Voicing the spiritual: a dynamic exploration and analysis of the role of the chaplain in English hospices

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Abstract
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Since Cicely Saunders founded the first of the modern hospices in 1967 the body of literature on spirituality and spiritual care in healthcare has grown. At the same time the role of Christianity as the dominant culture has declined and the role of the chaplain has changed. Spirituality is no longer assumed to be Christian but has an independent existence which has resulted in questions as to where and to whom spiritual care belongs. Despite finding that they have to explain, if not justify, their role and their salary hospice chaplains have largely failed to engage in research and written but a few articles. Therefore my initial research question asked: how do hospice chaplains understand spirituality and spiritual care? However, as a retired hospice chaplain, reflection on my own experience of the patient-focus, which leaves little time for anything else, led me to recognize that the question is too focused. Furthermore ministerial integrity, which results in a reticence to speak about the work and which struggles to accommodate the production of evidence to justify the role suggests that a broader question on the nature of the hospice chaplain's role is necessary to elicit the understanding of spiritual care. Therefore this study empowers hospice chaplains to speak openly about their work. However, as there was no data available on hospice chaplains it was necessary to carry out the first ever Profile Survey of the 162 members of the Association of Hospice & Palliative Care Chaplains. The survey was carried out online and included a question on willingness to be interviewed. From the 108 chaplains who responded twenty-five chaplains were selected, reflecting the profile, and interviewed using a semi-structured format. The findings of both the Profile Survey and the interviews are presented. From the interview data two connected themes, prophet and presence, emerged and are examined in detail. Using the work of Walter Brueggemann the prophetic aspect of the chaplain's person and work is explored, finding common ground in the concept of presence. Henri Nouwen's work provides the basis for exploring the formation of presence, revealing the importance of listening and leading to further exploration, through the writing of Jean-Pierre de Caussade, of the relevance of *kenosis*. In the process of analysis a number of shifting boundaries, related to the chaplain and the future of hospice care, were revealed. These are examined before presenting my conclusions and recommendations, ending with a picture of the hospice chaplain of the future.

Thanks and dedication

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I should also like to thank the chaplains who took part in this study, and the Executive and members of the Association of Hospice & Palliative Care Chaplains. Their support of my years in hospice chaplaincy was invaluable and I sincerely hope that they will be able to continue to support each other and the whole healthcare chaplaincy profession for many years to come.
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Introduction

'Everybody knows what spiritual care is.' Two male voices in unison. At six foot and standing ready to leave, one of them towered over me. I and other members of the Executive of the Association of Hospice & Palliative Care Chaplains (AHPCC) were still sitting. The meeting was drawing to a close, we had reached 'Any Other Business' on the Agenda and some were already gathering belongings in order to catch trains and planes (the members of the Executive came from all over the UK). I had asked for a slot and was anxious that I would not be able to express myself succinctly in the short time available. The moment came. I said that I was going to undertake some PhD research on the understanding of spirituality and spiritual care amongst hospice chaplains. Despite feeling crushed by the immediate response I managed to say that there was nothing in print about what hospice chaplains themselves thought and please could I have permission to conduct a survey of the membership to establish a population from which to select interviewees[1]. Permission was given, unanimously, and the membership were advised at the next AGM[2].

Looking back I can see the factors which have contributed to my ability to undertake this project. My first degree, a B.Soc.Sc., rejoiced in the title of 'Moral and Political Philosophy' and included economics, statistics, sociology, political sociology, and anthropology as well as philosophy. Suffice to say that I retained very little of what I learnt but what I have retained has been very useful. A graduate training place in pharmaceutical marketing was followed by an actual marketing job and then I changed companies to work in market research on small consumer goods. In this job I conducted both quantitative and qualitative surveys. In the 1980s a degree was still a requirement for training in Anglican lay ministry - I was licensed in 1991 - although it was not necessary for acceptance on the two-year Spiritual Direction course, run by the Oxford Diocese, which I then undertook. However a degree was necessary for acceptance on a Master's course in Applied Theology at Westminster College Oxford in the late 1990s. The

[1] To comply with Data Protection requirements the AHPCC membership form advises that email addresses will be used for membership mailings and asks members to agree, or not.
[2] The preliminary findings from the survey were presented to AHPCC at the 2013 conference. The full details are presented in Chapter Four.

course offered various strands and I chose the gender route. My thesis was entitled:

> The void and women's personal empowerment: An Exploration of the Critical and Experiential Nature of the Void, its Effect on Individual Christian Practice and the Implications for the Church's Ministry.

The void was my term for an experience which, according to the writings of Lucy Irigaray, Mary Grey and Grace Jantzen, could not yet exist for women in what they regarded as the patriarchally-dominated discourse of the Christian tradition. Therefore women could not develop a self-defined identity but had to be patriarchally-defined. My research was designed to show that at the grass-roots level women were experiencing the void and being empowered to a self-defined identity. Using the writings of Irigaray (1977,1990), Grey (1989,1991) and Jantzen (1995,1998) I constructed a framework of the experience which I used to analyse the data collected from eleven guided interviews. The analysis revealed that the women had established a self-defined identity and been empowered to some kind of ministry (in the widest sense) through a void experience. I then compared the findings with the experience portrayed in the Christian tradition, with particular reference to John of the Cross and Ignatius Loyola. I argued that the important common features were the absence of compliance with externally defined ontological reality, or lack of connection with church teaching, and the empowerment resulting from the experience. Approaching the current research I considered an awareness of empowerment might be relevant and was alert to the possibility that hospice chaplains might also focus on God, rather than the church.

Shortly after being licensed as a lay minister I started to work as a volunteer on the Chaplaincy team at the local hospital. Whilst watching my youngest daughter play lacrosse I met the Deputy Manager at the Day Hospice and was invited to include the hospice when visiting the hospital. She explained that her Roman Catholic colleague claimed to be providing spiritual care for Roman Catholic patients but tended to assume that patients of other denominations had no need of such care. She knew that holistic care should include spiritual care for all patients but did not feel confident of providing such care herself. I identified a need for extra training for myself, in the spiritual care of persons with a terminal diagnosis, and was duly funded to attend a short course at St Christopher's Hospice, Sydenham. I joined the AHPCC at whose regional meetings I experienced opportunities for reflection and mutual sharing and support. I attended annual conferences of the Association and in 2007 offered my services

as Conference Organiser, being responsible for organising the annual conference for the next four years. By this time the Day Hospice had merged with the local bedded hospice and my work covered the spiritual care of patients and staff at both sites, taking funerals and running workshops on spiritual care for staff. I appreciated the value of self-care so in addition to visiting my spiritual director bi-monthly I also visited an external Supervisor to reflect on my hospice and hospital work. However, at the end of 2012 chaplaincy, pharmacy and the Oncology Consultant's post were outsourced to the local hospital trust and my services were no longer required - so I retired.

As AHPCC Conference Organiser I was a member of the Executive and I represented the Association on the National Professional Associations Committee run by Help the Hospices (now Hospice UK). The AHPCC executive met four times a year to discuss a variety of issues of concern to hospice chaplains such as professionalization, pay scales, key skills and competencies, expectations, spiritual assessment and the difficulties of explaining the role of a chaplain/ spiritual care provider to hospice management. My experience on the AHPCC executive had reinforced my awareness of the issues which concerned hospice chaplains and in 2011 I applied and was accepted to undertake a PhD researching the understanding of 'spirituality', 'spiritual care' and 'chaplaincy' amongst hospice chaplains.

Through my membership of AHPCC, the only UK-wide organisation specifically for hospice and palliative care chaplains, I had become aware of the developments in chaplaincy in NHS Scotland, developments which were not happening in England[3]. I was also aware of the increasing pressure, in both hospitals and hospices throughout the UK, to prove the value of the chaplain's work. Through my own reading I had learnt of the lack of published literature authored by hospice chaplains and the profusion of literature on the subject of spiritual care from the nursing profession. It might not be fair to describe the situation in England as a 'turf war' but there was confusion caused by the lack of an agreed definition of the concepts of spirituality and spiritual care, further complicated by a lack of clarity about the role of the chaplain.

My initial research proposal framed the research question as: How do hospice chaplains in England understand the terms 'spirituality' and 'spiritual care'? I proposed to interview hospice chaplains to ask what they understood by

[3]The Scottish National Health Service, which operates independently of the NHS in England, started to address issues of spiritual care much earlier, producing *Guidelines on Chaplaincy and Spiritual Care in the NHS in Scotland* in 2002 (National Health Service Scotland, 2002).

'spirituality' and 'spiritual care' and thereby establish what constituted 'chaplaincy'. I thought that in explaining their understanding of spirituality they would reveal the theology underlying the understanding. I also thought the interviews would show whether or not their understandings related to generic chaplaincy (defined as the provision of spiritual, not religious, care regardless of the faith or belief system of both provider and recipient. Generic spiritual care is not the provision of religious care of all faiths by one chaplain) and what they perceived to be their unique contribution to spiritual care. However, in the process of designing the research, listing topics and questions, and reflecting on my own experience, I realized that such an approach sounded interrogatory and felt pedestrian. I found I was asking myself: 'what am I really interested in?' Carol Gilligan, feminist, psychologist and ethicist, points out that asking a question I am not really interested in means I am playing a role and my interviewee will then also play a role[4]. In contrast a question in which I am genuinely interested will elicit a genuine and vibrant response (Kiegelmann, 2009:7). What I really wanted was for an interviewee to talk about her[5] work. I had a script that I could check to see whether topics had been covered and use if necessary, but basically I wanted to give voice to hospice chaplains. I wanted them to describe their own work, to be open and honest about their experience, their feelings and opinions. In the process I hoped they would show how they are sustained in their work, how they understand their own spirituality and its place in their work, and the issues that concern them. To provide this information I anticipated that I would need to explore:

(i) the chaplain's own story of coming into hospice chaplaincy and previous experience.

(ii) how the chaplain understands the terms 'spirituality', 'spiritual care' and 'chaplaincy'.

(iii) how the chaplain practises spiritual care.

(iv) the chaplain's understanding of his own spirituality and its relevance to his work.

(v) the chaplain's awareness of management issues, especially the need for evidence-based practice.

(vi) what, if anything, chaplains perceive to be their unique contribution to spiritual care.

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[4] Carol Gilligan developed a voice-centred relational approach to interview analysis called *Listening Guide* (Kiegelmann, 2009).

[5] The pronouns he/she and possessive pronouns his/hers are used alternately as are men and women. I interviewed both men and women hospice chaplains.

(vii) the existence and nature of any theology underlying the work[6].

Information on these issues would fill several gaps in the existing published literature, which consisted largely of conceptual articles and commentaries and little practical work. Furthermore, the published literature was dominated by professions other than healthcare chaplaincy and what had been published from a chaplaincy point of view was mostly contributed by hospital, not hospice, chaplains. Therefore this research, giving voice to hospice chaplains (rather than hospital chaplains, nurses, nurse educators, doctors or social workers) would make an important contribution to the literature and to the future of hospice chaplaincy[7].

Although now retired from hospice chaplaincy I am still passionate about the vision developed by Cicely Saunders, the founder of the modern hospice movement. Early in my hospice career I heard Saunders speak about being inspired by the origin of the word hospice (Saunders, 2000). Rooted in the Latin word *hospes,* which means both host and guest, fourth century continental hospices were establishments where Christians offered hospitality, love and medical care to travellers. Saunders noted that this was spreading Christianity more through care than through preaching. She quoted from Henri Nouwen's *Reaching Out* to describe creating a space which a stranger/guest might enter and become a friend, a space in which he was not expected to adopt the host's lifestyle but rather find his own (Nouwen, 1980:68-69). Her vision of hospice was of a place where change could take place, where a person could find himself and become well enough to die. It was crucial that those who accompanied and cared for the person on this spiritual journey reflected on and were comfortable with their own spiritual journey. Throughout my own Christian faith journey, which includes twenty five years as a Licensed Lay Minister, twenty two years as a Spiritual Director, twenty years in hospital chaplaincy and fourteen years as a hospice chaplain, my concern has been, and still is, not only my own relationship with God but the recognition of and response to God in the life of another person. My interest in the spiritual welfare of hospice chaplains themselves arises out of my own experience, which provides the context for my critique of the hospice chaplain's work.

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[6] Unlike a normal focused research question my research question has fluid boundaries to facilitate the capture of the answers to this list.

[7] Some of the findings of this research have been used in my contribution to a chapter in a forthcoming book edited by two hospice chaplains.

To present the findings of my research with hospice chaplains the thesis has three sections, each of which has its own brief introduction. It is necessary to understand the soil in which the concept of the modern hospice was planted and flourished, so Section One focuses on the soil, the context of healthcare. Chapter One provides the background of the history of spirituality and spiritual care in healthcare in England, paying particular attention to the medieval hospital which has more in common with the concept of hospice than with a modern scientific hospital (Getz, 1998: 90)[8]. The decline of Christianity as the dominant discourse is described in the changes in the roles of nurse and chaplain and the story of Cicely Saunders is told. Whether the Christian narrative has been replaced by spirituality, as researched by Heelas and Woodhead (2008), is then briefly considered. The chapter ends without any clear answers as to the role of Christianity in healthcare or the understanding of spiritual care. Therefore Chapter Two provides a literature review exploring developments in spiritual care firstly in Scotland, whose advances were the envy of the Western world. Attention then turns to English spiritual care literature of the 1980s and 1990s and a selection of literature from 2000 onwards, with the unfulfilled aim of finding a common definition of both spirituality and spiritual care. My research was therefore conducted against a background of the declining influence of the Christian discourse, a lack of agreed definitions of spirituality and spiritual care and the absence of any guidelines from the Department of Health[9].

The three chapters of Section Two present the methodology and method of the research and the findings of both the profile survey and the interviews. In Chapter Three the deconstruction of the research question is described and the methodological issues are discussed. The method of research, and the means of collecting the data are explained and justified and the selection of interviewees described. To facilitate the selection of interviewees the first ever voluntary online Profile Survey of members of AHPCC was conducted. This covered gender, age, faith group, denomination if Christian, status if Church of England, job title, employment status, number of hours worked, number of years in Hospice Chaplaincy, length of time in present post, areas of training, geographical location, and the willingness to be interviewed for this project. The survey was open from September 2012 to July 2013 during which period 67% of the 162

[8] Brief biographical information is given in a footnote for the various sources referred to. Faye Getz is an independent higher education professional specializing in the history of medieval medicine.
[9] NHS Chaplaincy Guidelines were published in 2015.

members of the association responded. 84% of respondents were happy to be contacted to arrange an interview. Given that more than half of the members attend the annual conference, providing an unofficial unrecorded profile, there were few surprises in the findings. The results of the survey are given in Chapter Four.

Data collected from the twenty five interviews, conducted using a semi-structured format, is presented in Chapter Five. Lessons learnt from the guinea pig interview are described before presenting the detailed findings, which include the rich data of the two pilot interviews. Some interviewees talked with little prompting, others needed encouragement to describe how they came into hospice chaplaincy, previous work, experience of congregational work, how they conducted themselves, and what patients expected before being asked how they understood spirituality and spiritual care. They were asked to describe their own spirituality and their spiritual self-care. Also covered, either spontaneously or by prompting, were the hospice ethos, issues around evidence-based practice and record-keeping, spiritual assessment tools and the age-profile of AHPCC membership.

The collected data was very rich and the picture that emerged showed that it was much easier to give examples of the actual work of spiritual care than to define spirituality or describe the chaplain's own spirituality. Descriptions of spiritual care were pre-dominantly patient focused, demonstrating how the interviewee accepts the person as they are, and seeks to be with, listen, support, guide as appropriate. This does not sit easily with a scientific medical model which sees the patient as the object of attention, and the illness as a problem to be solved. Consequently the medical model is more amenable than the pastoral model to measurement and assessment, and in the current financial climate hospice management requires proof of the value of every member of the hospice team. The chaplain's role of being rather than doing, her 'presence', and her treatment of people as beings rather than objects does not lend itself to measurement and therefore makes her vulnerable in an evidence-based environment. The concept of presence emerged as a theme whilst conducting the interviews, as did the prophetic nature of the chaplain's role, the chaplain as sign or symbol of the value of humans as beings rather than objects to be measured. I therefore sought to explore the data for evidence of the prophetic role and for clarification of the concept of presence. In addition there was the question of whether either or both might assist in addressing the need for evidence.

Section Three presents my interpretation of the data on the hospice chaplain as prophet, and as presence. To explore the prophetic nature of the chaplains' role I compared them with the Old Testament prophets who offered the people a different perspective on their circumstances. Walter Brueggemann's work on the Old Testament prophets provided a framework which I applied to the material provided by the interviewees. The comparison confirmed the prophetic nature of the chaplain's role, indicating that the prophetic is an aspect of presence. Chapter Six presents the comparison ending with a description of the chaplain in the terms used to describe the prophet. Acknowledging that such a description presents the end product but not how the prophet or chaplain came to be 'presence' I then turn to formation.

In his book *The Wounded Healer* Henri Nouwen offers a three-fold analysis of what it takes to be a minister. Two of these characteristics, articulating inner events and compassion are then used in Chapter Seven to examine the concept of presence. However, I found Nouwen's third criterion, contemplation, ill-defined and limited in application. To explore the connection between presence and contemplation I examined the data for contemplative-type practice and explored the relationship of that practice with *kenosis*. Distinguishing between the self-emptying, already portrayed in Chapter Seven, and the emptying of contemplative-type practice or *kenosis,* Chapter Eight uses the work of Jean-Pierre de Caussade and others.

The experience of writing these chapters of interpretation drew my attention to the number of boundaries that had been exposed by the research. The fact that chaplains work on the boundary is much quoted, but the nature of that boundary is rarely discussed so the boundary of life and death receives little exposure. Furthermore the data revealed changes in the boundaries of Cicely Saunders' original vision and the overlapping boundaries of areas such as well-being and spiritual care. These may have an effect on the boundaries of the role of the chaplain as bearer of those memories. Then there is the boundary of hospice care in the future. Therefore Chapter Nine explores some of these boundaries, providing stepping stones to the final Conclusions and Recommendations, which focus on the self-care of the chaplain, the possible way forward for hospices and what that will require of the chaplain.

Section One: The Overview

Although the term 'hospice' has been used since medieval times for a place of hospitality for travellers, pilgrims and the sick and dying, the first of the modern hospices was founded in England in 1967 by Cicely Saunders. At that time spirituality was still generally associated with religion and regarded as the domain of the Christian chaplain. Since that time interest in spirituality and spiritual care in the healthcare context has increased exponentially.

This section seeks to set the scene for the research by describing the changing nature of healthcare in England and reviewing the relevant literature. Crucial to the character and practice of healthcare is the influence and role of Christianity and Chapter One begins by exploring that influence in the medieval period. A brief summary of post-reformation hospitals leads to a comparison of the past with the modern hospice. Noting the decline of the Christian influence the concomitant decline in influence of the paternalistic is demonstrated in the developments in the nursing profession since the founding of the NHS in 1948. The role of the healthcare chaplain in England in the same period is described before detailing the life and vision of Cicely Saunders. Finding that Christianity is losing its dominant role in healthcare, changes in the use of the term 'spirituality' are considered and my understanding of the term 'secularization' conveyed. The spiritual revolution as researched by Heelas and Woodhead is then examined before ending the chapter with conclusions.

Chapter Two reviews the literature on spirituality and spiritual care in healthcare, beginning with developments in spiritual care in the Scottish National Health Service (NHS Scotland) which were not only ahead of but also had an influence on the English NHS. The literature relating to spiritual care in England from the 1980s to 2000 is then reviewed. Since 2000 the amount of literature has increased and a selection has therefore been made. Contributions are considered from chaplains, nurse educators, theology lecturers, a chaplaincy researcher and mental health professionals.

Section One Chapter One:
Exploring the changing discourse: healthcare, Christianity and spirituality

Introduction

Over the centuries the relationship between spirituality and healthcare has changed. Where once the dominant discourse of Christianity pervaded the whole of life, including the foundation of healthcare, the decline of that discourse raises the questions: in what discourse is the healthcare system operating? Has healthcare invented its own discourse? Does the emerging understanding of 'spirituality' and 'spiritual care' require Christian ministers as chaplains?

To explore the decline of Christianity as the dominant discourse in healthcare, I begin with the history of healthcare, exploring the ways in which Christianity was manifest in English medieval hospitals. The description goes into some detail to show what healthcare grounded in and imbued with Christianity looked like, and to demonstrate that modern hospices have more in common with medieval rather than post-reformation hospitals. A brief description of post-reformation hospital developments and of the treatment of the sick poor up to the 1900s is followed by a comparison of past and present. I then turn to the modern era, from the foundation of the NHS in 1948. Since that time the status quo has been challenged leading to changes in attitudes to both personal and professional relationships, different approaches to organizational culture and a greater awareness and reflection on thought processes. To illustrate these changes the chapter continues with a description of the developments in the nursing profession from the introduction of the NHS into the new millennium. Although the majority of hospices are independent establishments, not part of the NHS, they monitor and are affected by events in the NHS such that the fate of hospice chaplains is influenced by that of hospital chaplains. I therefore give a detailed examination of the role of the hospital chaplain from 1948. The life of Cicely Saunders and the establishment of St Christopher's Hospice is then described. Having observed the decline of Christianity as the dominant discourse I present some of the changes in the use of the term 'spirituality' and state my understanding of the 'term 'secularization'. I then examine the work of Heelas and Woodhead on the spiritual revolution and briefly describe Woodhead's recent work on attitudes to religion and spirituality before ending the chapter with conclusions.

The history of healthcare in England

The first hospitals in Britain were established in the first century A.D. by the Roman armies using the continental model (Getz, 1998:90). Whether or for how long these institutions survived is not known and Getz states that there is then no firm evidence of hospitals in Britain until the Norman invasion (90). However, the first evidence of a hospice comes from fourth century Rome, where Fabiola founded an establishment in which Christians provided hospitality, love and medical care to travellers[10] (Saunders, 2000). It was a place where the guest was offered space to reflect and recover, and it was this continental hospice that inspired Saunders in the 1960s to develop the idea of a place in which a person would be offered hospitality so that he might become well enough to die. When Saunders was forming her hospice vision information on the English medieval hospital was limited. However, later historical scholarship has established the nature of English medieval places of care, commonly and often misleadingly referred to as hospitals. Getz (1998:90) states that medieval hospitals had more in common with the linguistically related concepts of 'hotel', 'hospice' and 'hospitality' than with our modern scientific hospitals. The later research has also addressed the confusion surrounding the founding of medieval hospitals.

Healthcare in the medieval period

The opening chapter of *The Hospital Chaplain's Handbook* begins with Jesus' care of the sick and his command to his followers to do likewise. Cobb (2005:2)[11] tells us that the church established places of care for the stranger, the traveller, the sick and the impoverished. These 'medieval religious foundations', hostels, infirmaries, almshouses, asylums and hospices, were 'generally small in size and run by religious orders'.

This brief description serves the purposes of the handbook but invites the questions: was the church the only driving force? Was care of the sick the only motive? Given the different types of people being served and the variety of institutions described what was the nature of the service being offered?

To answer these questions I shall explore how the dominant discourse, Christianity, is found in the motive, personnel, buildings and treatment of medieval healthcare.

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[10] Fabiola visited Saint Jerome in Jerusalem where she was inspired by Christians spreading the gospel by caring for people rather than preaching (Saunders, 2000).

[11] Mark Cobb is a Senior Chaplain and a clinical director at Sheffield Teaching Hospitals NHS Foundation Trust. His clinical speciality is palliative care and his primary research interests are in the fields of spirituality, end of life care and healthcare design.

Motive

Historian Carole Rawcliffe[12] (2011) advises that to better understand the English medieval hospital we need to discard the contemporary idea of the hospital as a place that provides medical care and saves lives. Rather, the main purpose of hospital care was not to save lives but 'to allow the pious to exercise charity' (Getz, 1998:91). It seems that care of the patient or inmate, was almost incidental to the opportunity for the demonstration of piety. Sethina Watson[13] (2006:76), argues that pre-1200 such piety was enacted by bishops, monasteries, the crown, local lords, archdeacons and townsmen, for all had founded and supervised charitable houses or hospitals, to look after the sick poor, the diseased, travellers, lepers and also to distribute food (bread and beer referred to as 'dole') to the needy. No matter the rank or title the founder decided the purpose for which the hospital was to be established, most commonly to provide for the sick and the poor (84). The rich would have been treated at home (Rawcliffe, 2011). The founder provided the site, specified how the alms were to be raised and used, and could also specify how any future income from other sources should be used (Watson, 2006:85,92). Such income might be alms from the local community and/or from individuals who were not wealthy but who wished to support the endeavour, thus demonstrating their piety. Watson defines such hospitals as 'a form of sited alms' which therefore came in various sizes and without constitution, statute or charter: 'A hospital's constitution was performed or repetitively re-enacted rather than recorded' (90). Evidence of hospitals as religious communities living under a rule is lacking and the idea is based on the assumption that England was the same as France and Belgium (81). Rawcliffe (2011) makes a similar point arguing that the loss of both buildings and documents during the Reformation has obscured the origins of the medieval hospital. However, Watson (2006:76) comments that by 1300 some hospitals lived by a rule, some practiced a liturgical day, some did both and some did neither. In other words there was no particular pattern. The nature of the establishment, and therefore the visibility of the Christian influence, was very dependent on who the founder was, the founder's piety and the local community's ability to provide support. Missing from Watson's account is the reciprocal nature of the relationship, that in return for the piety of alms-giving those who used the hospital, for whatever reason, were morally obliged to pray for the souls of the founders and benefactors (Abreu & Sheard, 2013:3), whose names were recorded in a 'register of obits':

[12] Carole Rawcliffe is Emeritus professor, School of History, University of East Anglia.
[13] Sethina Watson is Senior Lecturer in Medieval History, University of York.

> Here[14], from about 1296 onwards, were recorded the names of all the men and women whose charitable donations had secured membership of the house's spiritual confraternity, and for whose salvation prayers and masses were to be offered in perpetuity. (Rawcliffe, 2013:125)

Rawcliffe maintains that the motivation behind the alms-giving was not just the duty of care to less fortunate souls but the desire to ease one's path through purgatory (Rawcliffe, 2013:127).

In 1249 Bishop Suffield personally founded the hospital of St Giles, Norwich, not only out of sympathy for the poor and sick, but also 'to secure the remission of his sins' (Bonfield, 2013b:394). However, the great majority of alms-givers to this particular hospital were 'ordinary laymen and women from towns and villages scattered across Norfolk,' some of whom lacked a surname (Rawcliffe, 2013:126).

Personnel and buildings

The loss of buildings and documents due to the ravages of the Reformation has already been mentioned. However, where documentary evidence is available, mainly from the larger late-medieval hospitals, the role of Christianity may be inferred from the staff list, the design of the building or the treatment prescribed. The aforementioned hospital of St Giles had 'a master, four lay brethren, two clerks, a deacon and subdeacon and three or four sisters (aged over fifty) to change the sheets and take care of the sick' (Bonfield, 2013b:395). The 1523 statutes of the Hospital of the Savoy in London list a master who acted as overall superintendent, four chaplains who functioned as seneschal (administrator), sacristan, confessor and hospitaller, two priests, four altarists to assist in the chapel, and various domestic staff (Page, 1909:546). This hospital was unusual in that it was based on the continental model of the Santa Maria Nuova hospital in Florence, so that the main hall had sections, like cubicles, for patients' beds but the layout was such that each patient could see the services taking place (Getz, 1998:91). However, after the Reformation the emphasis moved from observing the mass to religious instruction (Swift, 2014:24).

