easier for me'. I'm not sure about her in that respect and  
315 that's difficult because I mean I've got what I feel is a  
316 dilemma, that I've got all these people who want to come and  
317 see me. You know I've got me family, I've got 2 sisters and  
318 me mother still alive you know. I've got ----- and -----'s  
319 children 'cos you know we're not married but she has  
320 children and I've brought them up and then I've got other  
321 relatives and friends and they all want to come, and I can  
322 understand why they want to come you know, they feel you  
323 know, they want to be supportive at times like this but on the  
324 other hand you know I really feel that that makes it harder for  
325 me 'cos you know they're wanting to express their loss and I  
326 don't want them to do that 'cos that makes it harder for me -

327 you know I don't want to sort of just lay down and give up,  
328 but on the other hand I don't want you know lots of people  
329 coming and trying to sort of be cheerful and so it's - you  
330 know I feel awful about it you know. Somebody said you  
331 know could they come and see you on Thursday afternoon  
332 and I've said 'well no I don't really want to see them' you  
333 know I don't feel up to seeing them - too many people you  
334 know it's a bit too much

335

336 **Q10** Where do you get your strength from to cope just  
337 now? What helps you?

338

339 **M** Well I suppose the thing that helps me is - I know  
340 those people are there and that you know I suppose my  
341 legacy to life is that you know I have those people there you  
342 know, they are genuinely concerned about my wellbeing and  
343 that you know they are genuinely concerned you know that  
344 things have turned out as they have. A lot of what I'm  
345 leaving behind are those sort of attitudes you know - perhaps  
346 later on they can look at things and say we'll - you know  
347 remember him for these things and you know there's nothing  
348 that I hope for- either ill-will or malice or anything like that  
349 to other people. The only things that they will have to  
350 remember me by are good things. I've tried to live my life in  
351 that way, to be genuinely a friend to people when necessary  
352 but not to be intrusive you know to allow them their own  
353 space

354

355 **Q11** Would you call yourself a religious person?

356

357 **M** No not really I mean I was brought up in the Church  
358 of England I mean I've been confirmed and when I was  
359 younger I was part of the church choir and also I became sort  
360 of like president of the youth programme, I ran like a little  
361 youth club. And being in York - I mean you know York  
362 tends to be little pockets of activities, so it tends to be a little  
363 bit more parochial sometimes or it did when I lived there. It  
364 might have changed a bit now but - so yeah I got involved in  
365 the church in that way because it was a social activity you  
366 know available for young people. We had a youth club and  
367 we had - I used to organise trips and put on shows and that  
368 sort of thing but I've never really been deeply religious. I  
369 mean sometimes I think it's because of the - it's not religion  
370 that I fall out with but it's the way in which it's organised. I  
371 mean I don't know whether you've experienced that, you  
372 know. A lot of people can be very religious and it's obvious  
373 that you know they turn to religion at sort of moments of

374 crisis. They wouldn't be sort of regular churchgoers so they  
375 might share some of the beliefs of the Church but they're not  
376 interested in a lot of the peripheral – well no, that's - perhaps  
377 they're not interested in the peripheral, things like the social  
378 aspect, it's the more religious aspects that they're not all that  
379 interested in. Whether you sort of understand that or not

380

381 **Q12** I do, I do. Do you pray at all?

382

383 **M** No, no

384

385 **MW** Do you feel that there is something bigger than just  
386 this world?

387

388 **M** Well yes. I mean where I live I mean we have the  
389 regular Jehovah Witness run so we have these Jehovah  
390 Witnesses come round. Now they're always saying – I mean  
391 their idea about God creating everything and, I mean I don't  
392 believe in that - but what I do believe in is that we are a  
393 union. We have a sort of a unity and if anything, you know,  
394 the creator of things is us ourselves. If we want to create  
395 something you know, we've got to do it for ourselves. If we  
396 want to create equality in society, if we want to create - well  
397 even sort of an establishment like this you know, or to create  
398 just the basic things like you know the microphone you know  
399 - it's a collective activity you know, it isn't one person on  
400 their own. It's where people have come together and that's  
401 how I see you know - this sort of larger being is really  
402 ourselves you know, the totality of humanity. Yeah?