Dainton (1976:536-537) describes St Bartholomew's, originally founded in the twelfth century, as having a master, usually a priest, responsible for running the hospital, eight brothers (three of whom were chaplains) and four sisters. Dainton observes that staff did not always behave well and the fourteenth and fifteenth centuries saw many complaints. Wardens/masters were guilty of mismanagement, neglecting duties and misappropriating funds. He also comments that the spirit of

[14] In the obit register of the hospital of St Giles, Norwich

public service and religious zeal that had founded the hospitals was fading and also notes that patrons sometimes abused the hospital by expecting free accommodation for themselves or their staff. Rawcliffe (2013:149) reports a 'rising tide of criticism about lax administrative standards and corruption'. She also comments on the need to adapt to changing circumstances[15]. Incidences of plague changed the demographics of need from the sick poor to the care of the elderly and incapacitated. Surviving hospitals adapted to become almshouses, not unlike today's sheltered accommodation, but still with chantry priests (149).

Medical care

In the medieval period in England the nature of the medical care provided was predominantly what we today call nursing care. Unlike the continental hospitals it is not until after the re-founding of hospitals like St Bartholomew's that staff records include trained medical men – surgeons and physicians (Dainton, 1978:810). Bonfield (2013a:22,43) argues that the care given was holistic with equal attention paid to body as to soul, providing good food and clean clothes and bedlinen, but he also acknowledges that the church taught that spiritual health was to be given precedence over the body (Bonfield, 2013b:396) in the view of the fourth Lateran council of 1215 that:

> spiritual health should be prioritized over physical medicine, since there was no possibility of physical healing without sacramental medicine (Davis, 2010:80).

However, there are some records of treatment we might term medical where religion seemingly played a part. The fourteenth century treatment for rheumatism is recorded in the text box.

> …the pharmacist placed some olive oil in a clean vessel, and then made the sign of the cross and said two prayers. The vessel was then put over a fire and had to remain there while part of a psalm, the Gloria and two prayers were recited seven times. The heated oil was then applied to the affected limbs (Dainton, 1976:535-536).

Dainton comments that religion appears to have played a significant part in the treatment but goes on to note that the lack of clocks and watches may indicate that the psalms and prayers were a means of timing the heating of the oil (536).

Healthcare after the Reformation

Many hospitals were associated with, though not necessarily part of, monasteries so the Dissolution of the Monasteries meant the disappearance of the hospitals

[15] The need for adaptation by today's hospices is discussed in Chapter Nine.

(Dainton, 1976:538). The resultant distress to the sick, disabled and helpless poor in London is noted by Denny (1973:87). He reports that 'the presence of a host of destitutes gave rise to considerable concern' such that the Lord Mayor petitioned King Henry to let the civil authority have what had been the hospital buildings 'for the aid of the poor, sick, blind, aged and impotent persons not having any certain place wherein they may be lodged, cherished and refreshed until they be holpen of their diseases and sickness by physicians, surgeons and apothecaries' (87). The Christian duty of care is still present, albeit with a hidden agenda. St Bartholomew's and St Thomas's, became the responsibility of the civil authority which appointed beadles to trawl the streets to find the sick-poor, the crippled, the blind, the infirm (Denny, 1973:87, Dainton, 1978:814-815). The hospital was still a religious space – its management was the responsibility of the 'hospitaller'[16] who was a person in holy orders[17]. At St Bart's he led three services each day and was responsible for everyday issues such as food and clothing (Dainton, 1978:813). Swift (2014:21-22) describes the hospitaller's duty to both God and the hospital governors. Duty to God was expressed in being a shining virtuous light for the benefit of the 'lewd & naughty' patients, whose salvation was his responsibility. Duty to the governors meant keeping order, in accounts and in practical matters such as the supply, cooking and distribution of food. When discharged the patient had to go down on his knees and recite a litany of wretchedness which gave thanks to God for the hospital treatment and pledged future good behaviour. Whether the re-founding of these hospitals was due to the needs of the sick poor or a means of social control, removing the unsightly from the gaze of the better-off, is not clear. Either way the chaplain/hospitaller was charged with making the patient compliant to authority (Swift, 2014:25, 27).

The concern with public order continued, culminating in the Poor Law Amendment Act of 1834, but before going any further I want to pause to make a comparison.

Comparing past and present

That the post-reformation hospitals, rather than the medieval hospitals, are the antecedents of the present-day hospital seems reasonable (Cobb, 2005:2). However, I do not think that it is helpful to see them as antecedents of contemporary hospices especially as Saunders (2000) took the fourth century hospices as her starting point. Furthermore contemporary hospices, like the medieval hospitals, do not cure, mend or save lives. The care they offer relates to quality of life for the

[16] The chaplain at Guy's and St Thomas' NHS Foundation Trust is still called Hospitaller today.

[17] At that time a person in holy orders was by definition male.

remaining time of a terminal illness. Both medieval institutions and modern hospices have sprung up in places where individuals or groups of individuals have identified a need. Some medieval units were founded by religious orders but only a few modern hospices have their origins in a religious order, whilst some use religious buildings and many were purpose built. Modern hospices are not funded by alms but they are largely funded by donations and like their medieval antecedents tend to be very small compared with acute hospitals – normally between eight and twenty beds compared with hundreds. Those who work in the patient-facing areas of a hospice may not be motivated by fear of purgatory or a concern with their own salvation but in my experience a sense of vocation, wanting to care for the dying, is common[18]. Many, but not all, modern hospices were built with a small room which was used as a chapel although it is now called a sanctuary, quiet room or prayer room. Christian symbols no longer dominate and artefacts for various faiths are available. Like the medieval unit most hospices have a person responsible for spiritual care who may, or may not, be called 'Chaplain'. In the medieval period the priest/chaplain was male but today the chaplain may be male or female. She may be called 'Spiritual Care Lead'. She may be full-time or part-time but either way she will be concerned for the security of her position, for the value of physical is prioritized over spiritual care and the changing economic situation means that the hospice, like the medieval houses, will need to adapt to survive.

Nineteenth and twentieth century developments

Returning to the history of healthcare, developments in this period played a crucial role in the development of the modern hospice. There was a continuing ethos of concern for public order and in 1834 the Poor Law Amendment Act changed the way the poor were treated. No longer were they seen as victims of circumstance – poverty, old age, too ill to support themselves - for whom the better off held a Christian duty of care. Now the poor were held responsible for their circumstances, deemed idle. The able-bodied poor, referred to as 'the deserving poor', might be offered a place in the workhouse where they were put to work, but there was little provision for the sick poor of an increasing population (Higginbotham, 2016). Nineteenth century voluntary hospitals were funded by charity and exercised great care over how those funds were spent. Those who were unlikely to recover quickly and who would therefore be a strain on resources were not admitted (Rivett, 2015). Neither were those of whom society disapproved such as prostitutes and sufferers of

[18] The caring professions had previously been referred to as vocations, a description itself indicative of the dominance of the Christian discourse.

venereal disease admitted. Neither were the dying - for hospitals could do nothing for them. The suffering and death of the poor were a particular concern for Father Gallwey, Rector of Farm Street Jesuit Mission. He wanted to alleviate the grim living conditions and provide a place where the sick poor could die in peace. Aware of the hospitals, hospices and schools founded by the Sisters of Charity in Ireland he invited them to come to Hackney to work. Initially the order was low in numbers and funds were lacking but eventually there were enough Sisters and sufficient funds for the Mother General to accept the invitation (Scott). Finally in 1905 the Religious Sisters of Charity opened St Joseph's Hospice, Hackney, as a place for the dying with no suggestion of control or concern for public order. Some fifty years later St Joseph's came to the attention of Cicely Saunders, who was working on the management of pain in the terminally ill at St Mary's Hospital. She arranged to work three days a week at St Joseph's where she continued her research and influenced the giving of drugs so that patients' pain was eased without making them comatose (du Boulay, 2007: 48). She involved the nurses at every step, at the same time keeping meticulous records to support her methods, which were so successful that 'Dr. Colebrook, energetic member of the Euthanasia Society' was 'impressed to the point of bewilderment' (48). I shall return to the story of Cicely Saunders later in the chapter but first I want to explore the decline of Christianity as the dominant discourse in the role of the nurse and the chaplain in the period from the establishment of the NHS.

The declining role of the Christian discourse

The dominant discourse in the modern nursing profession

In 2008 the *Nursing Times* commissioned journalist Adrian O'Dowd to write a series on the development of nursing since the founding of the National Health Service in 1948. The series was an oral history obtained from interviews with nurses who had worked in each of the decades.

Whilst the introduction of the NHS was 'one of the outstanding achievements of the UK's history in the 20th century' bringing change to the delivery of healthcare, some of the component parts of the service retained traditional roles: 'You still had Florence Nightingale values then and matron and sister had real authority' (O'Dowd, 2008a). Not only was paternalism, albeit in feminine form, present but power was seen to be exercised: nurses 'had to obey matron in their private life as well, taking instructions on how late they could stay out, how smartly dressed they were and the suitability of any young man they wished to marry – although getting married meant

leaving the job.' The nature of some of the recalled memories suggested that intimidation was the means of control.

The decade of the 1960s found 'nurses were starting to feel more confident within the brave new world of healthcare and beginning to develop greater independence' (O'Dowd, 2008b). Matron was still a powerful figure at the beginning of the1960s but the Salmon Report of 1966 marked the beginning of the end of her traditional role. Hierarchy was still in evidence in the control of nurses' lives (the age of majority was 21 until 1970), in separation by rank in the dining room with doctors having their own dining room and in a general respect for the position rather than the person: 'You didn't walk through a door in front of somebody more senior than you.' Nurses described their lives in the 1960s as 'regimented' compared with today but everybody knew their role, even the consultants – the deference paid by a consultant to Matron in the 1967 film Carry on Doctor was not entirely unrealistic. In the 1970s the strict discipline that had ensured the smooth running of the wards was being relaxed and nurses were no longer like cogs in a machine. Patients were encouraged to use nurses' first names and ward sisters were asked to consider nursing staff's requests for time off when planning duty rotas. However, the old hierarchy had not disappeared: one nurse remembered her first day on the ward as part of her training, which she thought meant learning by asking questions. She was firmly told that she was not there to ask questions but should do as she was told (O'Dowd, 2008c). The 1970s also saw the introduction of 'individualized care', entailing patient choice and autonomy, which gained ground in the 1980s and was finally established in the Patients' Charter of 1991 (Woodward, V., 1998:1047). One nurse observed that the 1970s was a changing environment where 'People were beginning to see nursing not as a vocation but almost as a stepping stone to something else,' (O'Dowd, 2008c). This may be an illustration of Brown's point that the way people formed their identities had changed[19]. Brown (2009:8) argues that as the dominant discourse Christianity had 'infused public culture and was adopted by individuals, whether church goers or not, in forming their own identities.' Nurses had regarded their role as a vocation but the decline of Christianity meant the loss of the legal and social rules which defined it so. They were released from the obligations attached to the vocation and so were not afraid to challenge what they felt was wrong with the health service (O'Dowd, 2008c). There were strikes for better pay and the Royal College of Nursing (RCN) became a trade union in 1977.

[19] Callum Brown is Professor of Religious and Cultural History at the University of Dundee, author of *The Death of Christian Britain.*

The 1980s were characterised by staff protests (O'Dowd, 2008d) giving further credence to the argument that individual identity was no longer determined by 'the complex web of legally and socially accepted rules which governed individual identity in Christian Britain' (Brown, 2009:8). However, self-confidence was not a characteristic of all nurses. Speaking of his first post in A&E one nurse said 'It was medical staff-led and nurses were not particularly assertive in questioning their decisions', although he did go on to say that he was encouraged to get involved rather than just observe.

Practice nursing boomed in the 1990s and a lot of previously entirely medical sacred ground, such as running clinics, prescribing, ordering investigations, was claimed by nurses (O'Dowd, 2008e), thus challenging the status quo. In the millennium years specialist nursing posts increased with nurses taking charge of functions, such as minor injuries, previously carried out by junior doctors. A further challenge to the established way of doing things was the arrival of Personal Medical Services, practices run by nurses who could hire doctors (O'Dowd, 2008f).

Nursing has changed considerably over the last sixty years from a vocational hierarchy, in which matron represented and exercised the power of the dominant patriarchal system, to proclaiming and proving itself a profession. In the context of the medical model, which dominates healthcare, nursing has felt the need to demonstrate efficacy in a scientific manner. Financial pressures have caused hospital management to require every department to produce evidence of value which necessitates measuring the tangible - not an approach conducive to the assessment of spiritual care. I now turn to the role of the principal provider of spiritual care, the chaplain.

The healthcare chaplain from post-war to today

When the National Health Service (NHS) was established in 1948 Christianity was still the dominant discourse and chaplains were included in the provision of services (Cobb, 2005:4). Initially twenty-eight hospital chaplains were appointed and expected to stay in post for five to seven years before returning to parish ministry. In his 2009 study Swift reports that the suggestion that the chaplain should be on the same pay-scale as a consultant was not acceptable to the church, which feared that a highly paid chaplain would not wish to return to parish ministry (Swift, 2014:41-2). A report in 1951 led to the cost of both chaplains and chapels being met by the NHS. The advent of District General Hospitals meant more chaplains, some full-time, some part-time but all Anglican and all part of the NHS. Also in 1951

the Church of England set up the Hospital Chaplaincies Council (HCC)[20] to resource and co-ordinate the approach to chaplaincy, recognized as specialist but which was to be 'encouraged, supported and carefully controlled'. The chaplain's role according to the British Medical Association (BMA) in 1955 was to assist in moulding patients' attitudes to comply with the treatment being given by the doctor. This may not be quite as extreme as the social control seen earlier but it is still the chaplain as a tool for influencing behaviour. Working in the 1950s Norman Autton, who has been described as the father of modern Hospital Chaplaincy, did not agree with the BMA's view. He saw himself as the technologist of the soul who redefines the patient's image of God, interprets and articulates what God is like. Autton maintained that such work was just as important as the doctor's and his style, though warm and caring, may be described as paternalistic, leaving patients in no doubt that they had been in the presence of a priest (Speck, 2002). That priest was part of the establishment – as he was in the 1960s when chaplaincy was described as 'biblically based and sacramentally expressed' (Swift, 2014:47)[21]. Despite the power and influence of HCC not all chaplains shared its views and other professional bodies, the College of Health Care Chaplains (CHCC) and the Association of Hospice & Palliative Care Chaplains (AHPCC), were formed[22]. The disagreements between these bodies and HCC[23] are beyond the remit of this research but the interested reader is referred to the assiduous work of Swift (2014). On the basis of Swift's work it is my view that the leaders of HCC continued to behave as if not just Christianity, but the Church of England, was still the dominant discourse.

By the 1990s the role of the NHS chaplain was being questioned: data protection, which denied access to chaplains, was an issue as was professionalization (Swift, 2014:58). However the Department of Health (DH) and the various chaplaincy bodies worked together to produce *NHS Chaplaincy: Meeting the Spiritual needs of*

[20] HCC continued to represent the Church of England's concerns and to influence the Department of Health until the professional chaplaincy bodies started to work closely together in 2004 (Swift, 2014:72).
[21] Mitchell & Sneddon (1999a:2) note that chaplaincy conferences held in England spent time discussing sacraments and anointing which were clearly important for chaplains in English hospitals but not significant in Scotland.
[22] AHPCC in 1985, CHCC a merger of two pre-existing groups in 1992.
[23] The HCC's desire to control extended to birthing the Multi Faith Group for Healthcare Chaplaincy (MFGHC) in 2003. HCC continued to support and 'guide' the group, even controlling who attended the meetings. AHPCC was invited to send a representative to the MFGHC meetings. To his surprise he was the only practicing healthcare chaplain in attendance, the other attendees being leaders of various faith groups but not healthcare chaplains. In 2014 MFGHC changed its name to Healthcare Chaplaincy Faith & Belief Group (HCFBG).

Staff and Patients (2003). This practical document gave a framework for the provision of chaplaincy-spiritual care services but it did not give a definition of spiritual care. Rather the purpose of the document was:

> to enable the NHS to provide flexible and innovative responses in chaplaincy-spiritual care for all patients, their carers and staff according to the faith or spiritual tradition to which they belong, or to those who profess no particular affiliation. (Department of Health, 2003:5)

However, the document did distinguish between religion and spirituality, quoting from the AHPCC Standards:

> Spiritual needs may not always be expressed within a religious framework. It is important to be aware that all human beings are spiritual beings who have spiritual needs at different times of their lives. Although spiritual care is not necessarily religious care, religious care, at its best, should always be spiritual. (AHPCC, 2003)

Swift argues that the document's title signals a change in attitude towards chaplaincy – it was no longer provided by the churches for the health service but belonged to the NHS. Also published in 2003 *Caring for the Spirit* raised questions of identity and the nature and purpose of spiritual care in an evidence-based institution (Swift, 2014:65).

Changes in society, often due to increasing multi-culturalism, had an effect on the NHS and chaplaincy became increasingly concerned not only with supporting a wide variety of religious beliefs but also supporting those with no beliefs (Mowat, 2008:15). *Religion or Belief* (Department of Health, 2009) was designed to help NHS organisations comply with equality legislation and understand the role of religion or belief in connection with healthcare. It therefore covered the beliefs and attitudes of various religions in relation to modesty, diet, contraception, abortion, childbirth, circumcision, palliative care, end of life care, drugs, mental health and suicide. The document was concerned with the various religions and did not purport to cover spiritual care, although it did mention the role of the chaplaincy/spiritual care team in connection with bereavement services, major incidents and palliative care. The spiritual needs of those who did not have a religion or belief were recognized only in the section on palliative care which stated that they 'therefore would not want to be attended by a religious person at such a vulnerable time'[24]. The document did not say who would be offering spiritual care to such a patient in the absence of a member of the spiritual care team. The document did not address the assumption that such a patient did not have any spiritual needs but was

[24] This appears to imply that a member of the chaplaincy and spiritual care team is not able to offer spiritual care that is not religious.

concerned only with the way that various religions and beliefs were likely to affect the behaviour of the patient.

In contrast to *Religion or Belief* (DH, 2009), the 2004 guidelines of the National Institute for Clinical Excellence (NICE) entitled *Improving Supportive and Palliative Care for Adults with Cancer* described spiritual support for patients with a life-threatening diagnosis in terms of the questioning of identity, self-worth and ultimate meaning:

> beliefs can be religious, philosophical or broadly spiritual in nature. Formal religion is a means of expressing an underlying spirituality, but spiritual belief, concerned with the search for the existential or ultimate meaning in life, is a broader concept and may not always be expressed in a religious way. (NICE, 2004:95)

The guidelines pointed out that the nature of appropriate support can vary from an informal conversation to a formal ritual. Key issues are listed and the nature of spiritual need further explored.

From 2004 AHPCC, CHCC and the Multi Faith Group for Healthcare Chaplaincy (MFGHC) worked more closely together (Swift, 2014:72) in order to present a united front to the Department of Health and in 2008 they formed the United Kingdom Board for Healthcare Chaplaincy (UKBHC). In the same year the government published the End of Life Care Strategy for England (EOLC) with the practical aim of improving care for those approaching the end of life, which included spiritual care services:

> This section deals with the recognition that each person has spiritual, religious or emotional needs. This may, or may not, mean that they have a strong faith, belong to a particular faith community or hold to a religious or non-religious belief system (Department of Health, 2008:75).

The need to make sense of things, find meaning, reconcile differences were all listed as aspects of spiritual care and the report endorsed the role of chaplains, making the point that in order to provide appropriate spiritual care a chaplain needed to be recognized as a core member of the disciplinary team.

The second annual report (Department of Health, 2010) of the EOLC led to the commissioning of a review of end of life care literature[25] and two conferences[26]. The third annual report (Department of Health, 2011) stated that these pieces of work contributed to the development of Quality Markers for spiritual care which were then

[25] Holloway, M., Adamson, S., McSherry, W., & Swinton,J. (2010) *Spiritual Care at the End of Life: a systematic review of the literature* commissioned by the Department of Health and discussed in Chapter Two.

[26] One of which was The National Council for Palliative Care (NCPC) conference: *The Missing Piece* in March 2010.

passed to NICE for inclusion in their Quality Standards. The literature review presented understandings of spirituality:

> It is a subjective experience that exists both within and outside traditional religious systems. Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning. (Holloway et al, 2010:18)

Reference was made to the difficulty of defining spirituality and to the idea that a lack of definition might actually assist those providing spiritual care to maintain an openness that created space for the spirituality of the individual patient.
From the End of Life Care Quality Standards, published in November 2011, Standard 6 related to spiritual support for the person approaching the end of life, and used the actual wording of *Standards for NHS Scotland Chaplaincy 2007* stating:

> spirituality is defined as 'those beliefs, values and practices that relate to the human search for meaning in life. For some people, spirituality is expressed through adherence to an organised religion, while for others it may relate to their personal identities, relationships with others, secular ethical values or humanist philosophies.' (NICE, 2011:29)

Thus the standard explored the understanding of spiritual care as making sense and finding meaning, and the identification of sources of strength. It also stressed that spiritual care is person-centred and chaplains are the main spiritual care providers.

Following the *Trotter Report* (2010) into the work of HCC, the Church of England ceased to 'broker chaplaincy' and relationships between the chaplaincy groups and with NHS England improved (Swift, 2014:73) such that the Department of Health stated that they would 'take a new, coherent, and better coordinated approach to the provision of healthcare chaplaincy services in the near future' (Thomas, 2012)[27]. Critical of HCC the *Trotter Report* yet affirmed the role of the Church of England in supporting chaplains to master the language[28] of the NHS without losing their fluency in theological language (Swift, 2014:67; Trotter, 2010:32-33). In December 2011 a letter was sent to the Chief Executives of Hospital Trusts announcing that there would be a new system for appointing hospital chaplains. It explained the withdrawal of HCC from its leading role of assisting the panel of assessors. The new system, agreed by the CHCC, UKBHC, MFGHC, the Church of England and the Department of

[27] This quotation is the response to my email enquiry as to whether the 2003 document *NHS Chaplaincy: Meeting the religious and spiritual needs of patients and staff* had been updated, and if not, were there any plans to give guidance to Trusts on the nature of spiritual care. Subsequently a new approach did take place and the new *Chaplaincy Guidelines* were published in 2015.
[28] Issues of language will be discussed in Chapter Two.

Health, established a panel of advisers drawn from the different religions and faiths in England. This panel would be set up and overseen by a reference group of five named senior and experienced chaplains, managed by a co-ordinator. The co-ordinator and three of the chaplains were, and are, Anglicans, one chaplain is Roman Catholic, one is Free Church and one is Muslim.

The letter gave details of the reference group's responsibilities, the role of the panel co-ordinator and requirements for the appointment advisers. Reference was made to different areas of health care chaplaincy work, knowledge of faith requirements, and different approaches to health care chaplaincy but there was no mention of spiritual care. Neither was there any reference to the spiritual care of those who did not espouse a particular faith. However the new *Chaplaincy Guidelines* published in March 2015, made specific reference to those who lacked a faith. Noting that people who do not have a particular religious connection might still be in need of pastoral care the document states:

> ***Religion or belief*** is as defined in the 2006 Equality Act:
> (a) "religion" means any religion, (b) "belief" means any religious or philosophical belief, (c) a reference to religion includes a reference to lack of religion, and (d) a reference to belief includes a reference to lack of belief (National Health Service England, 2015: 6)

The context of chaplaincy in the guidelines is clearly stated as not attached to any one religion or belief system but works to ensure that all people, religious or not, have access to high quality pastoral, religious or spiritual care when they need it. The guidelines have sections on chaplaincy in the various departments including specialist palliative care (21). They were authored by Revd Dr Chris Swift in consultation with the Chaplaincy Leaders Forum (which includes the president of AHPCC) and the National Equality and Health Inequalities Team, NHS England.

It has already been mentioned that from 2004 the various chaplaincy organisations worked more closely together and in 2008 formed UKBHC. Although the End of Life Care Strategy was relevant to hospice care hospice chaplains were not necessarily directly affected by the negotiations just described. However the AHPCC Executive monitored the developments closely because decisions related to the NHS tended to have a knock-on effect in the hospice world[29]. That NHS chaplains were struggling to justify their role had already come to the attention of some hospice managements who then started to question their own need for a chaplain. The NHS chaplain was

[29] An example of this was the ban on the use of the Liverpool Care Pathway (LCP) in hospitals. Some hospice staff have maintained that hospitals were not using it properly.

no longer a priestly paternalistic member of the establishment - for the establishment itself had changed. Not only had the direct influence of the Church of England declined but the balance of power in the organizational hierarchy of the hospital had changed, as illustrated in the developments in the nursing profession already described. I now turn to one particular nurse: Cicely Saunders.

Cicely Saunders and St Christopher's Hospice

When war was declared at the end of her first year at Oxford Cicely Saunders left to train as a nurse (du Boulay, 2007:14). Later forced to leave nursing because of her health, her back in particular, she still wanted to work with patients so trained as an almoner. A close relationship with one of her patients who subsequently died was instrumental in crystallizing her thoughts on her future – she wanted to work with the dying (36-38). Sharing her thoughts with a surgeon friend she was advised that nobody would listen to a nurse or an almoner so 'Go and read medicine' (40). (The dominant Christian discourse of the 1950s was paternalistic, valuing certain professions whilst dismissing others.) On qualifying as a doctor she went to St Mary's Paddington to research pain in the terminally ill (45). As has already been mentioned it was whilst at St Mary's that she found St Joseph's where she was able to apply her research and develop her ideas on pain-control and the environment in which patients died.

St Christopher's Hospice, often described as the first of the modern hospices, was established in 1967 as a result of Saunders' vision. Her motivation was a strong religious commitment accompanied by a concern to make the care of the dying more professional and a network of social contacts that would help fund raising (Clark, 1998a:46). She started working on the hospice vision in 1959, producing two documents 'The Need' and 'The Scheme' in which her style of writing was openly religious (du Boulay, 2007:63). The religious basis of the hospice could be seen in the central position of the chapel, the inclusion of prayers on the wards and the four theological students acting as male orderlies and porters. However, the influence of the Christian 'hospes' tradition resulted in responsibility for spiritual care being shared by the whole team, of which the chaplain was a part (Clark et al, 2005: 124)[30]. Saunders stipulated that religion was not to be forced on anyone:

> Considering how little used many patients are to paying attention to religion, it is necessary that they be approached with tact and gentleness and that they should suffer from no surfeit of food to which they are unaccustomed. (du Boulay, 2007:63)

[30] It is not clear whether Saunders' original vision included a chaplain. When recalling the ministry of the first chaplain she asked 'How on earth did I acquire him?' (Clark et al, 2005:124).

In 1965 Saunders asked:

> Is it possible for the gospel to reach those ignorant of even the simplest expression of the Christian faith during the last weeks or months of their lives? We can all remember patients who came to a real personal faith in their last days because they recalled memories of religious teaching given many years ago. Is this possible where there are no such memories to be found when the tired mind goes – as so often – back to the past? Can we reach such people, even at this stage with apparently entirely new ideas and help them to put their trust in the God whom they have totally ignored till now? (Saunders, 1965a:2-3)

In this article Saunders explores how the gospel message of love is communicated, through showing the person that they are valued. She observes that interpreting the unfamiliar gospel news in relevant terms is not only a problem but often not appropriate, whereas atmosphere and actions are more effective. 'The dying have shed the masks and superficialities of everyday living and they are all the more open and sensitive because of this. They see through all unreality.' (Saunders, 1965a:6) She says there is not time for explanations and neither are they needed, the offer of a simple prayer is very rarely rejected and invariably leads to 'real peace' (6). This paper was written for the Christian Medical Fellowship and it is based on the words of Jesus 'I was sick and you visited me' in Matthew 25:36. The flavour of this paper and the hospice vision documents indicate that Cicely Saunders believed Christianity to be the dominant discourse in the area of medicine and healthcare at that time. According to du Boulay (2007:120) Cicely Saunders' personal spiritual journey is expressed in St Christopher's, but I think that developments at St Christopher's also reflect the loss of Christianity as the dominant discourse in society. After her conversion in 1945, the evangelical All Souls, Langham Place provided Saunders with spiritual nourishment and an outlet for her enthusiasm for about ten years. After the death in 1960 of Antoni (the second dying patient with whom she had fallen in love) Saunders found that the evangelical one-to-one relationship with God was not enough - she needed to feel part of the communion of saints and was impatient of this church's failure to appreciate the significance of the whole communion, the whole church. However, to avoid community, when her father and a close friend died in 1961, she took refuge in a high Anglo-Catholic church. Even this was too much when the new priest stood at the door shaking hands to get to know his congregation – Cicely 'fled into the anonymity of Westminster Abbey' (122). Her biographer Shirley du Boulay attributes this unwillingness to promote herself not to

shyness but to a genuine humility which believed that St Christopher's and the care of the dying was more important than she was and that it was God's will (122)[31].

Saunders realized that she needed an arrangement with the Regional Hospital Board to provide and pay for patients but she was also clear that she did not want the hospice to be a part of the National Health Service:

> We want to be independent because we need freedom of thought and action; we want to be an inter-denominational but a religious foundation, and we want freedom to develop and expand as we are led to do so. (du Boulay, 2007:64)

Whether Saunders foresaw being part of the NHS as inimicable to being a religious foundation is not recorded and it is not clear whether the phrase 'as we are led to do so' refers to retaining control or to divine guidance as expressed by evangelical Christians… or both. Clark (1998a:49) records that in her correspondence with Christian friends and supporters Saunders writes of her sense of calling and the feeling that the hospice is 'meant' to be.

Clearly, St Christopher's was rooted in a deep and sincere Christianity (Bradshaw, 1996:411-412). In 1965 Saunders wrote:

> I am sure the most important foundation stone we could have comes from the summing up of all the needs of the dying which was made for us in the Garden of Gethsemane in the simple words 'Watch with me.' (Saunders, 1965b:1615)

The chapel was central to the project (Bradshaw, 1996:411), was centrally positioned and, after the 1973 extension, was immediately visible to anyone coming into the hospice, occupying half the width of the building. The Statement from the St Christopher's Foundation Group, which met from 1961 to 1965, gave the aim as:

> …based on the full Christian faith in God, through Christ. Its aim is to express the love of God to all who come, in every possible way; in skilled nursing and medical care, in the use of every scientific means of relieving suffering and distress; in understanding personal sympathy, with respect for the dignity of each person as a human being, precious to God and man. There are no barriers of race, colour, class or creed. (Wyon, 1988)

The 1988 version of the document ends by saying that discussion had occurred every few years but only minor alterations were made. Saunders remained an Anglican but in her sixties became convinced that all faiths led to the same God. 'She did not seek to impose her own faith, rather to set people free to find their own' (du Boulay, 2007:123).

[31] A similar reticence in hospice chaplains was a factor in the research design – see Chapter Three.

In 1988 at the age of seventy Saunders wrote 'Spiritual Pain', a paper in which she argued that the spiritual covers more than the higher moral qualities. 'Memories of defections and burdens of guilt may not be seen at all in religious terms and hardly be reachable by the services, sacraments and symbols that can be so releasing to the "religious group"' (Saunders, 1988). She explores the search for meaning and what it is to face meaninglessness, pointing out that to tell one's story requires a listener and the most important characteristic of that listener is their understanding of their own search for meaning[32].

Saunders died in 2005 so did not live to see the opening, in 2009, of The 40th Anniversary Project. The ground floor layout changed and the chapel lost its central location and metamorphosed into The Pilgrim Room on the first floor, where St Christopher's 'encourages people to feel free to express their spirituality or practise their religion in their own way'[33]. This appears to indicate that the hospice not only acknowledged that Christianity was no longer the dominant discourse in healthcare but also accepted the separation of spirituality and religion, seeking to accommodate other religious discourses with or without reference to spirituality.

Summary

The history of spiritual care and religion in healthcare in England and Wales shows that, although grounded in Christian care, it has been used, at least partly, as a means of social control. At the very least the authorities or management have taken advantage of the missionary zeal and good nature of the chaplain for the benefit of the sick poor. However, since the introduction of the NHS developments in chaplaincy appear to have been haphazard. The absence of a single chaplaincy organisation and the lack of a united approach amongst the several allowed HCC, and therefore the Church of England, to dominate chaplaincy giving the impression that Christianity was still the dominant discourse and the Church of England the rightful leader of that discourse. Progress on issues of standards, competencies and professionalization was slow until the professional organisations put their differences

[32] Tony Walter, Director of the Centre for Death and Society at the University of Bath, argues that the connection of spirituality with the search for meaning is not found other than in English-speaking countries (Walter 2002:134). He maintains that in Catholic countries the understanding of spirituality is traditional and orthodox – of the human being in relation to God, and that secular healthcare in the English-speaking Protestant world is developing a different language of spirituality in order to distance itself from religion (134). However, work undertaken by the European Association for Palliative Care (EAPC) on a common definition suggests that the traditional Catholic understanding is giving way to the Protestant (Leget et al 2013).

[33] From the Spiritual Care page of the St Christopher's website: http://www.stchristophers.org.uk/patients/spiritualandreligiouscare

behind them and challenged the paternalistic role which HCC had assumed. This is markedly different from the situation in Scotland which will be described in the next chapter.

Paternalistic control was also the issue for nurses whose ethos changed from submission to assertiveness and protests about pay and conditions, from a vocation of service to a profession taking responsibility for its own future. However, the medical model still prevailed and nursing sought to prove itself using a scientific approach. In contrast Saunders was aware of the limits of the medical/scientific approach. She was concerned that a patient should matter right up to and including death which led her to explore the understanding of the spiritual, its relevance to those who espoused no religious connections and the importance of telling one's story. Developments at St Christopher's appear to reflect a shift from the world of the 1960s when the hospice was founded, to the world of today in which Christianity is no longer the dominant discourse.

Altogether these descriptions suggest two main characteristics of healthcare over the sixty year period since the introduction of the NHS: rejection of paternalistic control and the decline of Christian influence. In the same time period the terms 'spirituality' and 'secularization' have become topics of discussion. Therefore I shall now consider some of the ways in which the use of the term 'spirituality' have changed and then give an explanation of my understanding of the term 'secularization' for the purposes of this study.

Spirituality and secularization

Spirituality

Sandra Schneiders[34] argues that the integration of theology, as articulate spirituality, and spirituality, as lived theology, was shattered in the thirteenth century when theology moved from the monastery to the university (Schneiders, 2005: 2). She states that by the nineteenth century theology had become a 'highly scholastic discipline', whilst spirituality was considered to be a non-academic practice of piety or even mystical prayer (of which the church did not necessarily approve). From the eighteenth to the mid-twentieth century spiritual theology was an aspect of theology concerned with prescriptive principles for the practice of prayer, for the priest or spiritual director to lead the faithful to uniform perfection (2). Then in the 1970s and 1980s a new academic discipline, 'spirituality' emerged. Schneiders says that the

[34] Sandra Schneiders is Professor Emerita of New Testament Studies and Christian Spirituality at the Jesuit School of Theology, Berkeley, California.

reasons for this were cultural as well as theological but centred on 'the search for meaning, transcendence, personal integration and social transformation' and 'the growing interest in studying Christian religious experience' (3).

In 1983 the Preface to the then newly published *A Dictionary of Christian Spirituality* began:

> 'Spirituality' is a word very much in vogue among Christians of our time. French Catholic in origin, it is now common to evangelical Protestants also (Wakefield, 1983:v).

The Preface goes on to point out that the Orthodox would prefer to speak of mystical theology rather than spirituality but all traditions, and many non-Christian faiths and philosophies, believe that to seek a relationship with the ground of our being is an intrinsic aspect of human nature. Spirituality concerns that relationship and how it affects our behaviour, our attitudes, how we live our lives.

Twelve years later in 2005 the Introduction to *The New SCM Dictionary of Christian Spirituality* begins by observing that the field of spirituality has changed radically in the past twenty years:

> The most significant development in the intervening years has been the growth of spirituality as a major academic discipline with its own methodology (Sheldrake, 2005: vii).

Sheldrake makes it clear that the dictionary is deliberately limited to Christian spirituality since by its very nature spirituality has to be grounded in a particular context, in this case Christian, which may or may not be explicit. No single definition is offered but:

> Christian spirituality embodies a conscious relationship with God, in Jesus Christ, through the indwelling of the Spirit, in the context of a community of believers. (2005:vii).

Furthermore, whilst spirituality concerns that relationship and how it affects our lives the extent of that effect has broadened in the intervening years, such that spirituality encompasses the whole of life – in relationship with God: 'the emphasis is on the holistic involvement of the person in the spiritual quest which is itself understood holistically' (Schneiders, 2005:1-2). More recently Flanagan has expressed concern for the appropriateness of established research methodologies for studying this lived spirituality, arguing that such research deserves and requires skills 'of heart, character, creativity, self-knowledge, awareness, attentiveness and mental flexibility' as well as the verbal and conceptual (Flanagan, 2016).

Janice Clarke[35] observes that the word 'spirituality' was not used and was of little or no interest to anybody outside theology until the 1950s (2009:1669). Holmes, a specialist in 'therapeutic community in a faith context', states that he first thought it necessary to find a definition of spirituality thirty years ago, which would be in the 1970s. He wrote:

> spirituality as a domain has broken away from its traditional religious moorings. The reason is that the concept of spirituality has begun to appear in numerous academic and professional disciplines, all outside traditional religion (Holmes, 2007:24).

Likewise, Woods[36] & Tyler[37] (2012:2) observe that 1970s journal articles of the nursing profession were the first to use spirituality with this broader and secular understanding. Supporting this observation a 1997 review of the meaning of spirituality in the nursing literature of the previous twenty five years stated: 'it should not be assumed that spirituality is either synonymous, or coterminous, with religion' (Dyson et al, 1997:1183)[38]. Furthermore, in his foreword to *Contemporary Spiritualities*, Ewert Cousins[39] attributed the appearance of spirituality in contexts where, traditionally, it was ignored or banned to the arrival of eastern spiritual teachers in the 1960s who, he claimed, awakened the West from a bland secularism (Cousins, 2001:xi).

Secularization

The various hypotheses on the nature of secularization are beyond the reach of this study which understands the term to refer to the demise of Christianity as the dominant discourse in society. In popular parlance the term 'secular' is often understood to indicate antagonism towards religion in general, and/or antagonism towards Christianity in particular. Whilst these may be amongst the many understandings of 'secular' (Woodhead, 2016) the most helpful definition for the current English healthcare situation is that the place of religious belief and practice in

[35] Senior Lecturer, Institute of Health, Social Care and Psychology, University of Worcester.
[36] Richard Woods is Professor of Theology at Dominican University, Illinois, USA. A prolific writer he is a member of the Board of Trustees of the Eckhart Society.
[37] Peter Tyler is Professor of Pastoral Theology at St Mary's University Twickenham, London. He is the Director of the Centre for Initiatives in Spirituality and Reconciliation (InSpiRe).
[38] More detail on this article is given in Chapter Two's Literature Review.
[39] Ewert Cousins (1927-2009) Professor Emeritus at Fordham University, New York, renowned theologian and prolific writer, editor of *The Classics of Western Spirituality* and *World Spirituality: An Encyclopedic History of the Religious Quest*.

a secular society is defined or limited (Stammers & Bullivant, 2012: 83)[40]. Common ground is found amongst interested parties such that agreed religious values are allowed expression in the public sphere (84). However, the agreement entails the principle that no one particular religion or denomination is to be privileged over the others, a position endorsed by the National Secular Society (NSS)[41]. Under these conditions the previous significant and high-profile role of Christianity, and in particular the Church of England, in public life is no longer acceptable. Nevertheless cultural or discursive Christianity, which until the 1960s maintained the status quo of 'the establishment', may still be found along with other moral narratives: feminist, gay, liberationist, green, New Age (Brown, 2009:232).

A Spiritual Revolution?

The extent to which spirituality has replaced the conventional religious narrative was researched by Paul Heelas[42] and Linda Woodhead[43] who conducted research in 2001 to assess the decline of conventional religion (Heelas & Woodhead, 2005). This was defined as a religion which emphasized a transcendent source of significance and authority to which individuals must conform[44]. They argued that the concomitant increase in New Age practices demonstrated what they termed the 'subjective turn' of using inner sources of significance and authority to construct the self (Heelas and Woodhead, 2005:6). The subjective turn is described as a major cultural shift (2), from 'life-as' to 'subjective-life'. Those who live 'life-as' belong to a community or tradition and follow, obey, a higher authority, finding their significance and sense of purpose in

[40] Trevor Stammers is Programme Director in Bioethics and Medical Law at St Mary's University, Twickenham. Stephen Bullivant is programme Director for the MA Theology at St Mary's University, Twickenham.

[41] Whilst arguing for the separation of religion and state, the NSS seeks to defend the equal rights and freedom of people of different religions and beliefs and states that it is not atheistic, although there are atheistic secularists.

[42] Paul Heelas is Professor in Religion and Modernity in the department of Religious Studies at the University of Lancaster, UK. As a classic 'babyboomer', growing up in the 1960s, he has a particular interest in and has written extensively on the development and change of inner life spiritualities.

[43] At the time of the research Linda Woodhead was Senior Lecturer in Christian Studies in the department of Religious Studies at the University of Lancaster, UK. From 2007 to 2013 she directed the £12million AHRC/ESRC Religion and Society Programme. With Charles Clarke she organized the Westminster Faith Debates from 2013 to 2015. Currently she is Professor in the Sociology of Religion in the Department of Politics, Philosophy & Religion at the University of Lancaster, UK. Her research explores the relationship between religious and social change worldwide.

[44] In some areas conventional religious approaches were part of the status quo maintained by establishment figures, people who thought they knew best and to whom others deferred. As these people either died or retired out of the area the sacred canopy of interwoven social and religious customs disintegrated (Thomas, 1997).

that following and obeying. Such people sublimate, through sacrifice or discipline, any characteristics which might lead them astray (3). Those who live a subjective-life do not follow or defer to a higher authority but seek to establish their own inner authority, which requires an awareness of their own inner depths(4). They do not aspire to become what others would have them be but aim to become who they truly are. Thus the subjective turn signals the rejection of hierarchy and deference, a refusal to confer status on teachers, doctors, priests or anyone who might have been considered to be part of the establishment (5).

The research was conducted in Kendal, Cumbria, and the method was to record the numbers of people who participated in spiritually significant activities related to either 'life-as' or 'subjective-life'. This meant counting congregations at church services and establishing numbers of people who attended events/classes designed to further the development of the true self. The results found little overlap between congregations and holistic spirituality, few people went to both. The beliefs and activities were still distinct and there was no evidence of what the media refer to as 'pick 'n mix' (Heelas and Woodhead, 2005:31-32). Heelas and Woodhead comment that despite declining congregations and an increased number of holistic care users there was no evidence that the spiritual revolution was happening (45). They note that the appeal of the holistic milieu had been strongest from the mid-1960s to the mid-1970s and that those interviewed tended to be older, and as they died they were not being replaced (132). Heelas and Woodhead also distinguish between spirituality as a commitment to a deep truth found within what belongs to this world and religion as a commitment to a higher truth which is 'out there', beyond this world, related to specific external items such as scripture, doctrine and ritual (Heelas and Woodhead, 2005:6). As the basis for the individual's source of significance, this distinction makes little allowance for the Christian turn of the self-in-relation with God (Sheldrake, 1994:33). The Christian subjective turn moves from the keeping of the Ten Commandments (Exodus 20:1-17) which exemplified 'life-as', demonstrating obedience to a way of life commanded by an external, transcendent source of authority, to the individual's subjective response to 'God so loved the world that he sent his only Son' (John 3:16).

In the Sermon on the Mount (Matthew 5), Jesus explained that conforming to the commandments such as 'you shall not murder', 'you shall not commit adultery' is not sufficient, but inner thoughts and feelings are just as wrong or unhealthy as the action. The person who is angry has failed to keep the commandment 'do not murder' as much as the person who has committed murder. The person who looks lustfully at another has failed to keep the commandment 'do not commit adultery' just as much as the person who has committed adultery. Jesus points to an inward

turn of self-awareness necessary for the keeping of the Commandments, a turn which recognizes that it is the relationship with God that enables the keeping. To be able to keep the commandments the authority has to come from within, from the absorption of the laws into heart and mind (Hebrews 8:10), from the self-in-relation with God or, to put it another way, from the in-dwelling of Christ as expounded by Jesus in chapters 14 and 15 of John's gospel. This subjective life has rejected the hierarchy and deference of institutional Christianity and recognized the authority of the God who dwells within.

Heelas and Woodhead associated this Christian subjective turn, of the self-in-relation with God, with the mystical tradition and therefore not relevant to their research (Heelas and Woodhead, 2005:6). Furthermore, practices related to Iona and Taize were categorized as holistic 'subjective-life', there being no category for the Christian subjective turn (157). I maintain that not only is the absence of the self-in-relation with God a serious omission but since the research shows that not all the participants in holistic milieu activities were concerned with self-in-relation[45] a different style of research interview is needed to explore the presence and nature of spiritual growth. Furthermore the preponderance of educated women aged over forty involved in holistic subjective spirituality (Heelas & Woodhead, 2005:94,107) might suggest the influence of feminism and/or the second half of life as described by Richard Rohr (2011) rather than the flight from religion. Supporting this very point is Woodhead's (2013:2) later statement: 'we were astonished to keep finding more and more 'holistic providers''[46]. When these people were profiled a significant number of them were refugees not just from the churches but from the NHS. The latter had given up the struggle with bureaucracy, targets and unreasonable managers and set up on their own (3).

Woodhead's most recent research, a survey of religion in conjunction with YouGov, throws further light on the subjective-life, suggesting not only the rejection of hierarchy but also the rejection of membership or identification with a particular group, religious or secular (Woodhead, 2016). Starting in 2013 a baseline of 37% of the population stated that they had no religion. By February 2015 the figure was 42% and by December 2015 it was 46%. Whereas the default position in previous societal attitude surveys was 'Church of England' the latest data shows a marked

[45] Just over half the respondents said their activity was 'not spiritual'. Only a quarter gave spiritual growth as the main reason for involvement (Bruce, 2011:144).

[46] Hospice chaplains would not have been astonished at the plethora of 'holistic providers' because complementary therapies have been an established feature of hospice care from the earliest days (Clark et al, 2005:54).

decline in this category and a concomitant increase in those saying 'no religion'. However, the survey found that the influence of secularism was minimal and only one quarter of those interviewed were confident that there is no God. Even although they said they had 'no religion' 25% claimed spiritual practices such as praying and 11% said they were spiritual. Woodhead interprets the data to indicate that the 'nones', as she called them, are not hostile to religion and the gap between church and culture has widened to the extent that any reason for identifying with the Church of England has gone. It would appear that the 'nones' have rejected domination by the Church of England, without necessarily rejecting spirituality. At the same time the tacit recognition of authority in teachers, doctors, and the vicar, who might be described as experts in their respective fields, has been displaced by the authority of the self (Walter, 2002:135). Therefore, the interviews are examined for the chaplain's perception of the attitudes of patients, co-workers and management to her status and role. Whether the nature of spiritual care has been affected by the decline of the Christian dominant culture is also explored.
Having identified the rejection of the hierarchical and paternalistic aspects of the Christian dominant culture I want to balance the picture with the cohesive role played by institutional Christianity during World War II. People from all walks of life and levels of society were willing to accept governmental control because they were united against a common enemy. Once the war was over the purpose of the cohesion disappeared. Gone were the constraints for constructing identity – the authority of the self meant defining my own identity. Gone was the traditional acceptance of 'this is how we do things'. Just as the nurses had felt free to challenge the NHS, itself a challenge to the dominant culture, so Cicely Saunders' development of the hospice concept in the late 1950s and early 1960s challenged the dominant culture of the medical model. However, her vision provided cohesion for those involved in the project. Other challenges to the dominant culture's way of thinking and doing, relevant to this study, are Alistair Campbell's work on pastoral care (Campbell, 1986) and Elisabeth Kübler-Ross's work on death and dying (Kübler-Ross, 1969) both of which privileged the person over the system.

Conclusion

Returning to the questions with which this chapter opened, the historical picture suggests that healthcare birthed in Christianity has grown up to question the paternalistic past, in which institutional Christianity had played a controlling part. An example of this was seen in the nursing profession's protest to reject the status quo. However, the continued desire to provide spiritual care for patients, albeit through

chaplains, suggests a recognition of the values enshrined in the Christian faith and may be a sign of the continued existence of discursive Christianity. Furthermore it appears that the maintenance and preservation of those values as part of the healthcare ethos is to be achieved through the good offices of the chaplain, who in the course of fulfilling his job is not to promote God or proselytise in any way. This survey will include an exploration of the extent to which the chaplain experiences a valuing of Christian values and the contradiction which may be entailed in his non-proselytising role. However, there is also the question of whether the literature reflects the desire to provide Christian values-based spiritual care and that will now be explored.

Chapter Two: The Literature Review

Introduction

The historical picture of chapter one showed the changing role of Christianity in healthcare from dominant culture expressed in paternalistic control to discursive culture expressed in ambivalence and an apparent desire to practise Christian values but without reference to Christ or God. This chapter examines the literature for the understanding of the concepts of spirituality and spiritual care and the existence or otherwise of Christian values in the English healthcare system. It is hoped that this examination will supplement the historical picture, thus providing a fuller backdrop for the exploration of the hospice chaplain's role.

Library catalogues were used to elicit healthcare literature which included the terms spirituality and spiritual care[47]. The aim was to enhance the picture of spiritual care in English healthcare presented in Chapter One, so literature relating to countries other than England was read for interest but not included in this review[48]. The presentation of literature from 1980 to 2000 takes a chronological approach, initially dependent on nursing literature, some of which related to hospices, and then including contributions from hospital chaplains as they started to appear[49]. As there was a vast increase in literature from the year 2000 a selection was made. The criterion for selection was that the articles convey, individually and together, the ambience of spiritual care development in England. Thus the context of the role of the hospice chaplain is supplemented by contributions from nurse educators, chaplains, theology lecturers and a chaplaincy researcher. Because of its significant contribution to thinking on spiritual care in healthcare a selection of mental health literature is also included.

Before embarking on the literature review relating to the English healthcare system it is important to note that whilst the NHS was established across the United Kingdom (UK) there was a separate body, operating independently, for each of the countries. NHS Scotland not only started the process of addressing issues of spiritual care earlier than the other countries but has continued to blaze a trail which has influenced others, not just in the UK but around the world. Therefore the first

[47] The facilities used were Summon and EBSCO accessed through the Library and Learning Technology centre at St Mary's University, Twickenham.
[48] Regardless of source References were perused for further relevant articles.
[49] Where possible, reviews of literature covering author-specified time periods have been used. Whilst this results in a reliance on secondary reading some primary source articles and books have been included.

part of this review focuses on literature through which the story of the development of spiritual care in Scotland is told.

How Scotland paved the way in developing spiritual care

In 1999 Mitchell and Sneddon[50] presented their research, carried out in 1998, into how Scottish healthcare chaplains[51] understood and practised spiritual care, (Mitchell and Sneddon, 1999a & 1999b) observing that chaplaincy in Scotland was different from the remainder of Great Britain (1999a:2). They gave three reasons for this: an awareness of the increasing focus on spiritual care in the nursing and palliative care journals of the 1990s; a response to the World Health Organisation's 1990 report which included 'spiritual' with physical, psychological and social in its definition of palliative care resulting in an increasing number of appointments of whole-time chaplains; the churchmanship of the Church of Scotland (Presbyterian) from which many chaplains are drawn[52] (1999a:2). In relation to the last point they say that the Presbyterian tradition is 'significantly less sacramental' in nature and practice than Anglican and other denominations (1999a:2 & 1999b:276) and that therefore Scottish chaplaincy would be expected to be less religiously functional (1999b:276). Their research revealed three main themes: no clear definition of spiritual care; person-centred care; 'being there' (276-277).

In 2002 the Scottish Executive Health Department sent out a letter, with guidance, requiring NHS organizations to 'develop and implement spiritual care policies that are tailored to the needs of the local population.' A Healthcare Chaplaincy Training and Development Unit was funded and a Programme Director appointed[53]. The directive explained the need to reflect interfaith and non-religious dimensions of spiritual care and stated that the term 'spiritual care' covered chaplaincy, spiritual and religious care. It also stated that chaplaincy departments might wish to be redesignated as 'Departments of Spiritual and Religious Care.'

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[50] David Mitchell was at that time a hospice chaplain in Glasgow. He is now a parish minister but also programme leader for healthcare chaplaincy and lecturer in palliative care at the University of Glasgow. Margaret Sneddon was Macmillan Lecturer in Palliative Care, University of Glasgow.

[51] The survey was limited to full-time chaplains but did include both hospital and hospice chaplains.

[52] The group of chaplains practicing in the 1990s and early 2000s in Scotland who jointly and individually have done much to promote the understanding and practice of spiritual care for all.

[53] With the title: Healthcare Chaplaincy Training & Development Officer/ Spiritual Care Co-ordinator. The appointee was an experienced hospital chaplain, as was his successor.

The guidance attached to the letter, *Guidelines on Chaplaincy and Spiritual Care in the NHS in Scotland*[54] marked the beginning of a process which was completed with the publication of *Spiritual and Religious Care Capabilities and Competencies for Healthcare Chaplains* in 2008[55]. However, this process was to have a ripple effect outside Scotland, and outside of the NHS, because two Scottish chaplains, Tom Gordon and David Mitchell, were also leading members of the Association of Hospice & Palliative Care Chaplains (AHPCC)[56]. In 2003 they pioneered professional standards for chaplains working in hospice and palliative care, revising them in 2006 (Association of Hospice & Palliative Care Chaplains, 2003, 2006). Additionally, in 2004, in partnership with Marie Curie Cancer Care (MCCC) they developed a set of competencies, outlining what would be expected of anyone working in palliative care[57]. Thus the Scottish understanding of spiritual care was introduced to hospices across the United Kingdom:

> Chaplains in healthcare settings who once offered a purely religious ministry to members and adherents of their own denomination now devote most of their working time to patients, carers and staff who have no link with any faith community yet may well profess a belief in God, recognise they have spiritual needs and, while they are in hospital or another healthcare setting, look to the NHS to provide spiritual care. Throughout the NHS today chaplains are still expected to offer an appropriate religious ministry to those who remain in membership of faith communities; they are also called upon to give spiritual care to the majority of patients, carers and staff who have no association whatsoever with any religious group (NHS Scotland, 2002:6).

This understanding of spiritual care is elaborated in terms of support systems, finding meaning in illness or injury, life and death issues, helping to cope with loss, suffering, fear, loneliness and ethical issues. NHS Scotland *Guidelines* observe that many patients will be addressing such issues for the first time but that the majority will have no religious or faith commitments to help them and will therefore be in need of:

> A person who will acknowledge the deep desires and stirrings of their spirit, recognize the significance of their relationships, value them and take them seriously. A person who can help them to find within themselves the resources to cope with their difficulties and the

[54] At this point in time NHS England had yet to produce any guidelines.
[55] Published by NHS Scotland
[56] AHPCC served England, Scotland, Wales and Northern Ireland.
Tom Gordon is a Church of Scotland minister and retired hospice chaplain who has published several books. He served as President of AHPCC and chairs the Chaplaincy Training Advisory Board in Scotland.
[57] These competencies were presented by the two chaplains at the AHPCC 2004 conference which I attended.

> capacity to make positive use of their experience of illness and injury (NHS Scotland, 2002:6-7).

The Scottish guidelines acknowledge that such care is given by many members of staff, family and friends in a variety of ways but that 'the distinctive contribution of caregivers who are trained in spiritual and religious care and have time to give it' is essential to the provision of spiritual care within healthcare (7). The guidelines also state: 'Spiritual care is not necessarily religious. Religious care, at its best, should always be spiritual' (6).