403

404 **MW** Yeah I understand that

405

406 **M** So when they come round saying 'You know who did  
407 this? God did it.' I say 'No, God didn't do it, you know it took  
408 you know - first of all somebody had to do the foundations  
409 and then somebody built up on that, and then somebody else  
410 built up on that. So you know it's a co-operation between us  
411 all and that if we want to create something worthwhile we're  
412 going to have to co-operate you know as a unit. We can't do  
413 everything all on our own. So you know that's what I see as  
414 the larger being, it brings us all together. It's like a lot of –  
415 can I just -

416

417 (Tape recorder switched off for rest period)

418

419 **Q13** You were just talking about the co-operation between  
420 all of us and the things that are created through that

421 co-operation. What's important to you just now, is it this  
422 spirit of co-operation that you feel is paramount to everything  
423 else?

424

425 M Well I suppose to my situation yes it is. I mean you  
426 know I've got to the situation where I'm going to have to I  
427 suppose cash me chips in now you know. I'm going to have  
428 to rely on other people perhaps doing things which really I  
429 should be able to do for meself. So I think this is now where  
430 I've got to instead of being you know wanting to do things  
431 for other people who I know need help or some support - and  
432 now I need them to sort of just provide something back to  
433 me. I don't sort of want to be greedy or anything but you  
434 know there are people here who are going to sort of try and  
435 help me out now

436

437 MW Yes that spirit of co-operation is very much around  
438 the hospice isn't it

439

440 M Yeah

441

442 Q14 It seems to be running right through it yes. What do  
443 you actually hope for just now then?

444

445 M I don't think I have any hopes. It's perhaps not the  
446 thing to say, I mean I don't think life has become hopeless  
447 but I don't feel that I have any hopes apart from you know  
448 just wanting to you know just let - well not slide away or  
449 anything like that, but you know, that whatever time I've got  
450 left that I can at least try and find some satisfaction - which is  
451 just a sort of wellbeing and you know having no fear of  
452 anything. You know I don't worry about things like dying, I  
453 think I've come to accept things like that, so I don't feel that  
454 I have anything - perhaps that's in a sense perhaps how we  
455 ought to go you know when you get towards the end of your  
456 life. you should feel some contentment that what you've done  
457 in your life has been useful, fruitful and that you know the  
458 rest of society are going to get something out of it. I've got  
459 the opportunity now just to try and sort of you know resolve  
460 some things. You know, just make sure that you know when  
461 I finally do die that you know whatever I wanted out of life  
462 or whatever I hope for other people out of life that they will  
463 have got that. So there's all the financial things obviously  
464 that are more difficult with ----- and I not being married but  
465 you know that finally she's in a stable position. Emotionally  
466 there's this problem about her having to accept that you  
467 know what I don't want from her is sort of this emotional

468 sentimentality. I just want her to say well you know we had  
469 some good times and you know that's over you know I must  
470 get on with the rest of me life now. I'm hoping to sort of  
471 instil those sorts of things into – because ----- principally  
472 because she is my partner she's the one I spend most time  
473 with but also here are other people, other relatives

474

475 **Q15** And have you found this sense of peace that you've  
476 been mentioning?

477

478 M Oh yeah, yeah

479

480 MW You feel content and peaceful?

481

482 M Yeah, yeah I do you know - it's just the discomfort  
483 which I get but I mean the nurses try and alleviate that and  
484 you know if it becomes worse well they've got ways of  
485 getting rid of that. So you know I don't need to worry too  
486 much on that side of it

487

488 MW But in your heart you feel peaceful and tranquil?

489

490 M Yeah, yeah

491

492 MW Emotionally?

493

494 M Yeah I mean I've tended to be of that sort of nature  
495 anyway but yeah I mean now that you know it's something  
496 which I need to think of a bit more you know I feel quite  
497 happy and contented

498

499 **Q16** Looking back over some of the things you've told me  
500 and shared with me today, you've actually touched such a lot  
501 of peoples lives haven't you with your teaching and your  
502 help

503

504 M Yes, yes, yeah

505

506 MW And I wondered if you sometimes in your quiet  
507 moments reflect upon those things in your life where you've  
508 lived out what you've actually been mentioning to me about  
509 supporting others and giving them things. Does that bring  
510 you some satisfaction?