As part of the development of spiritual care in NHS Scotland Mowat[58] and Swinton[59] were commissioned in 2003 to carry out a study amongst healthcare chaplains in which they sought to establish the relevance of Christian chaplaincy, the basis for the profession of chaplaincy in the light of the call for generic spiritual care and the issue of the integrity of the Christian chaplain 'within the emerging understanding of spirituality' (Mowat and Swinton, 2007:5)[60].

Mowat and Swinton (2007:43) address 'spiritual neutrality', finding that chaplains believe that spiritual care has to be available to people of 'all faiths and none'. The chaplain therefore moves beyond the boundaries of his own denomination to recognize the more general area of spirituality not observed when focused on religion. Nevertheless their faith was important providing support, strength and encouragement and they generally tended to believe that 'God's role could be implicit in many things without being mentioned directly' (43). They spoke of their own spiritual journey and faith enabling their spiritual neutrality (44) but they also spoke of being 'Christ-like' without evangelising. Exactly what being 'Christ-like' meant was not always clear but derived from the need of the patient, who might or might not have a knowledge of Christianity. 'So, the content of being 'Christ like' is often determined not by theology, but by secular humanism as it is communicated to the chaplain in the pastoral encounter'(44). Mowat and Swinton conclude:

> The separation of religion from spirituality and the strategic emphasis within the health service on the meeting of generic spiritual needs has opened up unique possibilities and challenges for chaplains. This

[58] Dr Harriet Mowat is Director of Mowat Research Ltd and an honorary senior lecturer of Aberdeen University.

[59] Professor John Swinton is professor in Practical Theology and Pastoral Care and Director of the Centre for Spirituality, Health and Disability at the University of Aberdeen and an ordained minister of the Church of Scotland. Trained as a nurse he specialized in psychiatry and learning disabilities for ten years. He has also been a hospital chaplain. He is widely published, was the founding editor of the Scottish Journal of Health Care Chaplaincy and serves on the boards of various journals.

[60] The findings were originally published as 'What do Chaplains do?' in 2005. The second edition was published in 2007 and is the reference used here.

> emerging division seems to be part of the new terms and conditions for chaplains in the health sector. In assuming that everyone has spiritual needs, not everyone has religious needs, the field of spirituality is opened up, but at the expense of effectively closing, or at least minimising an area of unique chaplaincy expertise (Mowat and Swinton, 2007:51).

They consider that it is the chaplain's training that provides the knowledge and skills base that enables her to provide religious spiritual care but the job requirement is the provision of generic spiritual care, hence the possibility of an identity crisis. They go on to point out that chaplaincy is unique amongst healthcare professions in that it does not impose solutions on perceived problems. Rather chaplaincy is a process of identifying spiritual need but the discourse of healthcare requires that a perceived problem be identified and a solution offered (51). This is a crucial aspect of the system's understanding of spiritual care, whereas chaplaincy's strength is its process – intuitive, skilled discernment of spiritual need (52) - which does not necessarily translate into problem identification and solving.

Mowat and Swinton (2007:53) speak of chaplains giving birth to a 'new model of chaplaincy which is currently gestating in Scottish healthcare'. They state that their research shows that there clearly is a role for chaplains but the question is whether chaplains can conceptualise and articulate that role in words which other healthcare providers can understand and relate to and without compromising the chaplain's own spiritual journey (53).

Also published in 2005, a scoping study commissioned by NHS Quality Improvement Scotland recommended that standards and capabilities for chaplains be developed and subsequently the NES strategic plan for 2007/8 stated:

> The NES Healthcare Chaplaincy Unit will support the provision of a broader based chaplaincy for the whole health community, through greater integration of chaplains into the healthcare team. (Foggie et al, 2008:2)

The scoping study stated that a post-graduate qualification for healthcare chaplains and a capability framework would be developed (4-5). Furthermore *Spiritual and Religious Care Capabilities and Competencies for Healthcare Chaplains* would be a core document for the future of Scottish healthcare chaplaincy (2). *Standards for NHS Scotland Chaplaincy Services* were published in 2007 and *Capabilities and Competencies* in 2008 (National Health Service Education for Scotland, 2007, 2008, Fraser, 2012:49). Both were developed in partnership with the various interested parties of the professional organizations, faith organizations, NHS managers and Higher Education Institutes. As it seemed likely that *Capabilities and Competencies* would have an impact across all of UK chaplaincy representatives of English and

Welsh organizations were also included (Foggie et al, 2008:3). The project group used existing publications as a contributing basis (3) viewing the capability language of NHS Education for Scotland (NES) and the competency language of *Knowledge and Skills for Health* (Department of Health, 2004b) as complementary rather than antagonistic (3)[61].

The original 2002 directive required recognition of the role that all healthcare staff can play in spiritual care. However training material for all staff was lacking until the development and publication of *Spiritual Care Matters* in 2009 (NHS Scotland), signaling that spiritual care was no longer the exclusive domain of the chaplain. To meet this need the two pioneering chaplains already mentioned, Gordon and Mitchell, joined forces with Ewan Kelly[62] to produce *Spiritual Care for Healthcare Professionals* which was published in 2011. Amongst the topics covered are: the confusion between spiritual care and religion, the need for self-awareness and spiritual nurture for the chaplain, and the role of chaplain to the institution, all of which arise in this research. Concern for the self-awareness and the nurture of the chaplain resulted in several books including *Personhood and Presence,* subtitled *Self as a resource for spiritual and pastoral care,* (Kelly, 2012) and *Pastoral Supervision* (Leach and Paterson, 2010).

Altogether the 'profound and sustained developments in chaplaincy' in Scotland have resulted in what Derek Fraser has referred to as 'benign envy' in chaplains not just in the rest of the United Kingdom but in other parts of the world (Fraser, 2012:48-49)[63]. Fraser describes the angry response of a Board of Governors at an English hospital when asked: is pastoral care cost effective? Incredulous that such a question should be raised they asked: 'After all who else goes in with empty hands, no toolkit but simply a heart of compassion to relate with the damaged, the defeated, the distressed and despairing across a plethora of circumstances?' They assumed that everybody was aware of the good work undertaken by chaplains (48)[64] and evidently did not appreciate that not everybody shared the Scottish assumptions that all

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[61] Competence describes knowledge, skill and attitude. Capability describes the learning and application of new knowledge from experience such that performance is improved.

[62] Ewan Kelly was a junior doctor who became a healthcare chaplain and university teacher. He worked with NHS Education for Scotland as Programme Director for Chaplaincy and Spiritual Care. Currently he is the Lead for Spiritual Care at NHS Dumfries and Galloway.

[63] Derek Fraser is Chaplaincy & Bereavement Care Lead at the Cambridge University Hospitals NHS Foundation Trust and Addenbrooke's Hospital. He was instrumental in the formation of UKBHC and currently organizes the Chaplains in Healthcare UK, Research Network (CHURN).

[64] Reminiscent of times past when healthcare chaplaincy was assumed to be a good thing (Mowat, 2008:15).

people have spiritual needs and that spiritual and religious needs are not necessarily identical[65]. The picture in England was rather different, as has already been seen in Chapter One and as the literature now reviewed demonstrates.

The English spiritual care landscape

The aim of this section is to supplement the historical picture of spiritual care in healthcare in England described in Chapter One.

Prior to 1980 there was a dearth of literature on spirituality and spiritual care in the context of healthcare (Dyson et al, 1997). However, Cicely Saunders was a prolific writer who wrote on all aspects of hospice and palliative care including the theological issue of suffering. Her first paper 'Dying of cancer', written when she was still a medical student, appeared in St Thomas's in-house publication and covered general management, nursing in the terminal stage, pain management, special homes for the terminally ill, communicating the diagnosis and prognosis with patient and relatives and spiritual care (Saunders, 1958; Clark, 1998a:45). Amongst hospice chaplains her two best known papers are probably 'Watch with me' (1965b) and 'Spiritual pain' (1988). The understanding of spirituality as finding meaning and purpose in life in the latter paper was noted earlier but she was not alone in that understanding - a systematic review of literature on the meaning of spirituality reported that finding meaning in life was a key theme (Dyson et al, 1997:1185).

Literature of the 1980s and 1990s

The concept of holistic care, which included spiritual care, had been introduced into nursing practice and guidelines in the 1980s (O'Dowd, 2008d). Andrew Oldnall[66] (1996:138,140) connected the nursing profession's concern with holistic care with its desire to be an academic discipline. However, his review of the literature on spirituality and holistic care in the period 1980 to 1994 found that the spiritual dimension had rarely been acknowledged (138) casting doubt on the holistic claim (140). Attempting to justify the holistic claim Oldnall examined twenty-six nursing theories. He found that twelve failed to acknowledge the significance of spirituality for holistic care and fourteen acknowledged spirituality implicitly. He found that spirituality had been associated with religion but that persons with spiritual needs,

[65] At the time of writing chaplains visited every patient but I have since learnt that cold calling is no longer acceptable in all Scottish hospitals.

[66] Charge Nurse, City Hospital NHS Trust, Birmingham. Later became Acting Assistant Service Manager in the Medical Directorate of the same Trust.

which he does not explain, may not be religious and that therefore it was necessary to define spirituality from both a religious and a humanist perspective and even these definitions will not be broad enough (139). However, he did find that spirituality was 'dependent on another, either in the form of God or a God substitute, for example, work, money, personal gain or caring relationships with significant others' (139). Oldnall argued that nursing was trying to prove itself as a science but spirituality was too 'woolly' for science so perhaps nursing should be regarded as an art or as both science and art (143) but if it cannot define holistic care he asks how was it to be recognized as an academic discipline? Nevertheless he stated that nurses did recognize spiritual needs but attributed those needs to the religious and so left them to the chaplain (143). He also maintained that nursing educationalists have chosen to ignore issues of spirituality, either because of embarrassment or lack of understanding, in the hope that they will go away (143). He points out that a decision will have to be made as to whether the declining number of nurses has the time and education to provide individualized holistic care.

Embarrassment was also identified as the cause of spirituality becoming a taboo topic by Dyson et al (1997:1183). The comparison was drawn with the Victorians who had discussed spirituality easily, if formulaically, but baulked at discussions of sexuality which was no longer a taboo subject in the 1990s. This review also arose from the nursing profession's claim to provide holistic care, which it acknowledged included spiritual care. The review reported that one of the major hindrances to defining spirituality was its connection to religion and those studies that did exist used subjects who had Christian beliefs[67]. The review covered fifty-seven articles: one from 1959, eight from the 1970s, thirty-five from the 1980s and thirteen from 1990 to 1997. Literature from the 1980s was found to suggest that expressing spirituality in religious terms was limiting and that 'spiritual well-being is neither synonymous nor co-terminous with religiosity' (Dyson et al,1997:1184). The review observed that religion may play a part in spirituality for some, or may provide 'a platform for the expression of spirituality' (1184). The concept of a relationship with God was observed to be changing due to a 'less restrictive view of God'. God might be seen as deity and connected to a religious system but equally 'God' might be whatever a person regarded as the highest value in life, and this might be work, money, a football team…Whatever provided focus and purpose to life was 'God' for that person (1185). The review suggested that the search for meaning was a major component of spirituality (1185) and that the discourse was changing – 'the emerging paradigm in the study of spirituality is one which takes a broader view '

[67] Unfortunately it is not clear which these studies are, nor from which decade.

which required a community context (1184). The review offered a framework for the exploration of spirituality based on self, others and 'God', the relationship between these three and the expression of meaning, hope, connectedness, and beliefs.

Many definitions but very little education for nurses

Despite the introduction of holistic care in the 1980s there was still a lack of education in spiritual care for nurses in the 1990s (Ross, 1994, 2006). Linda Ross[68] (1994:443) observed that nurses understood spiritual need, in descending order of importance, as: the need for belief and faith; the need for peace and comfort; the need to give and receive love and forgiveness; the need for meaning, purpose and fulfilment; the need for hope and creativity. In an overview of nursing research papers on spiritual care for the period 1983 to 2005 (Ross, 2006:860) she further reported that most studies found that nurses' understanding of spiritual needs reflected the broad range found in the literature but that they tended to focus on religious needs (853)[69]. Common factors in the reviews so far are the recognition of the lack of education for nurses in the 1980s and 1990s and the tendency for nurses to understand spiritual care predominantly in religious terms. Later, in 2011, Ross was to author *Spirituality in nursing care: a Pocket Guide* for the Royal College of Nursing (RCN) using, perhaps not surprisingly as she trained in Scotland, the description of spiritual care from NHS Scotland:

> That care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires (NHS Education for Scotland, 2009:6).

The RCN now also has an online resource: *Spirituality in nursing care* which can be downloaded in pdf format[70].

In 1996 Bradshaw[71] highlighted the concerns of sociologists that hospice care was becoming increasingly bureaucratized, compromising the movement's founding

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[68] Linda Ross is Reader in Spirituality and Healthcare, University of South Wales. Ross has made a significant contribution to nursing practice and literature which relates to NHS England as well as NHS Wales. In addition her PhD on Scottish nurses' perceptions of spiritual care was the first study of its kind and size, published 1997.

[69] Unfortunately only seven of the fourteen articles reviewed were UK based and it is not clear which were based in England and Ross herself is based in Wales.

[70] https://www2.rcn.org.uk/__data/assets/pdf_file/0008/395864/Sprituality_online_resource_Final.pdf

ideals (Bradshaw 1996: 409). Bradshaw stressed the Christian foundation of St Christopher's but emphasized that:

> There was no question of proselytizing for ultimately this theology was expressed not in words but in actions. (Bradshaw, 1996:412)

She refers to Cicely Saunders often reminding people that hospice was not a building but a philosophy, a way of caring (412). Bradshaw also refers to Weber's analysis of charisma which indicates that whilst radical change may be affected by special individuals the institution will then settle into routine, the motivating factor disappears and bureaucracy sets in (409). Whilst routinization may be pragmatically necessary for hospice survival she suggests that it may undermine staff who still see palliative care as a vocation. It may also suppress any religious conscience, thus 'losing the heart and soul of care precisely because its originating ethic is being marginalized' (418). She argues that

> while the social sciences have contributed much to understandings of human behaviour, that kind of knowledge in itself is inadequate for the sort of compassionate help and advice needed by one human being from another (Bradshaw, 1996:418).

This points to the need to consider, not just the skill and knowledge but the kind of people who are needed if palliative care is not to become mechanistic.

1998 saw the publication of *The Spiritual Challenge of Healthcare*, edited by Mark Cobb and Vanessa Robshaw, who argued that spirituality is fundamental to humanity and that spirituality is no longer synonymous with religious care[72]. They state that the latter is due to multicultural developments but it is not clear whether they mean that spirituality is no longer synonymous with Christianity (Cobb and Robshaw, 1998:ix). However it is clear that the themes emerging include 'the discounting of spiritual beliefs and values within the dominant scientific paradigm' (x). In their introductory chapter they observe that the sacred and the secular are not mutually exclusive and that the absence of religious practice does not necessarily mean the absence of a spiritual dimension (3). They also argue that 'the scientific reductionism of much medical care' is not synonymous with patient satisfaction and that there is 'a gap which spiritual care can usefully fill', by treating the patient as a person (4). They quote Sacks' reference to 'a perfectly rational yet practical scientific medicine, and an utterly beautiful and elemental "existential" medicine', the

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[71] Ann Bradshaw was Lecturer, National Institute for Nursing, Radcliffe Infirmary, Oxford.

[72] Mark Cobb is a Senior Chaplain and a clinical director at Sheffield Teaching Hospitals NHS Foundation Trust. His clinical speciality is palliative care and his primary research interests are in the fields of spirituality, end of life care and healthcare design. At the time Vanessa Robshaw was a sister at Derbyshire Royal Infirmary.

former seeking to mend the mechanism, the latter to inspire the person (5)[73]. Does the scientific reductionism suggest that so-called patient-centred healthcare does not always treat the patient as a person and that objectivization is creeping back in – or did it ever leave? Has there always been a tension between these two? Dehumanizing aspects of care, treating the patient as an object, are usually said to be the reason for the introduction of individualized care in the 1970s. The authority of experts being displaced by the authority of the self has already been mentioned[74], a point picked up by Vivien Woodward (1998:1047) who refers to suggestions that patient autonomy challenges the authority of the healthcare expert and helps protect the patient against 'professional paternalism' [75]. Whilst this may be true it does not take account of the fact that the expert's opinion may actually be in the patient's best interest and the patient may deprive himself of the appropriate treatment. This then raises ethical issues of professional harm by omission – for example the bed-bound patient who refuses to be turned develops pressure sores when he prevents the nurse from fulfilling the duty of care. Woodward (1051) argues that the fear of paternalism for nursing and the primacy of patient autonomy may have undermined ethical practice. The significance for this research is that it appears to demonstrate not merely the absence of the dominant Christian discourse but that nothing comparable has taken its place. However, it also appears to deny the dependency of those who are ill – which may suggest that self-focused individualism and the authority of the self are the replacements[76].

Literature of the 2000s

In their review of the English language literature from 2000 to 2010 *Spiritual Care at the End of Life* Holloway et al (2010) found that nursing and inter-disciplinary studies had each contributed 25% of the literature. Chaplaincy had contributed 14% and social work 10%. The review looked at the content of the literature and found that the disciplines had developed on different lines. Nursing had nurtured interest in

[73] Oliver Sacks (1933-2015) was a British neurologist who spent his professional life in America. Described as the poet laureate of medicine he wrote about unusual medical conditions in *The Man Who Mistook His Wife For a Hat*, *The Island of the Colour Blind* and most famously *Awakenings,* which was made into a film in 1990.
[74] See Chapter One
[75] Vivien Woodward, Senior Lecturer, Midwifery Education Department, Homerton College School of Health Studies, Cambridge.
[76] Stammers (2015:8) argues that autonomy can be inimical to ethical practice and needs to evolve from 'self-centred individualism to a more inclusive communitarian approach'.

spirituality and the implications for spiritual care[77] but is criticised for the poor quality of the early work on definitions and evidence[78]. Social work is described as 'remaining cautious' about spirituality but concerned to distinguish psychosocial from spiritual care and keen to address cultural issues. Chaplaincy is adjusting to a secular world, expanding its compass to include humanistically defined spiritual need and thereby 'raising questions about what is unique about what they do' (Holloway et al 2010:2)[79]. However, it should be noted that only 41% of the articles were from the United Kingdom and these included articles on the Scottish handling of spiritual care which has already been considered. To describe the developments of the period a selection has been made here of literature by chaplains, nurse educators, theology lecturers and a chaplaincy researcher[80], followed by a brief review of literature on spiritual care and mental health.

The view of an NHS Hospital Chaplain

2001 saw the publication of Cobb's *The Dying Soul: Spiritual Care at the End of Life*. Cobb writes in the context of holistic palliative care, observing that such care results in four interrelated ways – physical, psychological, social and spiritual – of approaching the relief of suffering and the promotion of human well-being (Cobb, 2001:1). He observes that the term 'spiritual' is vague and obscure but much used and that anything that isn't physical, psychological or social finds itself labelled 'spiritual' (3). However, he goes on to observe that as insights from psychotherapy and counselling were introduced into pastoral and theological training so pastoral care moved towards being more 'professional' and in the following decades detached itself from the church or faith community and entered healthcare organization which then incorporated humanistic elements: 'the spiritual could thus exist without an explicit theology' (5). Cobb defines pastoral care as the healing, sustaining, guiding, and reconciling of a person to family and community by a Christian person and his faith community. That carer is grounded in the theology of his faith which gives him spiritual authenticity. Spiritual care is defined as accepting the individual as they

[77] The International Council of Nurses had indicated in 1973 that spiritual care should be part of the nurse's role, including it in its Code for Nurses (Ross, 1994:441).
[78] The lack of critique was addressed by Clarke, included later in this chapter.
[79] Despite the stringent inclusion/exclusion criteria there appear to be some serious omissions – Rachel Stanworth's papers are not included. The paper by Paley, discussed later in this chapter, is included as is Ross's response to Paley. However, responses by Pesut, Leget, Nolan and Kevern are not included. All of these papers are listed in the Bibliography attached to this thesis.
[80] For a detailed description of the role of the Acute Health Care Chaplain the reader is referred to Swift (2014) and for a study of NHS chaplaincy in London to Orchard (2000).

are, facilitating their search for identity and meaning and is not prescriptive, judgemental or dogmatic (6). Where there is some Christian cultural background the carer may provide pastoral and spiritual care but where there is no Christian cultural background pastoral care would be an imposition although spiritual care is acceptable (6)[81]. Cobb (2001:14) states that spirituality is the foundation of being human, giving shape and direction to life. He finds that spirituality is hard to express and the language of palliative care spirituality is often second hand so that it fails to serve reflection. He suggests that poetry may be helpful (18) but nevertheless asks the question 'can spirituality exist without theology or without religious faith? Can there be a secular spirituality?'(24)[82]

The secular argument

In 2006 NHS Worcester planned to cut Hospital Chaplaincy jobs. In the ensuing fracas bishops (both Anglican and Catholic) with no direct experience of contemporary chaplaincy argued the case for chaplaincy within a predominantly religious framework. Spiritual care for those who were not religious was not included in the debate and it deteriorated into an argument with the secularists about the place of religion in society (Swift, 2014:85). The secularists argued that the patient who wanted religious care should turn to his own faith or belief group. They failed to acknowledge the universality of spiritual needs which may be experienced by people of all faiths and none. The chaplaincy reduction argument was also described as being between a view of the NHS as driven by a mechanistic approach to the body and finances and a view that affirmed technical care which was informed and validated by a pastoral and compassionate ethos. How much this event influenced spiritual care in healthcare is impossible to assess but in 2006 John Paley[83] asked: given Britain's increasing secularization 'what accounts for the current interest in spirituality among UK nurses?' (Paley, 2008a:175). His article was not published until 2008 when it evoked a plethora of responses. The article and the response of a hospice chaplain are now considered.

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[81] The terms pastoral and spiritual are frequently used interchangeably so these definitions are interesting and possibly unusual.

[82] Ray Anderson (2003) Professor of Theology and Ministry at Fuller Theological Seminary, Pasadena, USA, addressed this question developing the thesis that all care-giving is spiritual whether or not it is religious.

[83] Senior Lecturer, Department of Nursing & Midwifery, University of Stirling. His article was written and submitted in 2006 but did not appear in print until 2008. Despite its Scottish origin it is included because it caused concern at the AHPCC conference of 2009 and responses from Canada, the Netherlands, Wales and England were subsequently published.

The Nurse Educator: Paley's view

Paley observed that nursing literature on spirituality had blossomed in the last ten years, with a proliferation of definitions, most of which distinguished between spirituality, shared by all human beings, and religion, seen as institutional and theologically more restrictive. He claimed that the current concept of spirituality is 'of very recent origin, and is still "under construction", having become separated from its associations with Christian piety and mysticism only since the 1980s.'(Paley, 2008a:175). He suggested that nursing was claiming the territory of an extended spirituality as part of its claim to professionalization. Paley observed that in the UK people manage spiritual life very simply: 'the more specific and demanding the belief, the fewer people adopt it' (Paley, 2008a:178). Therefore the most popular faith is 'a vague belief in "something there", completely free of any practical implications'[84].

Ross (2008: 2795-2798) responded to Paley who replied that Ross had misrepresented his main argument that there was nothing to justify a universal concept of spirituality (Paley, 2008b:2799). Paley was looking for a scientific approach to the handling of existentialist concerns (Paley, 2008c:3), objecting to the claims being made such as spirituality is 'present in all individuals' including atheists, agnostics, humanists and hedonists. He appeared to be exasperated by claims about spirituality, for example that spirituality is an invisible or transcendental force, is a mode of perception beyond logical reasoning, is the means by which a higher level existence is recognized, because such claims are not substantiated by evidence (Paley, 2008d:138; 2008e:448). Paley stated: 'if "spirituality" authors can make such claims without argument, I can reject them without argument' (Paley, 2008d:138). As an atheist Paley is not denying the existence of issues of meaning, relationships, fear of loss of loved ones, but is arguing that they are not 'spiritual' but psychosocial (138). Issues of existential distress such as fear of death, despair and hopelessness, the afterlife, relationship with God are to be treated as 'positive illusions', a concept he takes from social psychology – and he does make the point that this expression should not be used in front of the patient! He is prepared to discuss religious beliefs with patients who have such a belief, in their terms, but any theoretical account will refer to the psychology of positive illusions, not to anything spiritual or theological. To sum up Paley's position:

> In an evidence-based health service, it is unethical to make claims (about 'spirituality') for which there is zero evidence. On the other

[84] *Something There* is the title of a book by David Hay (2006), whose work on spirituality is referred to in Chapter Six.

> hand, the naturalist perspective does not reject psychosocial care, nor does it recommend ignoring the patient's existential distress. Rather, it emphasizes the resources in scientific psychology that can be recruited to health care in order to make our response to this kind of distress all the more effective. (Paley, 2008e:451)

This raises the issue, already mentioned (Mowat & Swinton, 2007:51), that chaplaincy and spiritual care are not about imposing solutions. Paley appears to assume that spiritual care is about doing something, responding effectively to distress, and he wishes to do so by utilizing scientific psychology.

A response to Paley from a Hospice Chaplain

Nolan[85] (2009) gives a robust but sympathetic response to Paley, pointing out that whilst the decline of religious institutions cannot be denied Paley fails to recognize that religious consciousness is a subset of spiritual consciousness and it is to this that nursing educators and theorists are responding. Nolan argues that as the church's control, manifest in the priestly tradition, weakens so what has been controlled is released, and he identifies this as the prophetic or mystical tradition (205). This may or may not be associated with religion because spirituality is not merely independent of religion but is actually the source that inspires religious practice (205). Nolan also points out the danger of belittling and objectivizing the patient in Paley's supposedly scientific approach (208, 211). Rather than trying to prove spirituality as a metaphysical 'thing' Nolan suggests that spirituality is the discourse which allows and enables ways of being that are open to 'ultimate, radical otherness.' Some might regard this as openness to growth into the divine or the Ultimate, whilst others would understand it as knowing that a person is more than flesh and bone. Either way, spirituality is the discourse of being open to the unknown (211). Nolan's preferred definition describes spirituality as a way of being and experiencing through awareness of the transcendent, giving a way of relating to self, others, nature, life and the Ultimate. He expresses surprise at finding an example of this description of spirituality in *The Book of Atheist Spirituality* by August Comte-Sponville, but sees this as suggesting that spirituality is independent of religion and argues that therefore spiritual care should be part of healthcare.

[85] Steve Nolan is a palliative care chaplain in an English hospice. He is tutor on the MTh in Chaplaincy Studies at St Michael's College, University of Cardiff and a member of the European Association for Palliative Care Taskforce on Spiritual Care in Palliative Care. *Spiritual Care at the End of Life* describes his research, which is discussed in Chapter Three.

The chaplaincy researcher: spirituality as discourse

Listening to and analysing the stories of twenty-five patients Rachel Stanworth[86] (2004:97) identified metaphors that mediate spirituality, not suggesting that these are definitive but rather demonstrating ways of communicating that which is spiritually significant in non-religious language and actions[87]. She also considers the approach of the listener, exploring the nature of attention which affirms the patient (232-233). She points out that in order to stay with the pain of another the carer also needs attention. Self-reflection and a commitment to her own spiritual development, a sense of her own spirituality, will help her to recognize where working with the terminally ill is an avoidance of her own 'little deaths' (234).

> Simply becoming aware of the quality of one's touch, one's presence or even of how one breathes can be sufficient to foster positive changes both towards oneself and others without any further need to 'do' anything elaborate (234).

Stanworth purposely omitted the words 'spirituality' and 'spiritual care' from her research in order to avoid excluding patients who did not attend church or any other place of worship (1). Recognizing that religion and spirituality do not necessarily go together she found that the search for a non-religious 'language of spirit' became an important aspect of her research (1).