511

512 M Oh yes, yeah. As I say I mean I don't mind doing  
513 that but not in a patronising way you know - there's this  
514 attitude about people you know - they come, they come to

515 this country for whatever reason and need to learn to speak  
516 the language, English

517

518 (Side 2)

519

520 M ...and that makes me superior to you. I don't sort of  
521 feel that that's the right attitude. Some of these people that  
522 see are highly qualified you know and you get people who  
523 have got degrees in Medicine and Computer Science and  
524 things like that, so they've got a lot of expertise and you  
525 know you've got to sort of harness that in when helping them  
526 learn the language so you know I'm not the superior you  
527 know. I suppose the old Victorian sort of white man sort of—  
528 you know you can sort of sort out the natives

529

530 MW Yeah

531

532 M No I mean I think – I've lost the thread of it but I  
533 think it's you know I don't see that I'm the sort of all  
534 powerful being. Just because somebody is in a position  
535 where they can't do something which I can doesn't make me  
536 a better person than them

537

538 Q17 Well thank you for sharing all your thoughts and  
539 being so open with me. It's been a privilege to listen to you,  
540 thank you. I haven't got anything else. Is there anything that  
541 I haven't touched on that you might want to mention?

542

543 M I don't think so. I mean you know I mean - I don't  
544 know - well I think the purpose of the interview; I'm not still  
545 exactly clear on what it was for but - you know whether it  
546 was for my benefit or for yours - you know - sometimes you  
547 know, if I've got an opportunity to talk something through  
548 with someone you know that helps me in some way or  
549 whether - you're sort of looking for, you know, some overall  
550 trends in the way that people approach being brought into  
551 hospices and what – you know, you sort of thing about what  
552 hospices can do for people and what they can provide.

553

554 Q18 Yes. I mean, is there anything else: any other support  
555 that you would find helpful?

556

557 M I don't think there is, no

558

559 MW Thank you

560

561 M Right



## BIOGRAPHICAL ANALYSIS: TRANSCRIPT PATIENT A – 'ARTHUR'

## CHRONOLOGY

Born in (N) 9  
 Moved to (N) at eighteen 10  
 Went to London 11  
 Returned to work in father's grocer's 19  
 Sold the shop 33  
 Took a degree course at university 43  
 Graduated 1983 99  
 Became involved in adult literacy 101  
 Became involved in ESOL programme 113  
 Trained in language teaching 142  
 Joined the Learning Support Centre 176  
 Bladder cancer October 1999 206

## KEY WORDS/ PHRASES

Father...retail business 13  
 I decided to come back 18  
 (shop) wasn't something I could envisage 32  
 decided to sell the shop 33  
 degree course 42  
 chose to do drama 65  
 really enjoyed it (course) 72/ 136  
 We all got on well together 79  
 Drama...was a group activity 80  
 Got involved in adult literacy 101  
 (worked) on a voluntary basis 109  
 involved in ESOL 113  
 felt.. fraudulent, no teaching qualification 137  
 did a short course/Language teaching 141/  
 160  
 I drifted into these things 187  
 nothing really ethical 193  
 tumour... uncertainty 208  
 there was nothing they could do 222  
 pointless trying 225  
 I'll feel very poorly 230  
 Not...adequate support (in hospital) 234  
 (Staff) They've got limitations 239  
 Other patients 240  
 I can't do what I'd like to do 250

always been fit and active 274  
 never had any illness 275  
 I didn't imagine I had... cancer 277  
 shocked by it 281  
 difficult- impact on other people 294  
 hope we die in a satisfactory or peaceful  
 way 300  
 she (partner) was devastated 303  
 I don't want you saying.. miss me 307  
 makes it worse for me 310  
 (family) they're wanting to express their  
 loss 325  
 I don't feel up to seeing them 332  
 I have people...genuinely concerned 341  
 leaving behind (positive) attitudes 345  
 no ill will or malice 348  
 I've tried to be a friend to people 351  
 brought up C of E 358  
 part of the church choir 359  
 confirmed 358  
 president of youth programme 360  
 ran a youth club 361  
 organised trips and shows 367  
 never deeply religious 368  
 not religion I fall out with but way it's  
 organised 370  
 we (humans) have a sort of unity 393  
 the creator of things is us ourselves 394  
 the larger being is...the totality of  
 humanity 401  
 it's a co-operation between us 410  
 I have to cash me chips in now 427  
 I'm going to have to rely on other people  
 428  
 I need them to provide something back  
 to me 432  
 I don't think I have any hopes 445  
 I can try and find some satisfaction 450  
 I don't worry about...dying 452  
 feel contentment 456  
 life been useful, fruitful 457  
 rest of society get something out of it  
 (my life) 458  
 Difficulties: not being married 464

Emotionally there's this problem 466  
 I don't want ..this sentimentality 467  
 Feel quite happy and contented 497  
 Not patronising 513  
 Talk something through...helps me 547

## THEMES

- |   |   |
|---|---|
| <p>1 Transition in early life</p> <ul style="list-style-type: none"> <li>▪ Move to London</li> <li>▪ Return, sell shop</li> <li>▪ Degree course</li> <li>▪ Drifted into things</li> </ul> <p>2 Focus upon people</p> <ul style="list-style-type: none"> <li>▪ Got on well (with others)</li> <li>▪ (Like) group activity</li> <li>▪ Adult literacy – (involves others)</li> <li>▪ Attitude not patronising</li> <li>▪ Tried to be a friend to people</li> <li>▪ Allowed people own space</li> </ul> <p>3 Service</p> <ul style="list-style-type: none"> <li>▪ Enjoyment</li> <li>▪ Felt fraudulent (until trained)</li> <li>▪ Undertook training</li> </ul> <p>4 Illness</p> <p>4a Seriousness/ reality</p> <ul style="list-style-type: none"> <li>▪ Never had any illness</li> <li>▪ Didn't imagine I had cancer</li> <li>▪ Nothing they could do</li> <li>▪ Pointless</li> <li>▪ I'll feel poorly</li> <li>▪ Can't do what I'd like to do</li> <li>▪ Didn't imagine cancer</li> <li>▪ Felt shocked</li> </ul> <p>4b Hospital support</p> <ul style="list-style-type: none"> <li>▪ Not adequate</li> <li>▪ Limitations</li> <li>▪ Other patients</li> </ul> <p>4c Impact of illness on others</p> <ul style="list-style-type: none"> <li>▪ Difficult</li> <li>▪ Partner devastated</li> <li>▪ Relatives wanting to express their loss</li> </ul> | <p>5 Sources of strength</p> <ul style="list-style-type: none"> <li>▪ I have people there</li> <li>▪ They are genuinely concerned</li> <li>▪ Leaving behind (positive) attitudes</li> <li>▪ No ill will or malice</li> </ul> <p>6 Relationship with Church/ religion</p> <ul style="list-style-type: none"> <li>▪ Brought up C of E</li> <li>▪ Confirmed</li> <li>▪ Part of the church choir</li> <li>▪ President of Youth programme</li> <li>▪ Ran a youth club</li> <li>▪ Fall out with but way religion is organised</li> </ul> <p>7 Beliefs</p> <ul style="list-style-type: none"> <li>▪ Not a God creating everything</li> <li>▪ We have a sort of unity</li> <li>▪ The creator of things is us ourselves</li> <li>▪ Larger being is... the totality of humanity</li> </ul> <p>8 Support from others</p> <ul style="list-style-type: none"> <li>▪ Have to rely on other people</li> <li>▪ Them to provide something back to me</li> <li>▪ Talk something through helps</li> </ul> <p>9 Attitude towards death</p> <ul style="list-style-type: none"> <li>▪ Don't think I have any hopes</li> <li>▪ Hope we die in a satisfactory or peaceful way</li> <li>▪ Try and find some satisfaction</li> <li>▪ No worry about... dying</li> <li>▪ Feel contentment</li> <li>▪ Life been useful, fruitful</li> <li>▪ Society get something out of (my life)</li> <li>▪ Feel quite happy and contented</li> </ul> <p>10 Difficulties</p> <ul style="list-style-type: none"> <li>▪ Impact of illness on others</li> <li>▪ Not being married - finance</li> <li>▪ Partner's sentimentality</li> </ul> |
|---|---|