Speaking to Hospital Chaplains Jane Williams[88] (2007) observed that the NHS sees chaplains as providing 'something that isn't otherwise present', but she described this as:

> meeting people at a point where their secure mini-narrative have come unstuck, through illness, through fear, through bereavement, and constantly what chaplains are trying to do is to help people to find the thread of their own narrative again, to feel as though they are the tellers of their own story again, not done to, but actively doing. To find that their meaning and their significance, and their role in their own life stories, has not been ended by illness, even if that illness is terminal (Williams 2007).

Williams described spirituality as 'not some vague, contentless, category which supplies well-being by prescription.' Rather it is about 'each individual human story in relation to others and to the divine.' This appears to be a softer, accompanying, approach than Autton's paternalistic priestly chaplain, and in the provision of something that is not present suggests a link with Swinton and Pattison's contention

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[86] Rachel Stanworth, a qualified nurse, worked as Chaplaincy Researcher at St Christopher's Hospice, conducting doctoral research supervised by Heythrop College.
[87] One of her illustrations, the lady who refused to throw away the dead flowers, echoed my own experience of a patient who became upset when the nurse threw away a dead plant. The patient said that the sight of its decay was helping her come to terms with her own decay.
[88] Jane Williams is lecturer in theology at the St Paul's Theological Centre, St Mellitus College and visiting lecturer at King's College London.

(2010:228) that spirituality names a series of absences. However, Williams' version seems to have more substance than Swinton and Pattison (2010) who use the terms 'thin' and 'vague', arguing that strength and usefulness lie in the vagueness. Using Wittgenstein's understanding that words are performative rather than essentialist in meaning, they consider the function of 'spirituality' and 'spiritual care', the contexts of use and the people who use them. It is this mode of spirituality, not attached to any religion, which the NHS is offering to people of all faiths and none (228). Furthermore they argue that the dominance of the medical model of healthcare has ignored or side-lined issues of meaning, hope, purpose, connectedness, love, all of which contribute to a sense of well-being (examined in Chapter Nine). These are not objects to be acquired but aspects of life, ways of being – spirituality identifies those ways of being which contribute to well-being but are missing in times of poor health:

> In a highly secularized healthcare context, (an emphasis on the spiritual) seeks to recapture those dimensions of the human person that were once expressed in religious language and that are not captured effectively by biomedical discourse (Swinton and Pattison 2010:232).

They argue that it is therefore necessary to recognize what is missing and assist the patient in their quest to make what is absent present, acknowledging that, whilst for some this quest may be religious, there will be many for whom the quest is human or material. It appears that both Williams (2007) and Swinton and Pattison (2010) see the patient's humanity restored through the work of the chaplain – work which is not undertaken by any other member of staff[89].

Another nurse educator: critiquing the discourse

Janice Clarke[90] recognizes that nursing had contributed to a decontextualized spirituality, through a failure to critique its own attempts at definition (Clarke, 2009: 1666,1672) thus allowing it to become a portmanteau word, not easily articulated and often indistinguishable from psycho-social care (1667). Referring to Pattison's observation that such terms are constantly seeking a meaning and can actually be used to avoid serious consideration of their usage she quotes: 'Once they exist, they can take on a life and authority of their own which precludes actual consideration of reality' (1667). She argues that nursing literature treats spirituality as an independent describable entity (1667), for which references are sparse, and in the pursuit of professionalization nursing has sought to have its own body of knowledge, not connected to religion or theology (1668). The marginalizing of the role of

[89] This is not to deny that all staff may, to a degree, be involved in spiritual care.
[90] Janice Clarke PhD, RGN, is Senior Lecturer, Institute of Health, Social Care and Psychology, University of Worcester.

religion has led to nurses regarding it as a choice of culture or lifestyle and therefore failing to appreciate the role that religion may play in the lives of individuals (1668). Clarke argues that through these developments nursing has deprived itself of a valuable linguistic resource citing Davie's story of the Liverpool hospital chaplain[91] (1669 &1670).

Clarke (2009:1668) describes theology as being 'thought about God' and spirituality as 'the movement of the heart towards God', with each needing the rigorous critique of the other. She identifies various anxieties that have led to the separation of spirituality and religion: proselytisation, nurses' failure to distinguish between religion and spirituality, nursing being associated with theology and nursing using shared rather than unique knowledge. However she argues that the success of the separation has produced an unusable definition (1672). She suggests that as the scientific approach has not been helpful it would be better to take a philosophical or theological approach such as Wittgenstein's, of observing how language is used rather than developing theories about it (1671).

Mental Health Literature

Due to their significant contribution to the developments on spiritual care a selection of literature from mental health practitioners is now reviewed.

Sims[92] (2009:368) observed that the millennium brought significant change in the way spiritual issues were viewed by health professionals and managers. There was a marked increase in publications, and an increase in definitions of spirituality. He cites Swinton's *Spirituality and Mental Health Care* (2001) as seminal. Swinton points to the attitude to spiritual care – deemed to be soft knowledge of no scientific value, thereby excluding matters of meaning and purpose from care (Swinton, 2001:8). He appeals for a change from looking at care through a scientific lens to looking at care through the eyes of the cared for (9). Whilst he challenges the medical model he is not invalidating it but rather suggesting a broadening to incorporate a spiritual dimension leading to a new paradigm of care (63), a different

[91] The chaplain visited two groups of women, the young coping with miscarriage, stillbirth and sick babies and the older women with gynaecological cancers. Both groups were pleased to see the chaplain but the younger women had no way of expressing their grief whereas the older women remembered prayers from childhood. A similar personal experience was with a Greek Orthodox gentleman struggling with a terminal diagnosis. I discovered that, although no longer practicing, he had been a choir boy and I encouraged him to remember what he had sung. He actually sang parts of the liturgy - which he found very comforting – much to the annoyance of the other patients and I was not popular with the staff until the gentleman died!

[92] Andrew Sims is Emeritus Professor of Psychiatry at the University of Leeds.

way of viewing the world (175). For Swinton spiritual care is not just an action, it is a way of being (175).

In her speech to the Royal College of Psychiatrists mental health chaplain Julia Head observed that spiritual and religious needs are acknowledged as important in the National Institute for Mental Health in England's (*NIMHE) Guiding Statement on Recovery* (2005). This document states: 'Recovery from mental illness is most effective when a holistic approach is considered – including psychological, emotional, spiritual, physical and social needs' (Head: 2008:2). She observes that in the mental health setting spirituality can be a resource but it may also be at the heart of establishing a different quality of relationship with other people: 'authentic relationship speaks to the spiritual dimension in all of us, because it awakens and nourishes those things in life that touch on the essence of our humanity' (10). She argues that hope 'lays the groundwork for healing' and healing is about transcendence and notes that as suffering increased so did reliance on spirituality or faith (7).

The reference to hope is echoed in the Department of Health publication *Ten Essential Shared Capabilities* which stresses the importance of hope for the recovery process. However, it does not link hope with spirituality (DH 2004:15). Neither is hope included in any of the thirteen conceptual components of spirituality identified by Christopher Cook[93] (2004a) in his assessment of the definitions and descriptions in literature concerned with addiction and spirituality. Whether this is an example of the mismatch, identified by Cook (2004a:547), between the language and concepts used in spirituality questionnaires and the understanding of spirituality amongst clinicians might be a subject for further research, not only in the area of mental health but in any area where spirituality is addressed. Cook (2004b:150) also highlights psychiatry's past efforts to understand mental disorders without reference to spirituality, theology and religion, a situation gradually being rectified. He observes that mystical experience may easily be misdiagnosed as psychiatric disorder (155). Cook argues that mysticism is not only relevant to the diagnosis and treatment of such disorder, but contributes to the wellbeing of both the individual having the experience and the community of which he is part (160). This life-enhancing quality is cited by Mark Sutherland (2007) who refers to R.D.Laing's

[93] Christopher Cook is Professor in the Department of Theology and Religion at the University of Durham. He is President of the British Association for the Study of Spirituality and an Executive Editor of the *Journal for the Study of Spirituality*. He qualified as a doctor in 1981 and then specialized in psychiatry. He was ordained an Anglican priest in 2001 and is Director of the Project for Spirituality, Theology and Health, Durham. He has published widely in the area of spirituality and mental health.

observation on the relationship between the mystic and the diagnosed schizophrenic: they find themselves in the same sea – but whilst the mystic swims, the schizophrenic drowns[94]. Sutherland argues that the disciplines and practices of the spiritual life will over time facilitate openness to divine nourishment – he calls this the *spiritual ground* (his italics) - but he observes that suffering can precipitate this openness: 'The vicissitudes of life, the blocks, the ruptures, the failures can catapult us prematurely into the spiritual domain.' Belden Lane[95] made a similar observation when he asked 'What are the places in our experience where desert abandonment is forced on us with the same threatening insistence provided by fierce geographical terrain?' (Lane, 1994:203). His list of such places includes 'the steep cliffs beyond the waiting room of Radiation Oncology' and 'the harsh desert of addiction and mental illness' (203). He goes on to explain:

> The desert, as metaphor, is that uncharted terrain beyond the edges of the seemingly secure and structured world in which we take such confidence – a world of affluence and order that we cannot imagine ending. Yet it does. And at the point where the world begins to crack, where brokenness and disorientation suddenly overtake us, there we step into the wide, silent plains of a desert we had never known to exist. (Lane, 1994:203).

Both Sutherland and Lane point to this spiritual ground or desert as a place where we learn that we are loved unconditionally. Sutherland (2007) argues that those who are steeped in a faith tradition know what it is to be human and are equipped to be signs of the presence of something greater than ourselves. As a Christian he refers to being the presence of the Kingdom of God but acknowledges that other faith traditions will have equivalent concepts. The important point is that both Sutherland and Lane argue that those who involuntarily find themselves in this place deserve to be accompanied. Speaking from his own experience Christopher Newell (2007) a bi-polar mental health chaplain warns of the danger of associating spirituality 'with peace and inner unity rather than the psychic turmoil it often brings' and pleads:

> I only wish that, when the spiritual and psychic storm comes, people are not afraid to stay with me in it. I want them to keep me safe, yes, but most important is that they stay with me, stay with the language I use and the passion I have, and see me and the truth and beauty and not just the delusion that lies within. (Newell, 2007).

[94] Mark Sutherland was Presiding Chaplain at South London & Maudsley NHS Trust.
[95] Belden Lane Professor Emeritus of Theological Studies, St Louis University, USA. Lane was a Protestant member of a Roman Catholic faculty for thirty-five years. His interest in Christian spirituality is broad such that he has been introduced as 'a Presbyterian minister teaching at a Roman Catholic university telling Jewish stories at the Vedanta society' (Lane, 1998: 5).

Despite the range of literature reviewed it was not possible to provide a universal understanding of spirituality nor a common definition of spiritual care.

Summary

Comparing the spiritual care developments in NHS Scotland with those in England, described in Chapter One, indicates that Scotland had a unity and a sense of direction not present in England. In Scotland no one body tried to control or broker chaplaincy arrangements as happened in England. In Scotland all interested parties were at the discussion table from the start and chaplains were major players in discussions and developments. What the two countries did have in common however was a concern for how to express the chaplain's role without compromising the chaplain's integrity, and in words that are understandable and acceptable to healthcare providers.

The literature reviewed indicates that one of the main issues is that of language. NHS Scotland has published clear statements on spirituality and spiritual care but has yet to establish the language by which to record, and thereby evidence, spiritual care. In Chapter One it was observed that the Church of England was concerned for chaplains to retain theological language whilst also being fluent in NHS language. The *Trotter Report* (2010:32) acknowledged the necessity of maintaining the language of faith alongside the language of 'the world'[96] and this latter may be the language of secular professionalism which the NHS requires. This suggests a grasp of two corners of the language rectangle: the faith language which maintains the integrity of the chaplain and the NHS professional or management language necessary for evidence based practice, but what of the language of the patient? Does the patient use faith language? Does the patient use professional language or 'management speak'? It may be that neither language is used by patients or staff and the chaplain needs to be alert to a third everyday language used to express, often unwittingly, spiritual need and pain. The fourth corner of the language rectangle is medical language which is used by medical staff and often repeated in bewildered tones by the patient to the chaplain.

Looked at from a different angle Holloway et al find that 'spirituality is perceived as a generic characteristic of human beings that reveals itself in the search for meaning, relationships, purpose and hope' (Holloway et al, 2010:13). Therefore spiritual care is perceived as care which recognizes and responds to the needs of the human spirit which may relate to the description of spirituality or may simply be the need to be

[96] Swift expresses this as chaplains holding holiness whilst engaged in their work (Swift 2014:67).

listened to. The question remains: in what language is the need for meaning or the anxiety about relationships or lack of purpose expressed? How is the need to be listened to demonstrated? Is it through a language of words? Is it body language? Is it tears? Is the lack of language the reason why, even thirty years after the introduction of holistic care, nurses still state that education in spiritual care is lacking? (Ross, 1994, 2006). Lewinson et al (2015) conducted a systematic literature review to assess the presence of spirituality and spiritual care in nursing education. Whilst they found that nurses 'are aware of their lack of knowledge, understanding and skills in the area of spirituality and spiritual care, and desire to be better informed and skilled' they also noted the plethora of guidance material for educators and the failure to include such material regularly in teaching programmes. Perhaps this failure is due not only to the want of a language with which the educators themselves feel comfortable but it may indicate the absence of confidence in the educator's own sense of personal spirituality.

Conclusion

There are no definitions of spirituality or spiritual care which are universally acceptable across the various healthcare professions. The literature review does not provide a unified or clear picture. There are indications of both confusion and ambivalence, of wanting to provide holistic care but not wanting to address what this might mean in relation to spiritual care. This hazy backdrop of indecision and unease is the setting for this research with hospice chaplains whose job description denies them the facility to speak of their *raison d'etre.* As hospice chaplain David Buck begins his poem *Not speaking of God*:

> Constantly finding new ways
> of not speaking of God
> is not easy
> when God is the reason
> you live
> and breathe
> and have your being. (Buck, 2014)

This research was planned to give hospice chaplains the time and space to voice:

(i) the chaplain's own story of coming into hospice chaplaincy and previous experience

(ii) how the chaplain understands the terms 'spirituality', 'spiritual care' and 'chaplaincy'

(iii) how the chaplain practises spiritual care

(iv) the chaplain's understanding of his own spirituality and its relevance to his work.

(v) the chaplain's awareness of management issues, especially the need for evidence-based practice

(vi) what, if anything, chaplains perceive to be their unique contribution to spiritual care.

(vii) the existence and nature of any theology underlying the work.

From this data it would be possible to describe how chaplains understand their role, their ways of not speaking of God, and their perceptions and opinions of the hospice situation. The next section of this thesis is therefore concerned with the methodology for doing so and the presentation of the data collected.

Section Two: The Research

The overview presented in Section One showed the changing nature of healthcare in England. The role of the hospital chaplain was examined and the significance of Christianity as the dominant discourse in healthcare explored. A literature review was conducted in the hope of establishing a common, agreed understanding of spiritual care. Such an understanding was not found. Therefore this research, exploring and analysing the role of hospice chaplains, is set against an unclear background.

Section Two comprises three chapters examining the methodology and method appropriate to the research, describing the research process and presenting the findings, relating how the research arose from Section One. Chapter Three addresses the issue of how to answer the research question which evolved, largely in response to the richness of the data, from a static search for definitions of spirituality and spiritual care to a dynamic exploration of the hospice chaplain's role. The ontological basis of and the epistemological approach to the research are explored and the influence of developments in other disciplines described. Addressing the issue of the best way to conduct the research I identify the need to establish a population of hospice chaplains from which to select interviewees. The method of research, which would empower or give voice to chaplains themselves, is then explained. It was felt important that the interviewee was free to express personal perceptions, that she be as spontaneous as possible and that the interviewer not pre-empt an answer, especially when prompting or the posing of a question was necessary. The selection of interviewees, the ethical issues and the practicalities of organising the interviews are described, as are the process of interviewing, typing up transcripts and the recognition of common themes. The researcher's role and the importance of reflexivity is explored before considering methods of data analysis.

To facilitate the selection of interviewees a Profile Survey of the members of AHPCC was conducted using Bristol Online Survey through St Marys' University. Chapter Four describes the setting up of and the results from this, the first ever, survey of hospice chaplains. The survey included a question on the respondent's willingness to be interviewed for this research. After describing how the interviews were conducted Chapter Five presents the data beginning with that which relates to the chaplain personally. This is followed by the chaplain's understanding of spirituality and spiritual care, his own spirituality and his views on the workings of the hospice. The chapter concludes that the data, though rich, needs careful analysis to reveal the process by which the chaplain practises spiritual care.

Chapter Three: The design of the research.

The Literature Review in Chapter Two demonstrated the dearth of material published by hospice chaplains and the existing literature, from other professions, indicated a lack of understanding of the role of the chaplain. Therefore the aim was to design research that would produce well argued findings on how hospice chaplains themselves understood their role. This chapter argues the rationale for the research design, discusses methodology and method and describes the process. A short introduction is followed by consideration of the methodology underlying the research design including the influence of twentieth century developments in sociology, social anthropology, ethnography and feminist critical theory. The research method, the method of fieldwork and the reasoning behind it are then described, followed by the process of setting up the interviews, the selection of interviewees, the ethical considerations, practicalities and planning. The role of the researcher and the importance of reflexivity are considered and methods of analysis are outlined.

Introduction

In the *Scoping Review*[97] of research into the efficacy of chaplaincy and spiritual care Mowat observed that:

> the nursing research literature has developed a robust debate about the importance of definitions of spirituality and religion and the associated concern about whose territory spirituality is, in the healthcare setting (Mowat, 2008:32).

but there is little contribution from chaplains in this area. Furthermore she observed that most of the articles were conceptual and few were empirically based(59).
The Department of Health commissioned a systematic review of the literature (Holloway, 2010) to support the implementation of the *End of Life Care Strategy*[98]*.* This review observed that 'Chaplaincy has responded to increasingly secular work environments by broadening its remit to address spiritual need as perceived in humanistic definitions, thus raising questions about what is unique about what they do.' (Holloway, 2011:5) Furthermore Holloway reported that the literature indicates that 'The core task of chaplaincy is to respond to the spiritual needs of patients and staff by accompanying them on their spiritual journey' (16) but that the definitions of

[97] *The Potential for Efficacy of Healthcare Chaplaincy and Spiritual Care Provision in the NHS (UK), a scoping review of recent research (2008)* commissioned by NHS(UK) to identify and codify evidence for the importance of spiritual care within health care.
[98] Published in 2008 this was the first comprehensive strategy to seek to ensure that all who needed it had access to palliative care.

spirituality and spiritual care are open to debate and that there are a variety of models to be found. Initially my research question focused on these terms:

> The understanding of the concepts of spiritual care and chaplaincy amongst chaplains in hospices and palliative care units in England[99].

However, as I explored the issues of methodology and method I acknowledged that the wording of the question sounded like a rather lifeless exploration of terms. Furthermore my list of information sought suggested a more dynamic quest to research how hospice chaplains understood their work:

(i) the chaplain's own story of coming into hospice chaplaincy and previous experience

(ii) how the chaplain understood the terms 'spirituality', 'spiritual care' and 'chaplaincy'

(iii) how the chaplain practised spiritual care

(iv) the chaplain's understanding of his own spirituality and its relevance to his work.

(v) the chaplain's awareness of management issues, especially the need for evidence-based practice

(vi) what, if anything, chaplains perceived to be their unique contribution to spiritual care.

(vii) the existence and nature of any theology underlying the work.

The chaplain's understanding needed to be in context but even reframing the research question as: How do hospice chaplains understand the work they do? felt pedestrian, failing to capture the spontaneity and creativity I was hoping for and that I subsequently experienced in the interviews. As Gilligan observed, an interview is not about asking the right questions or having good questions but it is about what the interviewer would like to know[100] (Kiegelmann, 2009:7). Despite being invited to take part in research with the original banal title the two pilot interviewees responded warmly and the interviews produced rich data[101]. Each told their story, providing the information sought, answering the interview questions, and thus putting their understanding into context. From the pilot interviews I learnt that the interviewees gave the information sought, albeit sometimes prompted, even if the original title was not quite right. Therefore the conduct of the interviews needed to be like the pilot interviews, seeking the same information, answers to the same

[99] This was used on the email invitation to take part in the Profile Survey, on the Consent Form and on the Participant Information Sheet (see Appendices A, B and D).
[100] Gilligan also points out that the interviewer is in the risky place of not knowing, of being vulnerable to discovery, and dependent on the good will of the interviewee (Kiegelmann, 2009:7).
[101] The pilot interviews were so rich that they were included as proper interviews.

questions, giving interviewees the opportunity to speak, to describe the work they do as spontaneously as possible but with open-ended prompt questions where necessary. The resulting data was very rich and I was able to present a paper, which was subsequently published, at the 2014 Conference of the British Association for the Study of Spirituality (Thomas, 2015a). I also gave a presentation at the 2015 AHCPCC Conference (Thomas 2015b). As Flanagan observed: 'a contemplative stance towards the meaning of the findings may even exceed the contours of the original question' (Flanagan, 2014:136).

Reflecting on the inadequacy of the original research title I discussed with my supervisors the need to change the title in order to do justice to the presentation of the data and the analysis. The revised title reflects the fact that interviewees told their story, voiced the spiritual, providing rich data which invited much exploration and analysis:

> Voicing the spiritual: a dynamic exploration and analysis of the role of the chaplain in English hospices.

Methodology

Methodology may be described as the setting for the research process. It indicates what the researcher believes about the nature of reality (ontology) and how knowledge is gained and what is acceptable as knowledge (epistemology). Objective or realist ontology holds that 'the real world is out there and exists independently from us' (King & Horrocks, 2010:9) and that it is therefore possible to study human beings and their relationships in the same positivist way as we might study the physical world, collecting and analysing data to develop laws to explain events. Epistemological objectivism holds that knowledge is value-neutral, not affected by the research process or the role of the researcher, and reflects actual experience.[102] Constructivist or relativist ontology maintains that it is not possible to study social phenomena objectively[103] and 'society is the product of people engaging with one another' (9), resulting in many different interpretations of those engagements. Epistemological interpretivism seeks to reflect reality without reference to value or

[102] In order to establish the population from which my sample for the main piece of research was drawn I carried out a small on-line survey which was ontologically and epistemologically objective. This Profile Survey is described in Chapter Four.

[103] I make a distinction between the incidence of social phenomena, which may be objectively researched, and the nature of such interactions. For example the number of people using hospice services may be objectively researched using quantitative methods but research concerning the nature of their experience is best served by qualitative methods.

respectability and fully acknowledges and reflects that the researcher is part of the process. An interpretative approach explores the meanings for the people involved. The aim of the research was to enable hospice chaplains to tell their story exploring perceptions, feelings and experiences, including feelings on the need to produce evidence, their understanding of their own spirituality and how that spirituality related to their work. I was not seeking to elicit a theory of spiritual care but rather to paint a lively picture of spiritual care as perceived and practiced by chaplains. I do not believe that social phenomena such as the spiritual care provided by chaplains can be inspected or assessed objectively as if it were a syringe driver, and therefore an objective methodology was not considered to be appropriate. In order to evoke the story which would provide the material for painting a picture the research was ontologically constructivist/relativist rather than objective/realist and epistemologically interpretive, analysing the descriptive data recorded in interviews, rather than explaining or proving the data.

The tension between the positivist and the interpretivist or constructivist approach has been a characteristic of the social sciences since their inception and the role of the researcher has been the subject, and object, of much debate. I did not believe that as a researcher I could be totally objective, somehow removing myself whilst conducting an interview, but acknowledged that my being and my interaction would affect the nature of the data collected. The manner of presentation and interpretation of the data would also be subjective. Furthermore a crucial aspect of the methodology was an understanding of people as spiritual beings and a concomitant understanding of that spiritual dimension as a source of knowledge of self, others and the transcendent. The need for the ability to discern the transcendent had implications beyond the verbal and conceptual attributes commonly needed in a researcher.[104]

My understanding of research design, the researcher's role and data analysis have been influenced by twentieth century developments in sociology and social anthropology, ethnography and feminist critical theory and it is to these that I now turn.

[104] Typically the researcher needs self-awareness, role-awareness, flexibility and the skills of reflection and reflexivity. The role of the researcher and the importance of reflexivity is explored later in this chapter.

Twentieth century developments in the disciplines

Early Twentieth century sociology

The twentieth century saw many developments in sociological/qualitative research[105]. Initially, in the 1930s, such research was dominated by large-scale abstract armchair theories which tried to cover all aspects of social life. The paucity of empirical research led the eminent American sociologist Robert Merton[106], to suggest limiting the topic for research. He also introduced the use of the term 'paradigm' to refer to 'exemplars of codified basic and often tacit assumptions, problem sets, key concepts, logic of procedure, and selectively accumulated knowledge that guide inquiry in all scientific fields' (Merton, 2004:267)[107]. Merton recognized that social scientists were attracted to the positivist paradigm, commonly found in the hard sciences, where the purpose of research is to establish a single truth, via the testing of hypotheses, perhaps to predict and control, and where absolute objectivity is assumed, because of its apparent ability to produce proof/truth and thereby confer value and respectability.

In 1945 Merton accurately foresaw that the changing nature of society would lead to groups, even in academia, finding that their differences outweighed what they had shared and the existence of any one universe of discourse, or paradigm, challenged the validity and legitimacy of the other (Merton, 1973:8). Such a challenge was described in Chapter One when, in the 1980s and 1990s, the nursing profession felt the need to validate itself by proving efficacy in the face of the medical model. Today healthcare chaplains are experiencing a similar challenge and I would later hear an interviewee say that she experienced that challenge thirty years ago as a nurse and today as a chaplain she is facing a similar challenge of the need for evidence-based practice.

However Merton (1945:469) argued that empirical research should not only test hypotheses but should also engender new hypotheses and he warned of the dangers of allowing the paradigm to dominate and shape what the researcher saw rather than it being a starting point: 'this is a logical model, and so fails, of course, to

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[105] The debt owed to Weber has to be acknowledged but is outside the scope of this research.

[106] Robert Merton (1910 – 2003) was one of the most influential sociologists of the twentieth century. He taught at various universities including Columbia where in recognition of his lasting contributions to scholarship and the University, Columbia established the Robert K. Merton Professorship in the Social Sciences in 1990.

[107] Merton describes Thomas Kuhn's use of the word paradigm as 'at the least a terminological coincidence' remarking that he did not know why, despite the fact that they were in contact, they had not discussed the concept. Kuhn assumed major fields of science are dominated by a single paradigm whereas Merton assumed that scientific disciplines worked with a variety of paradigms (Merton, 2004:267-8).

describe much of what happens in fruitful investigation' (Merton, 1948:506). Several times he re-iterated a point he first made in 1949, that if it is recognized that a paradigm may be changed or amended it is preferable to a set of tacit assumptions (Merton, 2004:269). Merton's work leads me, the researcher, to recognize the danger of tacit assumptions, acknowledge the paradigm of the research and resist the temptation to adopt a different paradigm which would supposedly give respectability to the research. In my case to adopt a positivist paradigm would not only dominate and shape the work, it would fail to elicit the sought for descriptive material and would turn it into a completely different piece of research. Merton also alerted me to the possibility of differences outweighing commonalities producing conflict between groups of staff within the hospice setting.

Post-World War II sociology and social anthropology

In their monumental work Denzin & Lincoln (2011b:3) describe eight 'moments' of the development of qualitative research, each a specific time period such as the period from 1950 to 1970 which is described as modernist or golden. In this period qualitative research came under attack from quantitative scholars because of the lack of scientific rigour of the interpretive approach, and both approaches were guilty of colonialism - supposedly superior cultures studying 'primitive' societies.

For example, in the field of social anthropology, researchers following in Malinowski's footsteps realized that a rigorous description of a society rarely captured the ambience[108], leading the English anthropologist Evans-Pritchard to say 'social anthropology is best regarded as an art and not as a natural science' (Evans-Pritchard, 1951:85).[109]

However, it seems unlikely that Evans-Pritchard and his contemporaries would have gone as far as Denzin & Lincoln:

> a critical social science seeks its external grounding not in science, in any of its revisionist postpositivist forms, but rather in a commitment to critical pedagogy and communitarian feminism with hope but no guarantees. It seeks to understand how power and

[108] Bronislaw ve(1884-1942) born and educated in Poland, came to the London School of Economics to study and teach anthropology. Arguably he became the most influential anthropologist of the twentieth century through his revolutionary approach of living with the people he was studying rather than viewing them from the verandah of the missionary compound or government station. Those who studied under him included Evans-Pritchard.

[109] E.E.Evans-Pritchard (1902-1973), English anthropologist who studied under Malinowski at the London School of Economics. He lectured at the University of Cairo and at Cambridge and Oxford. He is famous for arguing that anthropology is not a natural science but belongs with the humanities, describing the main issue as the understanding and translation of a culture other than one's own.

> ideology operate through and across systems of discourse, cultural commodities, and cultural texts (Denzin & Lincoln, 2011a:x).

Neither would they have gone so far as to describe the researcher as a person who constructs and interprets his or her own world. However, there was some acknowledgement that what the researcher recorded would be 'in some measure the observer's construct or model' (Beattie, 1964:38) but this was usually 'based on the unanalysed concepts of common sense, that is of the observer's common sense' (38). No reason for privileging the observer's common sense was given. There was no mention of the observer considering his or her own situatedness of language, gender, social class, race, or ethnicity[110].

In contrast the Constructivist or Interpretivist paradigm held that:

> We construct knowledge through our lived experiences and through our interactions with other members of society. As such, as researchers, we must participate in the research process with our subjects to ensure we are producing knowledge that is reflective of their reality (Lincoln et al, 2011:103).

The production of material that reflects the subjects' reality is of paramount concern – reflexivity is serious and problematic - to avoid the danger at one extreme of producing Malinowski's accurate descriptions which have no colour (Erickson, 2011:49) and at another extreme avoiding the risk of describing what is not there, or steering the research. The richer the data, in what is heard, seen, and sensed, the greater potential for analysis. Charmaz (2006:14) points out that rich data requires Geertz's 'thick' description[111].

According to Denzin & Lincoln (2011b:1) the conflict between constructivist and positivist researchers continued until 1990 when postpositivists, constructivists and critical theorists talked through the issues of dissent and found a creative way forward for supporters of each paradigm. Reflecting on the shift from the sociology of the 1960s, that sought to document an established reality, to an ethnographic approach which produced 'close, careful observation and penetrating analyses' (Karp, 1999:599) Karp observes: 'one of the most important missions of sociology is to bring to centre stage the viewpoints of people who rarely get to speak' (599,600). Admittedly he is referring to those of whom society does not approve but there is no

[110] However, the same author asserts that a statement to the effect that bridewealth was paid in 72% of the sample was felt to be a better representation of 'the facts' than a description of behaviour with no statistics attached (Beattie, 1964:39). This appears to be another example of the attraction of the 'scientific'.

[111] Clifford Geertz (1926 – 2006) was an American cultural anthropologist perhaps best known for his use of the term 'thick description' which he took from the English philosopher Gilbert Ryle. Geertz held that the purpose of culture was to supply meaning not through art or music or literature but through webs of significance which are interpreted to give meaning.

doubt that this description could equally be applied to chaplains, and hospice chaplains in particular, who have preferred to get on with the job rather than speak out or publish their understanding of their world.

Empowering the Voiceless

Critical theory is concerned with transformation and empowerment and feminist critical theory was and is concerned with the transformation of a male-dominated society and the empowerment of women[112]. Feminist Epistemology:

> identifies ways in which dominant conceptions and practices of knowledge attribution, acquisition, and justification systematically disadvantage women and *other subordinated groups* (my italics), and strives to reform these conceptions and practices so that they serve the interests of these groups (Anderson, 2012).

Caring for others is an activity still often regarded as being characteristically female (Wood, 2009:397), and as such does not produce knowledge up to the standard of what Haraway called 'cognitive canon law' (Haraway, 1988:575). Since hospice chaplains, male as well as female, are involved predominantly in caring for others I considered whether they might be one of Anderson's 'other subordinated groups'. As part of my exploration I wished to include the nature of any perceived oppression or disenfranchisement of chaplains by management, should it be revealed by the research. The contextual nature - time, place and community - of critical theory and its concern not with a meta-theory but with specific structures and uses of power within them might be relevant to the data analysis. Other feminist arguments might also be relevant, such as that for women as carriers of culture across time and space and as 'traditional custodians of folklore and fable' (McNamara, 2009:161) whose meaning was rarely heard. If the data revealed that chaplains perceived themselves as carriers of a particular type of tradition whose meaning was rarely heard or valued this needed to be shown in my painting. Equally, the feminist perspective on the inability of existing language to express experience (Devault, 1990:96) might be relevant. If this were so the research would not only gain knowledge about chaplains' perceptions but also empower them if appropriate.

Whether hospice chaplains chose not to speak (like Saunders, believing that the focus should be on the work rather than on them[113]) or felt disenfranchised or felt that they did not have a place to speak from might be revealed by the data from this research and the very fact of giving voice might raise awareness and empower them.

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[112] Some definitions of feminism extend the concern for empowerment to any oppressed group, regardless of gender.

[113] See Chapter One

Before moving on to the method of fieldwork there is one other development in social research which influenced the design of the research.

Grounded Theory

The growth in influence of the positivist paradigm in 1960s and 1970s America meant that qualitative research lost ground to quantitative, but within the latter, theory and research were drifting apart, an unpromising scenario for the development of new theory. Into the space created by these 'turf wars' stepped Anselm Strauss and Barney Glaser with Grounded Theory. Influenced by his Chicago colleagues Strauss's interpretive perspective focussed on how meanings and actions are created, presented and changed. Glaser had studied under Merton at Columbia and followed his example in not embracing grand unfounded theories but developed middle-range theories 'of abstract renderings of specific social phenomena that were grounded in data' (Charmaz, 2006:7). Together they were concerned to discover the processes that lead to change in society and the attitudes to and roles of individuals in the process of change.

Charmaz (9) describes how Glaser and Strauss fought the dominance of positivistic research in the 1960s only for Grounded Theory to become known for its positivistic stance in the 1990s! Since then however, various researchers, not necessarily positivists, have used grounded theory against varying perspectives. Charmaz (2006:10) makes it clear that her paradigm is interpretive and that rather than theory emerging from the data, as Glaser and Strauss described, it is researchers who interact to construct the theory. Thus Grounded Theory has been described as a means of revealing the maximum of meaning from the minimum of data (Hildenbrand, 2000:21).

The concept of the researcher emerging as bricoleur or quilt-maker in the 'blurred genres moment' of 1970-1986 (Denzin & Lincoln, 2011b :4-5) seems to describe Grounded Theory – the quilt maker keeping an eye open for scraps, collecting them and considering the patterns they might make seems a reasonable description of the researcher's interactive role in the production of knowledge. In order to make the patterns or connections it may be that induction is used – or is it abduction? Accepting Reichertz's argument that Strauss's use of the term 'induction' is not appropriate (Reichertz, 2010:1-2) I use Peirce's term 'abduction':

> Abduction is therefore a cerebral process, an intellectual act, a mental leap, that brings together things which one had never associated with one another: A cognitive logic of discovery (5)[114].

Peirce states that his two illustrations of strategies for producing abduction have one thing in common : 'that the *consciously working mind*, relying on logical rules, is outmaneuvered' (7).[115]

Steve Nolan (2012:33) stated that he used 'a Grounded Theory approach' for his research in hospices – 'I am concerned with how chaplains care for people who are navigating the precarious route between hope and despair.'(12). His account of the research shows a transformation of the relationship he has with what he knows in that through the processes of initial and focused coding he realizes that he has assumed from the start that palliative care chaplains are concerned to help dying people to find hope (140). However, by his own admission he set out to explore chaplains' behaviour in relation to hope and despair in patients thus indicating that his is not a classic Grounded Theory approach. He also states that his coding of initial sampling data seemed to suggest an emergent theme of the chaplain's presence and the evoking of reactions, which he had not anticipated but which demonstrate the emergence of themes through Grounded Theory (140).

Robert Devenny draws on Grounded Theory to develop 'Grounded Presence' which he describes as a methodology coming:

> from an ontology which acknowledges the spiritual component of our being and an epistemology which assumes that the spiritual component is a source of understanding and relationship (Devenny, 2006:9)[116].

Devenny's data collection and analysis follow the 'constant comparative analysis process' (9) of Grounded Theory, with the researcher making notes and analysing from the start of the research and all the way through, and drawing on his own experience when analysing. However, Devenny makes the point that in Grounded Presence the researcher is grounded in his own spiritual awareness and 'is intentionally "being present" to the participants as they explore their feelings'(10).

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[114] Charles Peirce (1839-1914) was an American scientific philosopher who wrote voluminously on a wide range of subjects from mathematics and physical sciences to humanities and social sciences. For over thirty years he was involved in practical and theoretical problems of accurate scientific measurement but ultimately he rejected scientific determinism.

[115] I wondered whether my consciously working mind had been out-manoeuvered as I made an unexpected connection with the Russian Orthodox concept of the tying back of the wings of the intellect (de Hueck Doherty, 1975:161).

[116] Robert Devenny was Head of Spiritual Care for NHS Lanarkshire, Scotland where, as described in Chapter Two, spiritual care was accepted as part of healthcare and regarded as enabling and promoting healing in the fullest sense (NHS Scotland 2002).

He states that therefore the researcher needs to prepare or centre himself before the interview in order to be present to the deeper feelings of the participant, to his own deeper feelings and to the transcendent. Devenny's research was with stroke patients and he describes his role as:

> with the help and expertise of the participants, to articulate a deeper understanding of the spiritual experiences of people dealing with a specific illness (11).

As with Grounded Theory reflection is a necessary part of the on-going analysis, if only to ensure that the researcher has not become a counsellor (10)[117], but in Grounded Presence there is also the need for spiritual reflection and the issue of Chaplain or Spiritual Care giver as researcher is not addressed[118]. Devenny realised that the stroke experience led patients to a heightened appreciation of relationships, the natural world and the vulnerability of others, which he describes as 'a deepening spiritual awareness'(11). He observes that he felt 'the presence of the participants' spiritual awareness, which invoked a sense of privilege' (11) but he does not give any further detail of language to describe how he felt that presence or why it invoked a sense of privilege.

The research method

As I was seeking to present an argument, albeit as a picture, rather than to elicit a theory I did not consider Grounded Theory wholly appropriate but I felt that the researcher as bricoleur or quilt-maker and the epistemological processes of induction and abduction applied equally well to a picture-painter. In addition the understanding of people as spiritual beings, and the spiritual as a source of knowledge as expressed in Grounded Presence methodology, was an essential aspect of my methodology. In this heuristic method of enquiry, which may be described as Contemplative Discernment[119, 120], the researcher is the principle research tool, balancing intellect with intuition and discernment. The approach is grounded in the researcher's own faith and experience of divine presence. Every stage of the research is dependent on intuition, openness to abductive connections

[117] Swinton & Mowat (2006:66) point out that it is very easy to slip into counselling mode when an interviewee is speaking of something emotional or difficult.
[118] Devenny acknowledges that the area of Chaplain or Spiritual Care giver as researcher needs 'further discussion' (Devenny, 2006:10).
[119] A description suggested by my co-supervisor Lynne Scholefield.
[120] Flanagan (2016) references Robert Romanyshyn in making a case for 'doing research with contemplative sensibility' such that no finding, no matter how unorthodox, is precluded or ignored.

and discernment of the transcendent[121]. However, it is important to note that the stages are not discrete events but may overlap and reappear.

The initial stage of this research method is identification of topic and audience. Recognizing that I wanted to do some research that would contribute to the future of hospice chaplaincy I was prompted, even chased, by reminders of the absence of universally acceptable definitions of spirituality and spiritual care and by the need for published information about the hospice chaplain's work. With hindsight I can say that I may have identified the research topic but there was a very real sense in which the topic chose me and guided the thinking, the process of data collection and the presentation and analysis of the, then unknown, findings [122]. However, identifying the research topic, the information sought, is not the same as formulating the research question. Reflection and discussion on the wording of the question continue to this day[123]. Nevertheless I was clear about my audience. The research was for hospice chaplains, to help them reflect on their role and be articulate in defence of that role with management. The process of interviewing and analysing the interview data suggested that there was also a secondary audience: hospice management.

The second stage of the research was concerned with the wider context or setting of the hospice chaplain's role, describing the history of spiritual care in healthcare and establishing the provenance of the modern hospice[124]. Despite the factual nature of the history, discernment was needed to decide what was relevant and what was interesting but tangential. Context included the literature review, mainly of material from other disciplines.

The third stage was to identify disciplinary influences, described earlier in this chapter, and preconceptions. I also acknowledged my role as researcher and prayed that I would not get in the way or try to control the data.

The fourth stage established the population of hospice chaplains from which to select interviewees and finalized a checklist of information I hoped to gather from the interviews. I spent time with the checklist imagining various responses and how I would handle them. A guinea pig interview was arranged to iron out the creases, which it did but it also drew my attention to my lack of preparation for being

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[121] Or 'structured attentiveness to mystery' (Flanagan, 2014:129).

[122] Only later did I discover Rosemarie Anderson's work on Intuitive Inquiry which joins intuition to intellectual precision. She observes that she encourages her doctoral students to study topics that appear to be chasing them because the call of the topic may actually be a call from the wider culture (Anderson, 2004:308).

[123] My Supervisor commented that some students do not know the exact question until eighteen months after finishing the thesis.

[124] See Chapter One

sensitive to the movement of the Holy Spirit[125]. Such awareness is not uncommon in spiritual direction but, despite noting the need for the ability to discern the transcendent, I had not included discernment in my preparation. Later I would discover that it was just as apparent and necessary when listening to the recording and typing up the transcript as in the actual interview. Thus I was reminded of the need for balance between the intellectual rigour required to ensure useable data and the discernment and intuition necessary to affirm the interviewee, handle the data and facilitate the emergence of co-created knowledge.

The fifth stage collected and presented the data and is particularly characterized by on-going reflection and reflexivity[126] during and after each interview, whilst typing up transcripts and writing pen portraits or vignettes and on many additional occasions. I recorded my reflections and noted emergent themes. How to present the data so as to do it justice? It was rich enough to paint a picture but I am no artist and eventually approached the data like a jigsaw, intuitively finding where pieces fit. Despite being immersed in the data Stage six, the selection of themes to be explored, was difficult. There were ninety-two topics mentioned by more than one interviewee[127]. Through reflection, intuition and contemplative discernment I produced thirty topics but my diary entry says: 'Selecting themes and prioritizing was like looking into a murky pond – eventually I sat down, gave myself half-an hour and typed what came to me.' From this I wrote headings for each of twelve possible themes on pieces of paper and laid them out on the floor in my study. Each day I spent time with the pieces of paper, 'dwelling with' the data, hoping to discern, intuitively recognize, which themes had a 'halo effect'. Unfortunately a family problem then necessitated personal spiritual reflection, pulling me away from data reflection[128]. Returning to the material I was able to recognize the looked for halo effect and reduce the papers from twelve to six. Further reflection revealed that one theme was the chaplain as prophet and the other five were related to the chaplain as presence.

The final stage concerns the interpretation of the selected themes, discerning appropriate analytical lenses, and the discernment of conclusions and recommendations.

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[125] I later found reference to this by Flanagan (2014:135). The interviews were conducted in 2013.

[126] Reflection and reflexivity are discussed later in this chapter.

[127] Established by use of the word-search facility in Word on the Mac OSX 10.6.8 operating system.

[128] Personal reflection revealed that my vulnerability contributed to my discernment difficulties. I was not aware that the intuitive researcher invites the enquiry to transform her understanding of the topic and her life (Anderson, 2004).

Methods of data collection

This project uses both quantitative and qualitative methods of data collection. Quantitative research collects information in the form of numbers to show how many or what proportion of a given population behaves in a particular way. For example, quantitative research is used to establish what percentage of the population attends a church service on a Sunday. It is not necessary to interview the entire population to establish this percentage, rather a random sample, of sufficient size to predict that it reflects the entire population, is interviewed. Such information would be gathered by means of a questionnaire, either filled in directly by the respondent or administered by the researcher. The questionnaire is the same for all respondents and it is designed in a way to elicit the required information. No changes are made during the completion of the questionnaire. The concepts are pre-defined and most of the questions are closed-ended in that the respondent chooses one of a set of pre-defined answers. In this way many questions can be asked in a short space of time. In short, a survey is a tool by which a researcher may interview a small sample of people and establish a picture of what a much larger group of people think or do (Neuman, 1994: 28). The online Profile Survey presented in Chapter Four is an example of quantitative research.

However, if I want to know what people think about an aspect of the church service they attended some form of qualitative research is more appropriate. Qualitative research collects information not in numbers but in words, pictures or feelings and is therefore appropriate for exploring the hospice chaplain's world. However, there are various kinds of qualitative research: case-study, focus group, or individual interview. Taking each of these in turn: case-study technique would require observation of the experience of the chaplain (Neuman, 1994:321). In a normal case study the researcher '"hangs around" and observes a social group for an extended period of time' (321). Such an approach might require a long period of participation in the life of the interviewee, which was not a practical option for me. The second option, a focus group, brings people together with a moderator to discuss one or more issues for one or two hours (245). The moderator needs to be flexible whilst ensuring that everyone has the opportunity to express their opinion, and the group members need to be 'homogenous enough to reduce conflict' (245-6). Homogeneity would normally be found in a characteristic such as product usage, for example usage of a shampoo, or white goods ownership such as owning an iron. In this research a focus group would be homogenous by virtue of being hospice chaplains. However, I had observed the variation in strength of personality amongst hospice chaplains and felt this might lead to an interplay which I could neither manage nor eliminate. To

ensure that each respondent could speak without fear, without interruption, and that I had the opportunity for clarification I needed to be in a one-to-one situation. Therefore I chose an individual interview as offering the best form of qualitative research. Individual interviews can take different forms: structured, open-ended, semi-structured or guided depending on the nature of the data sought. To maximize the material for analysis the data needed to be rich or 'thick', to use Geertz's term. A structured interview, like a questionnaire, would risk pre-categorisation and would not provide chaplains' own spontaneous words and neither would it provide rich data. However, an open-ended interview might well provide rich data but not of my desired kind as a chaplain might seize the opportunity to air his particular grievances rather than focusing on the topics of interest to me. Therefore a semi-structured, or guided, interview, was chosen because it offered the best method of obtaining rich data, giving opportunities for clarification whilst at the same time helping me to keep the interview focused. The semi-structured interview attempted to elicit the non-quantifiable, by asking the interviewee to describe. Where the information was not spontaneously forthcoming open-ended questions were used to elicit that information. Whilst each interview started with an invitation to say how she came to be in hospice chaplaincy the sequence and shape of the interview thereafter depended on the respondent. The interviewer did not offer her own opinions, even when asked, or share her own experiences. The interviewer attempted to understand the interviewee but no matter how much playing back, or repetition, or how many alternative ways of expressing, there is no guarantee that the understanding is exact or true. Other than the interviewee there is no other source for the information, no other means of verification. Threlfall-Holmes & Newitt (2011: xvi) argue that much chaplaincy occurs in marginal places and hospice chaplains not only work in one of these marginal places but work 'on the boundaries of recognized religion' (Blake, 2002). Blake, an experienced hospice chaplain, says of hospice chaplains:

> We stand in places where others fear to go, alongside the Medicine men who occupy the boundaries between health and illness and the Shamans who hold boundaries between life and death. As Our Lord found, demons live in deserts because kings occupy the defined boundary land. (Blake, 2002)

The language used to describe marginal places is itself problematic for the formulation of questions. I needed to ensure that my questions did not pre-define the very concepts I sought to elucidate but encouraged the interviewee to be open and honest about her feelings and her experience and not just quote theory. In effect I was asking the interviewee to expose her deepest self and be vulnerable. I could only hope that I would recognize that vulnerability and respond appropriately

and sensitively.

The Interviews

Sample and Selection of Interviewees

There are 223 hospices in the United Kingdom, 164 being voluntary units and 59 NHS units. Whether all of these units have a chaplain was not known but it was known that, at the time of designing this research, 147 chaplains were members of the Association of Hospice & Palliative Care Chaplains. Those members comprised the population from which the sample was drawn. Given the aims of the research there was no requirement to show that findings from the sample were representative of the entire population. Neither was there any requirement to generalize findings in order to develop explanations and theories. 'Non-probability samples do not yield generalizable findings, but ways of seeing data that may be applicable to other cases' (Lynch, 2012:6). Non-probability sampling was therefore used and the need for caution in the way findings were presented was noted. Whatever the form of presentation it would be necessary to ensure that findings would not be mistaken for theories but might be seen as helpful ways of viewing data.

In preparation for fieldwork and as my interviewing and analysis skills had not been used since completing my MTh in 2001 I undertook some revision. In addition to the postgraduate training offered by St Mary's University I attended external sessions on Qualitative Data Analysis and Academic Writing at the University of Surrey.

As a member of AHPCC and Conference Organiser I could have selected interviewees from amongst the chaplains whom I considered I knew quite well. When I first spoke of conducting research interviews several volunteered or responded with keen interest. However, this could produce a very unrepresentative sample[129] which might render the findings interesting but irrelevant to some chaplains. AHPCC had very little data on members and I therefore requested the Executive to allow me to provide a short optional online profile survey for members. The results of such a survey would aid the selection of as wide a range of interviewees as possible and also give the Executive a picture of the make-up of the membership, which would help their decision-making on the content of future meetings and Conferences. The survey was sanctioned by the Executive and accepted by the membership at the Annual General Meeting at the Conference in May 2012. Several chaplains responded immediately offering to be interviewed and their names were noted.

[129] Such as: Male chaplains all in the 50 to 60 age bracket, all full-time, all Church of England, all in post for longer than ten years, all in the south-east of England.

Details of the Profile Survey, the questions asked and the results are presented in Chapter Four.

The survey enabled the selection of an initial sample for interviewing but theoretical sampling was needed to supplement the data (Merkens, 2000: 168) and explore insights. Variables such as personality strength/ thought leadership, involvement in research projects, membership of the Executive were also considered, giving a maximum variation sample (Lynch, 2012:6). Merkens (2000:169) also discusses the quality of interviewees and the need for them to be especially knowledgeable. He defines them as needing to have the necessary knowledge and experience, be capable of reflection, be articulate, have time to be interviewed and be willing to be interviewed. However, whilst time and willingness to be interviewed were essential to this research, knowledge, reflective capability and articulateness were not pre-requisites but rather aspects of the data being researched. In the event of snowballing occurring – an interviewee suggesting another possible interviewee – the details of the individual were checked against those already interviewed so that the sample was a reasonable, but not statistical, representation of AHPCC membership.

The size of the sample had been estimated at twenty but this figure was extremely arbitrary. Merkens (2000:168) refers to Kvale's proposal that the sample is large enough when no new information would be obtained from new interviewees. This is described as 'theoretical saturation'. Lynch (2012:7) observes that this can be helpful but it can also lead researchers to find closure to the research by focusing on common themes rather than staying with the variety and complexity of the data. Lynch suggests that an acknowledged pragmatic approach of available time and resources is not only acceptable but also encourages critical thinking about the nature of the data collected, or not collected, and its similarities and differences with other contexts. There was also the consciousness of the danger of loss of impetus so November 2013 was set as the date by which all twenty-five interviews were to be completed, and this was achieved.

Ethical Considerations

Potential interviewees needed to feel under no obligation to be interviewed. Willingness to be interviewed was initially indicated in the online Profile Survey. Consent was then freely given when arranging interview details and formally given in the witnessed signing of the Consent Form (Appendix B).

The use of a semi-structured interview was designed to elicit the opinion and experience of the interviewee. I expressed clearly at the start of the interview that I

was not there to give my opinion or experience, neither was I there to comment on anything that the interviewee told me. I also assured her of privacy through the use of pseudonyms and secure data storage. The need for confidentiality extends beyond the interviewee to the institution in which she works so there must not be any identifying characteristics. However, where the interviewee was of a faith group other than Christian he may be the only member of that faith in AHPCC. Consideration was therefore given to the handling of data which would identify that interviewee and consequently the institution that employed him. Where more than one chaplain from a hospice was interviewed there was no reference by me to the other interviewee and both interviewees were assured of my absolute confidentiality. The availability of interviewees for interviews in working hours raised an ethical decision which was left to the interviewee. Location for the interview was also the interviewee's decision but I checked the privacy of the location to ensure that the interview was not overheard. Whilst it was not anticipated that there would be any risks involved in the interview it was anticipated that interviewees might be led to reflect on personal beliefs and attitudes and on professional practice. This was clearly stated in the Participant Information sheet (Appendix C), but on re-reading and personalizing the sheet I felt it unnecessarily formal. I therefore revised it to be more 'user friendly' (Appendix D). The interviewee was also advised that she could withdraw from the research at any time and facility to do so was given at the bottom of the Consent Form (Appendix B). Both Participant Information Sheet and Consent Form are part of the Ethics Application (Appendix E) which was completed in 2012. When arranging interviews some chaplains offered me hospitality which I graciously declined as I felt the need for separation of research interview from social interaction of any kind[130].

The interviews : practicalities

I proposed to visit interviewees but in order to set up the interview needed to ensure that each could give me about an hour and a half without interruption. Being on-call in the hospice would not be conducive to a relaxed and productive interview. Therefore I established a suitable time and place, when the interviewee was not on-call and a place somewhere in or near the hospice in order to minimize the interviewee's time of absence. A chaplain does not necessarily have an office, and certainly not an office that is not shared. However, most hospices have Counselling rooms which can be booked. Once a date and time was agreed I sent the

[130] A research grant from St Mary's University enabled me to pre-arrange bed & breakfast accommodation where necessary.

interviewee a Participant Information Sheet (Appendix D) and a Consent Form (Appendix B). The Participant Information Sheet gave details of the research and the interview arrangements and assured the interviewee of confidentiality. The Consent Form needed to be signed with a witness, and photocopied so that both the interviewee and I, the interviewer, had a copy.

Each interview was recorded, using a small unobtrusive but high-quality voice recording machine (Olympus M3 4/47), and I familiarized myself with the recorder in order to minimize apprehension about its function (Hermans, 2000: 210). Permission from the interviewee was sought at the very beginning of the interview 'to save me having to make notes I've brought a small recording machine… which I hope you will not object to…' (switch on machine) 'I'll just test that it is working properly. My name is Jacki Thomas and I am at *Name of Hospice* to interview… ' The interviewee was invited to give her name and recap the information given in the profile survey, such as hours worked, length of time in chaplaincy. Hopf (2000:210) says that 'the interviewer's main task in the opening minutes of an interview is to *set the stage* so the people involved can find their roles.' I then assured the interviewee of confidentiality via the use of a pseudonym for any material used.

As well as recording equipment I had a check list to ensure that the interview was not wasted. Broad categories had been identified but I anticipated that ideas and concepts would become clearer in and through the research process (Merkens, 2000: 170). I constructed a script, an outline of questions (Appendix F), in everyday language (Hermans, 2000:213), which began by inviting the interviewee to tell me about himself and how he came to be in hospice chaplaincy, leading into his description of what he does. Borrowing Kvale's metaphors (2009:48-9) I was initially like a miner asking the questions that would find the buried metal of the given knowledge of what brought him to hospice chaplaincy and then I became the traveller collecting and interpreting stories. I also had some laminated quotation cards: a definition of 'spirituality', a definition of 'spiritual care', a comment on the work of pastors and a statement of what is unique about a chaplain's work (Appendix G). These were to be offered to the interviewee for comment at the end of the interview, where appropriate and time-permitting. The source of the quotations was deliberately not identified as the definitions of 'spirituality' and 'spiritual care' had been used by AHPCC. It was intended that the quotations would act as a means of assessing interviewee's consistency, but I did not always use them.