## **STORIES**

- 1 Work in the grocer's shop 18-33
- 2 The humanities course 59-89
- 3 Working with English Speakers of Other languages 122-182
- 4 Diagnosis and prognosis 205 -240
- 5 Journey to the hospice 244 -263
- 6 The bad news 281 - 334
- 7 Sources of strength 339 - 353
- 8 Memories of Church life 357 -379
- 9 The Jehovah's Witness run 388 - 473

## **SIGNIFICANCE OF THE INTERVIEW**

The data appears to reveal a person

- in the process of becoming detached
- comfortable with his personal beliefs, not wishing to change them
- beginning to focus upon his impending death
- reaching a stage of integration
- strengthened by thoughts about the way he has lived, his perceptions of the value of his life and the legacy he will leave behind
- recognising that he will come to need the increasing support of others
- finding no need of formal religion
- focussing upon what his dying needs will be
- unwilling to take responsibility for the emotions of his family and friends

**EXTRACTS FROM PATIENT NOTES – HOSPICE 2**

**Hospice Patient C** Female patient aged 62. Rectal cancer.

17.7.00 (N) does not want to be told what the lump is that is in her bottom. She said 'what I don't know can't hurt me'. She knows that it is inoperable and she can't be cured. She does not want any more chemotherapy and is taking each day as it comes.

28.8.0 (N) denies any fears. However, is obviously fearful of dying in her sleep. Some spiritual distress from previous relationship with husband who is now dead. Encouraged to voice her concerns.

**Hospice Patient D** Male patient aged 89. Cancer of the bladder and prostate

Multidisciplinary team meeting mention under Psycho-spiritual heading: confused/ disorientated. Worried about his wife. Wants to go home.

**Hospice Patient E** Male patient aged 65. Cancer of the bladder.

Jewish - very important, but not orthodox. His beliefs have helped him through bad experiences.

**Hospice Patient F** Female Patient aged 48. Cancer of the duodenum.

Religion: C/E - important, but not a churchgoer.

(N) has said she is accepting of the situation and feels at peace. Has talked a lot about the process of dying. Feels that by having completed a corneal donation form she is going to help others

**Questions about Meaning of Life:** Feels it's unfair she is going to die - feels she has always led a good life.

(N) struggling to find meaning in the waiting (Chaplain)

28.7.0 Have given (N) relaxation tapes...also discussed with her some use of visualisation/ guided imagery (Chaplain)

- 8.8.00 (N) very weepy - feeling very despondent - felt very insecure when she went home on Sunday. Feels things are getting on top of her - vicious circle. Wants to sleep and not wake up. Also worried about her family - boys and husband. Advised that the service was here for all family and staff willing to talk to family too.
- 13.8.00 Spent time in conversation with (N)'s mum and uncle who were both acutely upset when visiting (N). Mum V. distressed. Doesn't feel she wants to come again. It may be important she is offered bereavement support.
- 15.8.0 (N) asked me 'how long it was going to be before she died?' I told her days/ weeks rather than months... I said for her to continue asking and that we would answer her questions.
- Expressed issues and concerns regarding dignity - reassured her that we would respect her dignity and honour her individuality.
- 27.8.0 (N) feels her dying is too slow
- 11.9.0 (N) said there were some questions she wanted to ask.
- What is dying like?
  - How can we guarantee she will have no pain?
  - How will we know that she has pain if she can't speak?
- 19.9.00 (N) was interviewed by the Rev. Michael Wright about the spiritual dimension of care and her journey to date. (N) enjoyed the interview. Feels that things are changing for her again and thinks that when she has done some business for the employment that she will be able to 'close her eyes' (Chaplain)