Bearing in mind the constraint, mentioned earlier, of not being able to remove myself from the interview I endeavoured to adapt my role of enabling the

interviewee to speak to each person interviewed.[131] Empathy was needed to understand how the interviewee perceived his world but without creating the impression that our worlds were identical. Questions, where used, were designed to reveal the layers of meaning and whether the interviewee assumed these to be common to all hospice chaplains. Hermans (2000:210) describes the interview as a drama, explaining the need for the interviewer to consider how the interviewee wishes to present himself. I needed the interviewee to offer his perceptions and not what he perceived as the acceptable view (Gilliat-Ray, 2010:6) or what he thought he should say or what he thought I wanted to hear. Empathy was needed for me to portray the interviewee's perception of her world but I also needed her to explain the terms and expressions used. If necessary I asked her to explain another way or to give an example.

Each interviewee was asked permission for a follow-up phone-call if necessary and each received a thank-you email a few days after the interview. All the interviews were recorded and transferred to a secure computer with back-up hard drive which was stored separately. Recordings were transcribed as MP3 files on the same secure computer and on the back-up hard drive.

Planning the Interviews

The Pilot interviews

I termed the first interview I undertook 'the guinea pig' because when I mentioned, to a friend who is a priest, my apprehension at interviewing after a gap of more then twelve years she volunteered to be a 'guinea pig' first interview. As a curate, over ten years ago, she had had a small amount of hospice chaplaincy experience when the hospice had a temporary home in the community hospital whilst building work was being undertaken.

I planned two pilot interviews with a male and a female chaplain currently in post, Both interviews were arranged using email to suggest a date and time and both were possible within a day by driving rather than using public transport. They were conducted a week apart to allow for typing up the transcript and time for reflection. After the first of these interviews I replaced the quotation on the work of pastors with a quotation about evidence-based practice which was increasingly becoming a matter of concern (Appendix G)[132]. After the ninth interview I reviewed my script and quotations and added a further extract about personal spirituality.

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[131] Where the interviewee appeared to make an abductive connection I followed the interviewee. When I made an abductive connection I generally made a note on my script to return to the connection later in the interview.

[132] The original quotation elicited a tangential response.

The data from the two pilot interviews was so rich in thick description that they have been incorporated as 'proper' rather than 'pilot' interviews.

The Interviews proper

My aim was to conduct all the interviews by the end of November 2013, with a review at the half-way point of ten interviews. Following the two pilot interviews which became proper I used the findings from the Profile Survey to guide my selection of seven interviewees over the next two months. The first two of these interviews were two weeks apart in March, the next three were grouped together geographically and chronologically in April and the next two were the following week. The arrangements were time-consuming and in each case several emails were exchanged before mutually convenient dates and times were arranged. The group of three was particularly difficult to arrange as one of the chaplains was on annual leave and several phone calls were necessary as well as the emails. After each of the first two interviews there was time to reflect, transcribe and reflect again.

The next interview was with a chaplain who had offered to be interviewed. When making the offer he had said 'and whilst you're in my part of the world why don't you interview Eric as well,' giving an example of unsought for snowballing. They were in the same age range and of the same status but of different denominations. There was also a female chaplain in the area who fulfilled a number of criteria: age, denomination, status and length of experience. As I was able to stay with a friend who lived in the area, thus maximising the opportunity and minimizing the expense, I arranged to visit all three of these chaplains in the same week. I also tried to visit a fourth chaplain in the area but she was not available that week. In order to minimise travel I travelled to the area on day 1, conducted two interviews on day 2, conducted the third interview on day 3 and drove home that afternoon. It was therefore extremely important for me to note my immediate reactions to each interview as there was little time for reflection and no time to transcribe between interviews.

The remaining two interviews took place the following week– one with the employed chaplain and the other with a volunteer chaplain in the same hospice.

Immediately after each interview I noted my impressions of the attitude of the interviewee, the ambience of the interview, and any points emerging or that I wanted to follow up. Whilst typing up transcripts of interviews I noted common themes and individual passions.

Having conducted nine interviews I reviewed the script and the quotation cards and decided that in the next interview I would assess whether I needed more exploration

on the nature of personal spirituality and its connection with spiritual care. The next interview was already planned for June and it was with someone whom I felt I could encourage to reflect deeply. At the end of the interview he commented 'that was quite deep'. This surprised me as I did not feel that it had been particularly deep and I realized that I would need to be more alert to unanticipated preconceptions. Also in June a further sixteen chaplains were contacted and thirteen interviews were arranged in six different areas of England from Gosforth to Exeter to Margate and places in between[133]. In order to explore consistency of approach to their work I considered it important to interview non-Christian chaplains and therefore interviewed a Buddhist, a Moslem and a Jewish chaplain.

I was able to arrange some interviews on consecutive days to minimize travel. I tried to arrange three in the midlands on consecutive days but after much trial and error only two interviewees were available, whereas it was easy to arrange two interviews in the west country on consecutive days staying overnight in between and four in the north and north east over three days. These interviews took place in July and August.[134]

This number of interviews resulted in a lot of transcribing but even without transcriptions I realized that I was not finding new information. Themes might be expressed differently but essentially I felt that theoretical saturation had been reached. I also felt that I was tiring of the interview process and I yearned to have time to type up the transcripts and do some analysis. Nevertheless two final interviews were conducted in September and November.

Altogether I travelled some 3,600 miles to conduct twenty-five interviews for which the profile reflected the survey profile reasonably closely[135].

Transcripts, pen portraits and themes

I chose to type up the transcripts myself in order to maximise my contact with the data. Typing up the transcripts of the first interviews showed me the unwieldiness of the data in transcript format. Even with the elimination of 'er', 'um' and repeated words the transcripts were not easy to read nor did they always convey what I felt was the essence of the person or the ambience of the interview. I therefore wrote 'pen portraits' of the first twelve interviewees, using my notes from immediately after the interview, my impressions of the interviewee when we met and from the

[133] I have not included a map giving locations as most areas have only one hospice, making the interviewee identifiable and thus compromising confidentiality.

[134] My supervisor commented on my planning being like a military campaign – I had to plan it that way in order to ensure that I kept going!

[135] The guinea pig interview is not included in the twenty-five.

original transcript the sections which seemed to me to convey the essence of that person and how they viewed their work[136]. The writing of the pen portrait allowed me to omit repetition, bring together scattered comments on a subject, identify themes mentioned by other interviewees and, most importantly reflect on the interview.

Where relevant I used direct quotations from the interviewee but at other times I modified what I considered to be poor English so that for example:

> on that level um I think the circuit ministry um I was, I experienced as sometimes confining and um, what else, open-ended so you're living on the job.

became:

> on that level I sometimes experienced circuit ministry as confining but also open-ended because I was living on the job.

Where comments on a particular topic were scattered throughout the interview I gathered them together and summarized the viewpoint, as I understood it. These pen portraits enabled me to have a clearer picture of each interview, thus acting as a transition from transcript to analysis. After the first twelve interviews I reviewed the time taken to type up transcripts and then write pen portraits[137]. Themes had emerged such that for subsequent interviews I either wrote single paragraph summaries or vignettes of about a page, rather than pen portraits.

I undertook thirteen interviews in July and August leaving little time for typing transcripts.

Transcripts took several days to type up and the greater the time delay between interview and typing the harder it was to re-enter the ambience of the original interview. Some were easier than others and the observations noted immediately after the interview were helpful. However, even when I typed a transcript soon after the interview I sometimes found that I had questions. Some questions, for example a reference, were asked by email but for others I arranged a telephone follow-up for clarification.

The role of the researcher, reflection and the need for reflexivity

As the number of interviews increased and themes emerged I found myself reflecting on earlier interviews and wondering whether something that had been said was an aspect of a particular theme. For example: the concept of 'mystery', named as such, was mentioned by a number of interviewees. However, one interviewee had

[136] An example of a pen portrait is attached in Appendix H.

[137] Transcripts took several hours to type up and were usually between nine and twelve pages of A4. A typical pen portrait might take the same amount of time but would be half the length (Appendix H).

described her personal experiences in a way that suggested mystery but she had not actually used the word 'mystery'. By email I arranged a phone follow-up but did not tell her what I wished to explore. I was concerned not to put words in her mouth, nor to ask leading questions. I asked her to tell me a little more about her experience and without my prompting she spoke of 'being happy to sit with the mystery'. Later in the process, when considering the interpretation of the data, a similar everyday type of reflection[138] led to the realization that I wanted to know more about the concept of the emptying of the self. Again follow-up telephone interviews were arranged by email.

Reflexivity

Self-awareness is a crucial characteristic for any interviewer who is essentially the 'primary tool' in qualitative research (Swinton & Mowat, 2006:59 -61). Kvale and Brinkmann observe:

> When the person of the researcher becomes the main research instrument, the competence and craftsmanship – the skills, sensitivity and knowledge – of the researcher become essential for the quality of the knowledge produced. (Kvale and Brinkmann, 2009:84)

They use the term *phronesis* to describe the ability to recognize and respond to what is most important (61). Kelly refers to *phronesis* as the application of knowledge acquired in and through practice together with insightful understanding gained from experience (Kelly, 2012:36). He also makes the point that *phronesis* needs cultivating through the development of reflexivity and reflective practice with other people (36)[139].

Reflexivity gives depth to self-awareness. As I look thoughtfully at myself, it reveals my attitudes, how those attitudes may influence both the conduct of the research and the presentation and interpretation of the findings (Bennett & Lyall, 2014:198). It reveals the existence of the previously unacknowledged and the assumed, and may be painful. It is an essential aspect of the hospice chaplain's work as she seeks to step outside, or at least acknowledge, her normal frame of reference in order to walk alongside the patient in his framework[140]. For hospice chaplain and interviewer reflexivity is essential, personally, professionally, epistemologically and spiritually.

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[138] Which might be defined as giving serious thought to.

[139] At the time I was not aware of Flanagan's work on *quaestio divina*, with its process of reading (*lectio*), reflecting (*meditation*), seeking guidance (*oratio*) and being open to mystery (*contemplatio*) (Flanagan, 2014:134).

[140] Doehring (2011:68) comments on the paradoxical need for spiritual caregivers to engage in complex theological reflection in order to set their theological understanding aside.

On a personal level my experience of and interest in hospice chaplaincy inspired this research and it was therefore inevitable that my concerns would influence the nature and pattern of the interviews. Stanworth speaks of realizing that her own expectations as interviewer might prevent her from hearing what was actually being said by terminally ill patients, and the need to use what she termed a 'divesting' methodology[141] (Stanworth, 2004: 37-39). She also considers the Husserlian requirement of bracketing out preconceptions in order to prevent bias and preserve objectivity but observes that 'immaculate perception' is an impossible goal. She goes on to make the point that without her located-in-self perceptions she would not be able to differentiate between a knowing look and an empty gaze (55). In my case the located-in-self perceptions relate to both the personal, as explained by Stanworth, and the professional. I was concerned that my loss of professional status might affect the research[142]. If I were still in post as a hospice chaplain I would have been regarded as an insider and interviewees would have responded in a particular way, perhaps making assumptions about shared experiences and values. However, I was no longer in post but had not left the scene entirely so I was no longer a 'proper' insider but reactions from those who attended AHPCC Conference that year, 2012, indicated that I was not yet seen as an 'outsider' either. Gilliat-Ray observes (2010: 12) 'empirical researchers are rarely complete insiders, nor complete outsiders, but usually somewhere in-between'. Balancing those two positions, finding a middle path, required reflection before, during and after each interview. Before starting to interview I needed to be comfortable with how I saw myself: a researcher with experience in the field of my research.

Just as I needed time for personal reflection after each interview, recording my observations in my research diary or my spiritual journal I also needed time for professional reflexivity. I arranged for my external supervisor from my hospice days to provide supervision during the period of time when I was conducting the interviews. I regarded this type of intentional reflexivity as a necessary part of my duty of care to both interviewees and myself, as well as a process necessary to the development, transcribing and presentation of the research. Reflexively I considered how I experienced myself, how I experienced the interviewee, how the interviewee experienced his or her self and how the interviewee experienced me. In the case of the interviewee's experience of his or herself I could only reflect on what he or she

[141] For example she had assumed that the terminal diagnosis would be the worst thing that had ever happened to the patient but divesting herself of that assumption she heard that the worst thing was the break up of the marriage.

[142] Organizational change in the hospice where I had worked resulted in my early retirement.

made available to me and my observations of body language[143]. Similarly the interviewee's experience of me was confined to what he or she shared and what I perceived through body language.

However reflexivity also requires that the researcher is aware of her effect on the process and outcome of the research. There was the possibility that an interviewee would reverse the focus thinking that I was in need of support because of my unexpected early retirement and finding myself interviewing chaplains rather than being a chaplain. In the event this was not an issue: apparently I was accepted as a researcher, and interviewees talked about their work at length. Even so, I acknowledged that an interview might trigger concerns not yet recognized (Ahern, 1999:408) and I noted these as they arose in order to be able to recall and reflect. Hughes (2006) stresses the value of retrospective reflection, which I found particularly relevant for issues of control in one interview, issues of transference in a couple of interviews, and recapturing the ambience of each of the interviews. Reflection on the interview in which I felt there were issues of control was difficult. In my previous dealings with him he had appeared confident, sometimes assertive. This was the only interview in which I could have felt like the audience. In the other interviews, even when an interviewee talked spontaneously the ambience was of sharing – a shared space, a shared purpose and a working together to elicit information. This interviewee had decided beforehand what he wanted to say - and he was going to say it! When I had first proposed undertaking this research he was one of those who had been dismissive, saying that everybody knew what spiritual care was, so was I reacting to his dismissal or was he manifesting 'not-invented-here' syndrome? Or was he trying to prove something? Only at the final draft stage did it occur to me that whereas other interviewees had responded well to the reversal of role, of being asked to talk about themselves and of being listened to, he may have been out of his comfort zone.

Intentional retrospective reflection on each interview enabled me to acknowledge where the interviewee had cast me not as interviewer but as confidant and I needed to check that I had not accepted and retained any of this material. I also needed to reflect on the nature of the interaction. In one case his body language when I met him said he was not happy and he asked me to turn off the recording machine in

[143] Non-verbal behavior in which thoughts and feelings are expressed in facial expression, tension or fidgeting in limbs, or bodily movement.

order to 'explain his current position'.[144] In retrospect I felt that he was fully aware of the role change that this implied and once he had finished his explanation he was happy for me to switch the machine back on and return to being interviewee and interviewer. In the other case I felt that her personal and work life were inextricably interwoven and I wondered whether she was conscious of the extent of the entanglement and whether she was aware of how she was handling it. However, there was no time for my intentional reflection or the conscious making of a plan. Rather 'embodied reflection' (Schon, 1983:49)[145] enabled me to find a path that fulfilled my research requirements but also allowed her to say that God was encouraging her to take care of herself.

Epistemological reflexivity explores the way the research question has affected the method of research and the data presentation. It reveals the assumptions made during the course of the research (Swinton & Mowat, 2006:60) and leads to the consideration of how such assumptions might colour the presentation of the findings. For example my awareness of the concepts of disenfranchisement and empowerment[146] might colour how I interpret and present relevant data. That awareness cannot be removed although it may be acknowledged and used to assess data and then included or excluded. Equally such an awareness may be the reason for considering data in a particular way which would not occur to another researcher.

Spiritual reflexivity was necessary because this research explored the nature of the interviewee's own spirituality and his understanding of its relation to his work. Therefore discerning listening skills, spiritual self-awareness and awareness of and sensitivity to spirituality outside my own cultural, religious, denominational and personal practice were necessary both during the interview and in retrospective reflection. There was also a need for awareness of and sensitivity to the language used to express spirituality and spiritual experiences, acknowledging that this might be religious language, using words such as God, redemption, disciple, gospel, or it might not.[147] Therefore I was reflecting on my ability to discern that the interviewee

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[144] I was aware that this changed the dynamic of the interview relationship and that he was relying on my sympathy to allow him this opportunity to give me background which I could not use. However, he later described the same situation in different words without asking for the machine to be switched off.

[145] Occurring as part of professional practice (Kinsella 2007: 408, 2010: 571), without reference to scientific or pragmatic knowledge, such reflection had been crucial to my professional practice as a hospice chaplain and it was apparently equally important for interviewing.

[146] Outlined earlier in this chapter.

[147] The language used to express spiritual awareness is explored in Chapters Six and Seven.

was describing the spiritual regardless of the nature of the language used and regardless of whether he described it as a spiritual experience[148].

Data Analysis

Analysis of the online Profile Survey of hospice chaplains was the means by which the population for the research was established. Details of the survey are given in Chapter Four and a poster presentation of the findings is included as Appendix I.
To explore and analyse the role of the hospice chaplain I used data from: my notes made immediately after each interview, the recording of each interview, the transcript of each interview, my notes from follow-up telephone conversations with interviewees, my reflections as I typed transcripts and pen portraits, reflections throughout and after the interviews and reflections whilst writing this thesis.
In their paper on interpretive adequacy Altheide & Johnson (2011:593) quote the artist Paul Klee: 'a line is a dot that went for a walk', commenting that they are trying to capture the intersection of many lines, made up of many dots, which are all going in different directions. Their concern is how to interpret the lines, and dots, so as to reflect meaning for both an individual participant and for the overall group. This seems a valid representation of the researcher's position when first considering all the transcripts. The overall picture would be made up of smaller pictures but were those pictures to be of individual chaplains or of stories told by chaplains or of stories and pictures used to express the concepts in the research questions or a mixture of all of these? It seemed likely that some of the individual pictures would convey an element of disempowerment, whereas the overall picture might convey creative searching.
Various levels of analysis were possible:

(i) thematic analysis of concepts as individual words or phrases. A list was started whilst conducting the interviews. Common themes were noted and consciously listened for in subsequent interviews. The word-search facility in Word on the Mac OSX 10.6.8 operating system enabled the scanning of both transcripts and pen portraits for specific words or phrases. It was also necessary to explore whether a concept was being spoken of with different words, or as mentioned earlier was spoken of without being named.

(ii) analysing the understanding of specific topics and terms, such as 'spirituality', 'spiritual care' and 'chaplaincy'; the nature of the chaplain's spirituality and its relevance to his work; what he perceived to be his unique contribution to spiritual

[148] This is a crucial aspect of spiritual care in hospice chaplaincy.

care and the theology underlying his understanding; the understanding of the hospice ethos.

(iii) treating each interviewee's story holistically, analysing: the spontaneous versus the prompted; the visual or 'performance' aspect of the interview; the language, metaphors and pictures used to convey the story; the threads that run through the account[149].

(iv) analysis of the stories interviewees told within their own story. Following Van Maanan (1988) these might be confessional, impressionist, literary or realist in nature[150].

(v) a 'factual' analysis over all interviewees reporting the ethos of the institution, the position held by the line manager, whether management had changed recently.

(vi) cross analysis of, for example, the factual analysis of (v) with the nature of the stories in (iv) or the understanding of the terms in (iii) with the stories in (iv).

By applying these possible types of analysis to the data I learnt that some were more productive than others. Thematic analysis was possible after conducting just a few interviews because common themes emerged. Analysis of interviewees' understanding of terms such as 'spirituality' and 'spiritual care' was relatively straightforward, but the term 'ethos' was not readily understood by all. A factual analysis of the position of the line manager was included in the material on ethos. An analysis of an interviewee's story might yield metaphors and pictures but was otherwise not as productive as thematic analysis. Analysis of stories told within the interviewee's story revealed the metaphors and pictures already discovered from the overall story. Neither type of story analysis yielded enough material to warrant cross analysis. There were, however, two themes which emerged, discerned by the halo effect, from my reflections during the course of interviewing[151]. One was the significance of the transformation of personal tragedy and the other was the leaving of self at the door. Both occurred during the first group of interviews so I was able to listen for and explore these ideas in subsequent interviews. However, only when writing the chapter presenting the data did I realize that leaving the self at the door might relate to emptying or *kenosis*. Neither term had been used by interviewees but further exploration would reveal whether there was a connection. Therefore I used the word-search facility to find similar material and subsequently arranged

[149] That this type of case-centred analysis would be more or less helpful than thematic-centred analysis (Thomas, 2008: 428) seemed unlikely given the list of common themes that emerged during the interview period.
[150] In the event there were few stories within the story.
[151] Halo effect is an aspect of stage six of the method described earlier.

follow-up telephone calls to four interviewees. I wondered whether I should have tried to explore further in the original interviews but given that each interview lasted an hour and a half, and sometimes more, decided that it would not have been fair to the interviewees – or me!

A further example of knowledge emerging in the process of writing occurred in the application of Brueggemann's work on the Old Testament prophets to the data. This exercise revealed aspects, such as the evocation of alternative perception, not apparent in the straightforward presentation of the data - which itself is such an evocation. Similarly, only when writing up the concept of presence were the connections between the chaplain's integrity in the quest for union with God and the ambivalence to providing evidence for her work revealed.

Summary

My initial project title related to establishing how hospice chaplains understand spiritual care and chaplaincy. Recognizing the static nature of such an enquiry I acknowledged that I wanted to know how chaplains understand their work. Using data gained from guided interviews I would be able to paint a picture to answer this question. The methodology was ontologically constructivist rather than objective and epistemologically interpretive. There was no hypothesis to test but themes or a theory might emerge. I considered that an awareness of the value of critical theory in empowering the voiceless might be helpful and that various types of narrative analysis would need to be explored. I therefore felt the need to be flexible and that like Denzin & Lincoln's bricoleur (2011b:5) I might mingle or synthesize paradigms and perspectives. This was not saying that 'anything goes' for underlying the entire work was my understanding of people as spiritual beings and I conducted the research grounded in my own sense of spirituality, my own sense of the presence of God. It was this grounding that sourced the ability to 'think from the narrative lives of others' (Anderson, 1999:15). Narrative has been described, amongst other things, 'as the core element in an interpretive and constructionist methodology' (Stanley & Temple, 2008: 275) and predominantly narrative methods of analysis were used: thematic, structural, performance, and visual.

However, the first step in conducting this research was the Profile Survey of members of AHPCC. The report on this survey is presented in Chapter four and Chapter five presents the interview data.

Chapter Four: The hospice chaplains' profile survey.

Introduction

As preparation for selecting interviewees a voluntary online survey was conducted to establish a basic profile of the membership of the Association of Hospice & Palliative Care Chaplains (AHPCC). The survey also included a question on willingness to be interviewed. This was the first time AHPCC had collected data from members and this is therefore the first profile of hospice chaplains. The profile enabled the selection of interviewees to be representative of the AHPCC membership.

The survey, which was piloted before inviting all members of AHPCC to take part, asked for information on: gender, age, faith group, denomination if Christian, status if Church of England, job title, employment status, number of hours worked, number of years in Hospice Chaplaincy, length of time in present post, areas of training, geographical location[152], willingness to be interviewed and the ease or otherwise of filling in the questionnaire. Every member of AHPCC received a personal email giving an explanation and the link to the survey URL which was facilitated by Bristol Online Survey through St Mary's University (see Appendix A).

The survey was launched on September 24th 2012 and closed on July 14th 2013.

The expectation of response level was difficult to establish. Professional people are generally reluctant to respond to questionnaires even when their company is supportive. Even when incentives are offered a 50% response rate is held to be good.[153] Spam filters are assessed as eliminating 9% of emails and inaccurate email addresses would lose a few. I hoped to receive 50 responses.

Over a three-day period, in September, personalized emails were sent out to some 150 AHPCC members and there were 50 responses in the first two weeks[154]. Thereafter the response rate slowed and the following three weeks saw sixteen further responses. Since the majority of respondents were happy to be interviewed and gave appropriate details it was possible to eliminate these from the list and email those who had not responded with a reminder in November 2012. Twelve new members were also emailed at this point, bringing the total number of approaches to 162. By January 2013 there were 93 respondents, 79 of whom were happy to be interviewed. The survey was closed in July 2013, by which time there were 108 respondents, 91 of whom were happy to be interviewed. Reasons for not wanting to be interviewed were not requested but a few respondents wrote in the comments

[152] Geographical location is not reported in order to maintain confidentiality.
[153] Information obtained from a Consultancy firm specializing in human resources information dissemination and retrieval.
[154] The email was sent as an AHPCC membership mailing.

box that they were returning to parish ministry, going on sabbatical, or short of time.

The findings

Table 1 shows that the 162 members of AHPCC are evenly split between male and female. 108 of the members responded to the survey with a slightly higher response amongst males (60 or 55%) than females (48 or 45%). Willingness to be interviewed was expressed by over 80% of both males and females. The majority of respondents, 93, are located in England with seven in Scotland, five in Wales and three in Northern Ireland. The data presented in this chapter is based on all 108 respondents.

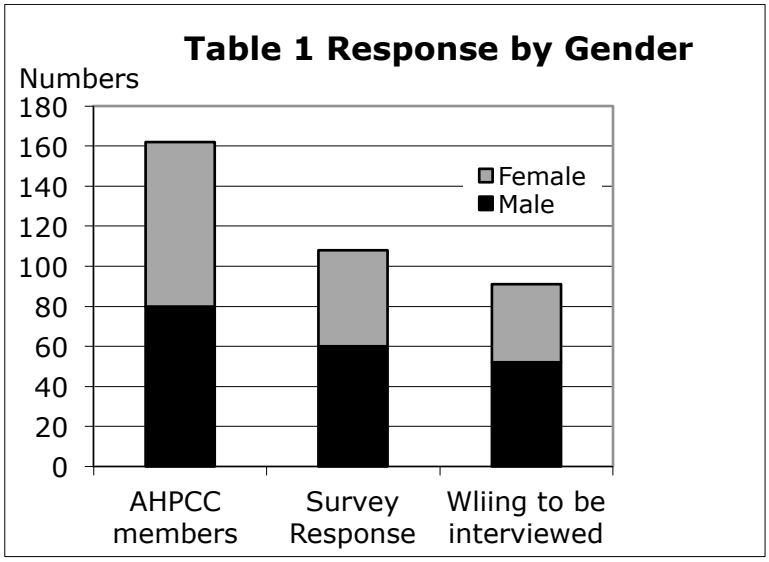
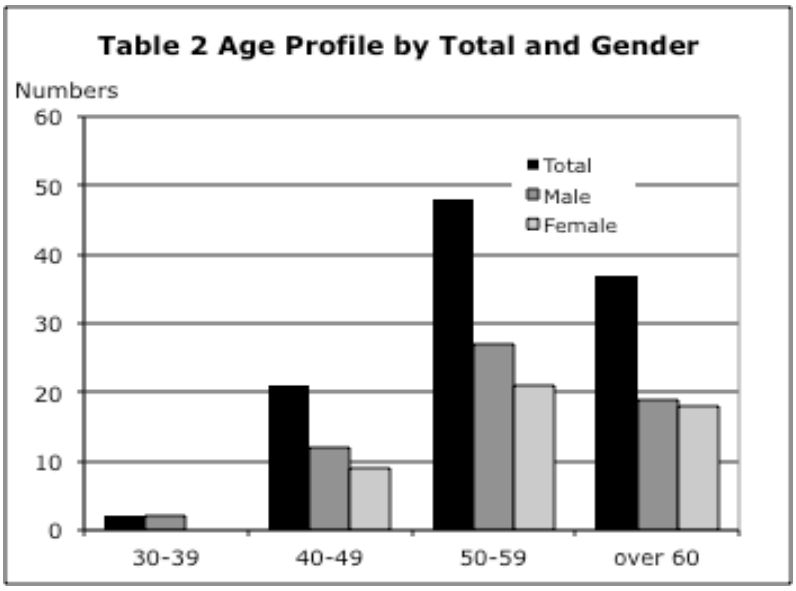
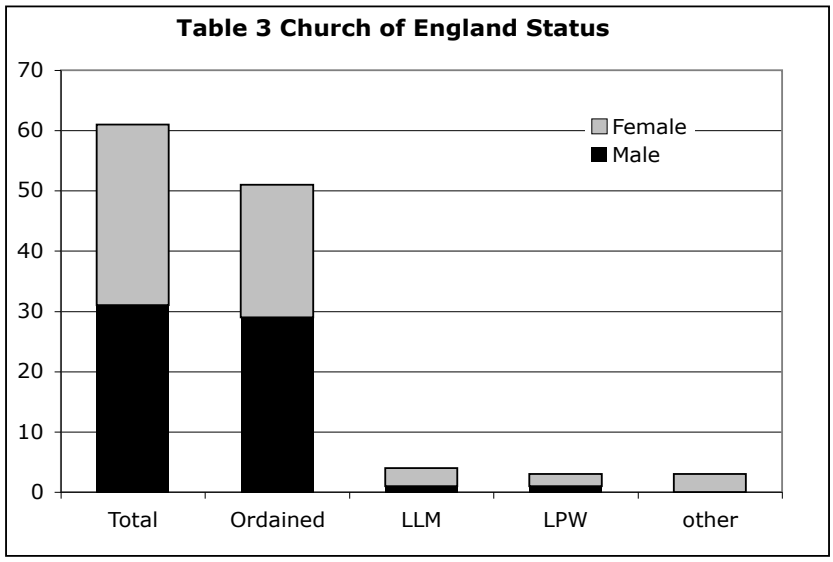


Table 2 shows that the majority of survey respondents, 85 out of 108, were over fifty years of age. Only twenty-one were aged between 40 and 50, and of these twelve were male and nine female. Forty-eight were aged between 50 and 60, twenty-seven males and twenty-one females, and thirty-seven respondents were over 60, nineteen males and eighteen females. This age profile, 79% of respondents being over 50, is similar to the age profile of hospital chaplains[155] but contrasts markedly with the age profile of the workforce in the healthcare sector based on the 2001 Census (Yar, Dix and Bajekal, 2006:47). Over 60% of the healthcare workforce, both male and female, are under 44 years of age and over 80% of males and 90% of females are under 55 years of age.

[155] Data obtained from CHCC's kindly supplied membership profile which consists of a list of the dates of birth of members in random order.



All but three of the respondents were Christian, and of these sixty-one were Church of England. The other denominations were Methodist (9), Baptist(12), Roman Catholic(7). The remaining sixteen respondents were from the Church in Wales, the Church of Scotland, Scottish Episcopalian, Salvation Army, Congregational and Fellowship of Independent Evangelical Churches. The Anglicans were evenly divided between males (31) and females (30) and the majority, fifty-one, were ordained, as shown in Table 3.



However, Table 3 also shows that ordination was higher amongst males than females with 29 out of 31 males ordained whilst the figure for females was 22 out of 30. The other Anglicans were four Licensed Lay Ministers (also known as Readers), three Licensed Pastoral Workers and three unspecified others.

The most commonly reported job title, by 38 males and 35 females, was Chaplain. Only nine respondents were designated Spiritual Care Co-ordinator, and three Spiritual Care Lead with nineteen different combinations of these terms. However four of these variations included both Chaplain and Spiritual Care in the job title and three titles included a reference to bereavement.

The employment status of the 108 respondents is shown in Table 4. More than two thirds are employed by an independent hospice, thirteen by the NHS, ten are volunteers, eight are employed by various arrangements[156], and one has a contract for services.

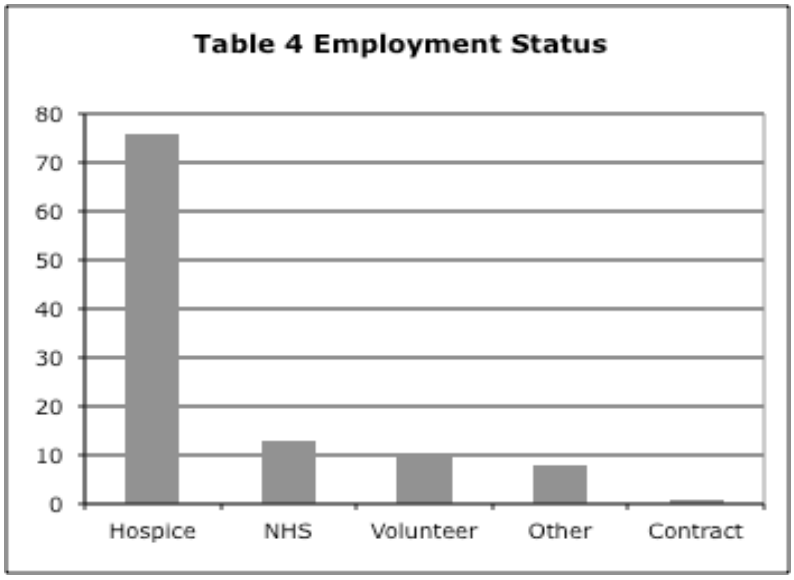
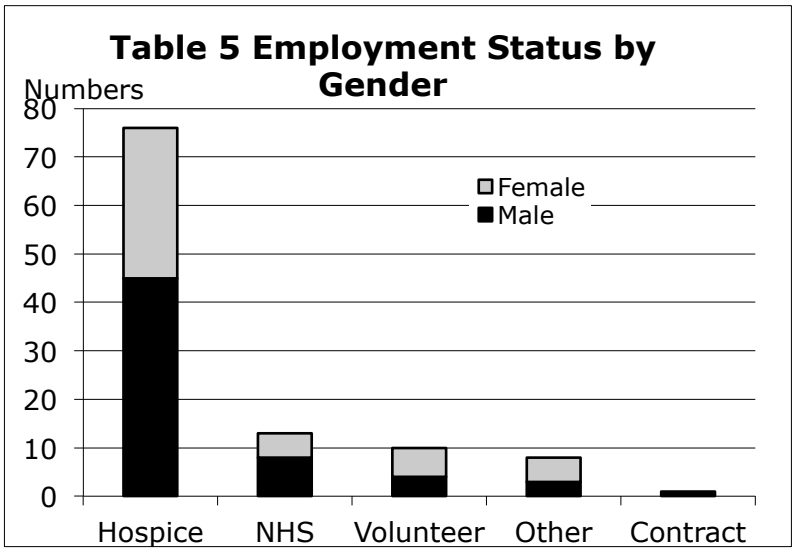
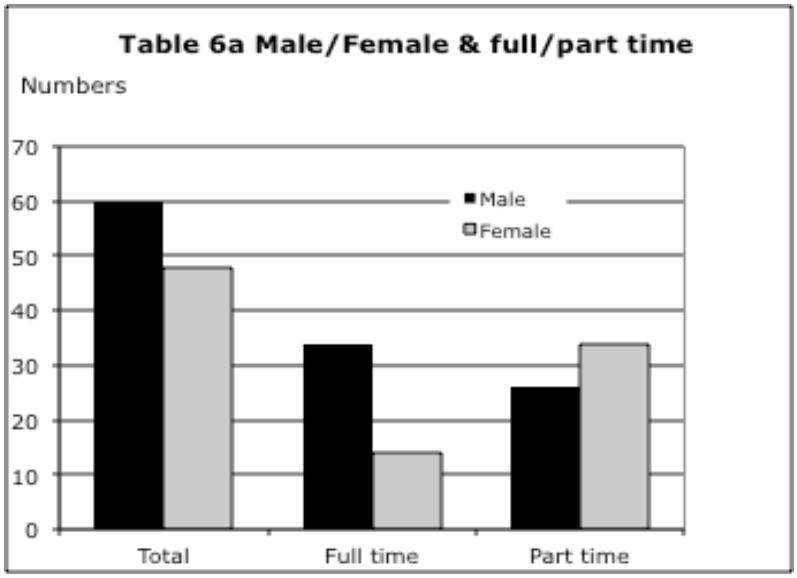


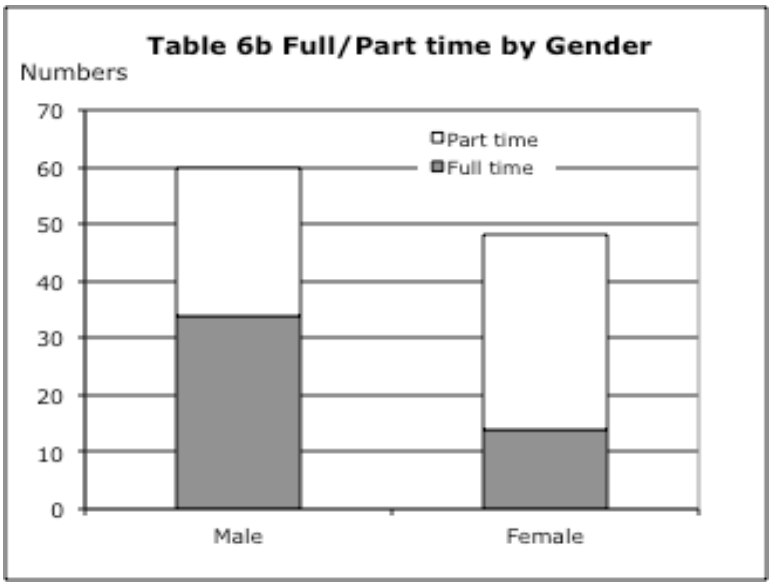
Table 5 gives the gender breakdown of the employment status showing that of the sixty four employed by an independent hospice, 45 are male and 31 female. Of the thirteen employed by the NHS, 8 are male and 5 female. Seven of the volunteers are female, three male and of the eight employed by various arrangements five are female and three male. The single contract for services is male.

[156] Arrangements such as the hospice paying the Diocese for the part-time services of a chaplain who also works in a parish; all or part of the chaplain's salary coming from a special charity; a service level agreement between independent hospice and NHS.



The split between full-time and part-time chaplains and the gender breakdown within each category is shown in Table 6a. The breakdown of full time and part-time within each gender is shown in Table 6b. There are more part-time (60 or 56%) than fulltime (48 or 44%) hospice chaplains, which is the reverse of the situation for hospital chaplains, 36% of whom are part-time and 64% full-time (CHCC Annual Report, 2011/2012:4). The full time respondents to this survey are more likely to be male, (34), than female,(14). Amongst the part-time respondents the reverse is the case with fewer males, (26) and more females, (34).





Respondents were asked to indicate areas of training from a list: counselling, psychotherapy, spiritual direction, pastoral care, none of these and other, which they were asked to specify. Most frequently mentioned, by three quarters of respondents (84 or 78%), was pastoral care[157]. 45 listed counselling, 39 spiritual direction and nine psychotherapy. There were eight chaplains who owned to none of the list. However 40 other trainings were mentioned, including bereavement, palliative care, listening skills, nursing, pastoral supervision.

The majority of respondents, 93, are located in England with seven in Scotland, five in Wales and three in Northern Ireland.

Just under half, 49, of respondents had joined UKBHC at the time of the survey. Twenty-eight respondents also belong to the College of Health Care Chaplains (CHCC), and five also belong to Scottish Healthcare Chaplains (SCH). All respondents found the questionnaire either easy or straight-forward to complete.

Summary

There was little surprise in the finding that membership of AHPCC is predominantly Christian, with the Church of England at 61 out of 108, being 56% of all members and 58% of Christian members. However, the most revealing aspects of the survey were that only two respondents were under the age of 40 and the fact that 85 out of 108 members, that is 79% or four fifths, are over 50 years of age. The male/female split is slightly less than equal at 60 and 48. The full time/part-time split is 48 to 60.

[157] It was hoped that respondents would indicate specialist training in these fields but interviews have revealed that some have included fields that were part of a theology degree or part of general ministerial training.

Females have more part-time than full-time positions and males have more full time than part-time. There were only eight volunteers, with the majority of respondents employed, the most common job title being Chaplain. The results on gender, age, hours worked, faith group, job title and nature of employment were presented in poster format at the 2013 Postgraduate Conference at St Mary's (see Appendix I). The training qualification most frequently undertaken is pastoral care, followed by counselling and spiritual direction. In view of the work of UKBHC, of which AHPCC is a part, towards the professionalization of chaplaincy the level of uptake of UKBHC membership, 49 out of 108 or 45%, appears low. The willingness of 91 respondents, 84%, to be interviewed is a good and pleasing response level.
Influence of these results on the topics to be included in the interviews was confined to the age profile which invites the question 'why?' Therefore interviewees were asked their opinion on the reasons for this profile.
My concern to ensure a good geographical spread of interviewees across England was guided by the results of the Profile Survey and the next chapter presents the data collected in the interviews.

Chapter Five: The data from the interviews

Introduction

In order to explore and analyse the role of the hospice chaplain I wanted to hear the chaplain's own story – her past experience, how she came to be in hospice chaplaincy, how she understood and practised spiritual care, how she was sustained in that work, the nature of her own spirituality. These were all aspects of the overall picture, which were gleaned from twenty-five guided interviews[158]. At the end of chapter three I described various possible methods of data analysis. As the interviews progressed I was aware of emerging themes so thematic analysis was the primary analysis undertaken. However whilst the term 'theme' implies more than one appearance, preferably several appearances, it is possible that issues with only one appearance may be important to the overall analysis (King & Horrocks, 2010:149). In identifying themes I was careful to preserve the integrity of each interview and not alter or amend what is said. Equally I had to avoid shrinking from presenting a dissenting voice. Themes, and single-mention issues, contributed to the overall picture, aspects of which began to emerge whilst conducting the interviews. The experience was akin to doing a jigsaw without a picture for guidance. Therefore further reflection, described in Section Three, was necessary to consider the interpretation of the data. This chapter presents the basic pieces of the jigsaw, the data collected from the interviews. However, there are some relevant points from the initial 'guinea pig' pilot interview which are presented first.

The 'Guinea Pig' Interview

Material gathered in this interview was disappointingly thin – a point subsequently brought home to me by the two planned pilot interviews, which were rich in thick description[159]. However, the 'guinea pig' pilot interview with Mary drew my attention to practical issues, such as the use of the recording machine, and to matters of relationship, power and the ability to engage with the questions. Mary had had a small amount of hospice chaplaincy experience as a curate ten years previously. Her one abiding memory was of a gentleman who spoke of dying as 'going to Brighton' and he explored with her what this might be like. On reflection I felt that, although she engaged with the questions, her answers were thin due to the time delay and the limited nature of her experience, which was as a parish curate visiting the hospice rather than as a hospice chaplain. Should one of my selected interviewees

[158] The data from the guinea pig interview is given separately.
[159] These two interviews were so rich in 'thick' description that they are included as 'proper' interviews.

perform in similar fashion I would need to decide whether to curtail the interview – in the event that was never an issue. Mary had no knowledge of criteria for spiritual assessment so after the interview I explained that there are a variety of tools to help staff explore how the patient is being sustained, what gives him the strength to stay with the pain, how he is adjusting to illness-induced changes, whether he has existential or religious issues he would like to talk about[160]. I told her a story (text box) from my own experience, to illustrate the nature of spiritual assessment. That the story made quite an impact showed in her body language[161] which reminded me that an interview is not just what is on the recording machine. Body language, facial expression and interaction between interviewee and interviewer all required my attention.

A Day Hospice patient gradually lost his mobility so that he could no longer walk his dog, which had previously given him a sense of purpose. The nurses picked up on this as spiritual pain but as the dog was still alive and featuring regularly in his conversation I felt there was more to it and asked him where he had walked the dog. 'oh, down the road. At the end there's a path to the woods.' There was something about the way he spoke that made me encourage him to explore what walking in the woods meant to him and I then suggested that with his son's help he could still visit the woods, albeit in a wheel chair. He then told me his son was taking him on holiday to Devon. When he returned he described the house he had stayed in – upside down with the living room upstairs and a balcony which took the wheel chair. As the house was in the woods, sitting in the chair on the balcony was marvellous! He returned from holiday more like his old self, never mind the wheelchair.

The Interviews

I began each interview with a recap on the data given in the online survey and I obtained permission to record the interview. My first question was a general question on how the interviewee came to be in hospice chaplaincy. Most responded in detail and some actually covered topics without my prompting. Where prompting was necessary the question was not identical from one interview to another. Some interviewees talked easily and in so doing demonstrated how they understood their work and the concepts of spirituality and spiritual care and others needed questions to stimulate and guide them. The quotation cards were used where necessary, appropriate and time-permitting and queries and omissions were followed up by email and/or telephone.

[160] Spiritual assessment is too wide-ranging a subject for further discussion here.
[161] Explained in chapter three as non-verbal behavior in which thoughts and feelings are expressed in facial expression, tension or fidgeting in limbs, or bodily movement.

The data is presented in two sections, the first focusing on the chaplain, the second focusing on the hospice. The first section begins with data on how the chaplains come to be in hospice chaplaincy and, where relevant, their thoughts on the difference between congregational and hospice ministry. I then report Church connections and how they think the Church sees their role, followed by what chaplains wear and how they introduce themselves. Then chaplains' perceptions of the patients' expectations are followed by views on training and life experience. The section culminates in the chaplains' understanding of the concepts of spirituality and spiritual care in relation to their work and their understanding of their own spirituality. The second section focuses on the hospice, its ethos, the need for evidence and issues related to recording in the patients' notes and the use of spiritual assessment tools.

The data about the chaplain

How the chaplain came to be in hospice ministry

Chance or serendipity[162] played its part for several hospice chaplains. For Doreen it was a part-time opportunity when her children were small, for Norman an advertisement on the Diocesan website appeared just at the time he was looking for something to complement his existing ministry. Timing was mentioned by several chaplains - there was no stipendiary post for Beth and a friend told her about the hospice job: 'I said oh, no, no, no, that's not for me because actually I still do feel called to be a parish priest,' but other doors closed so she put in an application, went for an interview feeling 'unsure whether God was calling me or what…' and got the job. Having worked in a hospital she had not wanted to be a hospital chaplain as that would 'blur the boundaries' but she found that becoming a hospice chaplain was entirely different. She was amazed at how spiritual the hospice was, full of light and energy and 'it is the most wonderful, joyful lively place I've ever worked in.' Charles said that he thought that God in his wisdom and with his sense of humour, 'invites us to confront things that we don't wish to confront but need to confront, like our mortality.'

For several interviewees the interview process itself was a tool for discernment. Some described being encouraged by friends to apply for the job, others needed a paid job when they moved house for family reasons. Eric described how he had

[162] A word coined in 1754 by Horace Walpole, who built the gothic villa Strawberry Hill House which is now a feature of St Mary's University campus. The concept describes an ambiguous process of discovering something unexpected and unlooked for. The ambiguity lies in the absence of definition of the roles of luck and the skill of the searcher.

fancied a move but had not really been looking when friends advised him that the hospice had advertised. Then they told him the advertisement was withdrawn so he assumed that, from a Godly perspective, it was not right for him. Then the same friends persuaded him to visit the hospice and he was asked if he would like an application form – they were about to advertise again. He was the only person short-listed for interview and the date was changed for his convenience. He felt that the job had chased him and it was right to accept it when it was offered. For others the first experience of healthcare chaplaincy was a placement during training, for some their original hospice role was part of congregational ministry, and some did voluntary chaplaincy work alongside congregational ministry before becoming paid chaplains. Several, like Tracy, were prepared to have a go when asked. She had started as a part-time volunteer and gradually over twenty-five years increased to a full-time post. Her journey into full-time hospice chaplaincy is in the text box.

Tracy came into hospice work slowly, starting as a volunteer whilst still responsible for several congregations. In her next post a member of the congregation, a trustee at the local hospice, invited her to look round with a view to doing some free-church chaplaincy - 'which I'd never entertained or even thought about'. She had: 'no training or anything to give me credence to do the job – just a sense of it being a good idea so have a go. I began very tentatively, going along one afternoon a week. From just that I found the atmosphere, the welcome, the rapport that began to develop, felt very comfortable.'
Later she was offered and accepted a twelve-hour-a-week paid post. Then, eight years ago, she and her husband moved and she was appointed to the full-time post at her present hospice.

Only one chaplain, Queenie, described feeling something akin to horror when she was asked to give a few hours a week to the hospice:

> my first reaction was 'I couldn't possibly do that – it's all full of death and dying and that's not me' but actually once I got here it just began to feel as if it drew on so many previous strands of my life, and various gifts that I have, and began to feel more and more right.

The chaplain's view of congregational versus hospice work

As part of the introductory questioning I asked interviewees, where appropriate, to compare congregational work with hospice work. All but two of the interviewees had some degree of experience of working with a congregation and eight were still involved in congregational-based ministry. Responses were mixed with some saying that both situations were pastoral, some saying congregational work had more variety and some saying hospice work had more variety.

Beth had responsibility for a congregation, splitting her time between them and the hospice and saw little difference in the nature of the work: 'In a way the hospice is a parish of its own'. Xelda did not have congregational responsibility but said 'my parish is the hospice'.

For several years Doreen had had a foot in both camps – church-based ministry and hospice chaplaincy. Her description of the two main differences of dynamic and buildings was heart-felt, clear and succinct. She stated that the Christian nature of church-based ministry is not found in chaplaincy: 'people are people of any faith or *no* faith, (her emphasis) and you simply work with that so that's a very different sort of dynamic'. Ian also commented that in the hospice he was involved with the spirituality of everybody, regardless of race or religion whereas in Church the involvement is primarily with Christians. On buildings Doreen said:

> when you're in a church-based ministry so much time and effort can be taken up with building schemes and what happens when the roof blows off

so the absence of such responsibility was very liberating. Yasmin mentioned buildings as part of the bureaucracy which she hated. Being restricted by the congregation's willingness, or otherwise, to accept change was hard work and whilst the hospice work was also hard there was a freedom to it as she was not involved in management and the patients were not demanding in their expectations – when in a parish she had sent a pastoral worker to make visits but the parishioner wanted the vicar! Congregational ministry was described by several interviewees as task-oriented whereas hospice ministry was agenda-free, about being rather than doing[163].

Yasmin, Xelda and Tracy all felt that relationships in the hospice were built more quickly than in a congregational setting and to a greater depth. However, Yasmin also observed that hospice relationships were also built over time and lasted longer than relationships in the church which were often fleeting: as vicar she was expected to take a funeral but the family did not want any contact afterwards. Larry said that he had shared 'more conversations of a spiritual nature since working in hospice chaplaincy' than he ever did working in church-based ministry. Tracy also found it wonderful to have 'pastoral conversations that are significant and demanding'. Xelda observed that she didn't think congregational work got to the same depth quite so often, but also some such relationships were likely to be much longer term. Queenie contrasted the broadness of spiritual care in the hospice with 'the shepherding of the flock' in the church. Greta spoke of church-based ministry as being for a specific

[163] This will be explored further in a later section.

audience who have 'chosen to attend your church, sit in your pew and accept you coming into their home'. Like Yasmin she mentioned their expectations and that they will let you know if you step outside what they understand to be your remit. For Eric that remit included a responsibility for the congregation that was not found in hospice work but the latter was a greater challenge, much more on the front-line because he was meeting people at a significant point in their life's journey.

For some chaplains the difference between congregational-based and hospice ministry was personal. Fred found congregational ministry lonely and the weight of responsibility for the cure of souls was tremendous. He had felt stifled by the congregation's expectation that he would have all the answers whereas he found chaplaincy, characterised by 'a sense of inadequacy and an inability to answer questions', actually freeing and creative. He felt that the hospice was the coal-face of what life is about but it was also the place where he could truly be himself rather than trying to fit the model expected by the parish. Fred also described church-based ministry as 'living in a bowl' and Charles said it was like 'living in the shop', unable to separate ministry from personal life. He too felt he was 'more myself' in chaplaincy than in church-based ministry. Larry and William also felt less constrained in hospice work. Contracted hours enabled Keith to shut the door and be with his family which was wonderful:

> … in the parish I was trying to bring up a family of three girls and I just felt as if I was this guy who was around in the house but really I was so busy most of the time 'not now dear, later, because I've got this meeting' - loads of meetings in the house, phone always going, meal times the phone was always going… as they came into early teens I was there, I've been able to be very much more present in their development as young adults…

Tracy also commented that it was wonderful to have boundaries. However, Oliver commented on the contained hours but he was struggling to adjust to having to build relationships in part-time hours rather than being available twenty-four seven as he had been in congregational ministry.

Another difference between congregation-based and hospice ministry was the nature of the support available for the minister. In congregation-based ministry, across the Christian denominations, support was not readily available nor was supervision part of the culture. Doreen commented that in her previous church-based ministry there was no regular professional supervision but in hospice work she goes to supervision every month and is much more disciplined about reflecting in a fairly structured way on what she is doing and what it is doing to her. Most interviewees with congregation-based experience found support in those congregations but had to find external supervision for themselves. Beth, with congregation-based as well as

hospice responsibilities, stated that her diocese was very supportive, but she recognized that this was unusual. Ian has external clinical supervision and engages in theological reflection with his local ministry colleagues – and yet commented that the interview facilitated a depth of reflection not found in either of those. Keith reported that support in congregation-based ministry was patchy at best:

> There were some appalling situations of not experiencing the sort of support I would have expected from the church which did leave some pretty deep scars. Some of the support was crass – inappropriate, not meeting need.

Norman commented that nothing was offered by the church but the hospice more than made up for that with both external chaplaincy supervision and internal clinical supervision. Alan received both internal and external supervision saying:

> we have an external supervisor as well so if I ever had any problems with management then I've got somebody who comes in from outside so I can whinge about how awful the management is, but I have to say the management is very good.

Martin commented that external supervision kept him sane but observed that the sharing of stories helped get some experiences out of his system, and writing pieces and articles helped him address issues in an intellectual, less spiritual, way.
Fred was very relaxed about supervision. The hospice offered both internal and external formal supervision but he chose informal external supervision, sometimes a telephone conversation with a peer. He recounted being criticized by other chaplains who could not understand how he managed without regular formal supervision. In contrast Greta was passionate about spiritual self-care saying 'if a chaplain loses sight of his own spirituality how dare he sit by the bedside of others to encourage them to discover their own spirituality'. William quoted a speaker at the AHPCC conference: 'how dare we go and invite someone to share their soul if we haven't actually owned our own'.
Self-care is written into Queenie's contract and she is encouraged to take time off for pastoral supervision. She also attends supervision for her spiritual direction work and is able to use this for hospice work as well if necessary. Tracy commented that her external supervisor validates her:

> I go and talk to her about all the palaver that goes on here and what I come away with is a sense of confidence to come back and do what I do and that's really helpful to put it mildly!

She was also one of only three chaplains to mention AHPCC regional meetings as a source of support. Clinical supervision from a line-manager was mentioned by several interviewees but with no evaluation and no mention of it being a

management tool. Just over half the Christian interviewees had a spiritual director and a further two thought that having a spiritual director might be helpful.
In short hospice chaplaincy was more likely to be an example of serendipity rather than part of a career plan. When compared with congregational or parish ministry the hospice ministry has fewer constraints, expectations and meetings, resulting in freedom for the chaplain to be herself. The absence of buildings to be responsible for and the presence of boundaried hours means that personal life and ministry can be separated. Congregation-based ministry offers little in the way of supervision, nor are ministers expected to have spiritual directors, but supervision is part of the culture in the hospice.

Chaplains' Church connections and their view of how the church regards chaplaincy

Apart from those with congregational responsibilities, committed regular connections with a church were noticeable by their absence. A few interviewees filled in for local churches on an irregular basis but most found it unhelpful that churches saw them as a resource for taking services when what was needed was as Tracy said: 'a place for my own refreshment.' Fred had deliberately not sought out a church family, attending irregularly, because

> I'm here Monday through to Friday and by Friday evening I'm ready for a break, I'm ready to allow myself to be nurtured, nourished in a way that I find spiritually enriching…

Greta needed to be 'where I'm going to be nurtured spiritually and where I can share my personal story… and be accepted.' She was having difficulty finding a place to worship where she was not distracted by the pain of the minister with issues about women in leadership[164]. Tracy also observed that a sermon about mission and outreach felt quite remote from her own experience and even appeared to neglect pastoral care which she believes is, or should be, the heart of the church. Several chaplains described being criticized for 'not doing the proper work': 'you've copped out and gone into chaplaincy'. Larry was told that he was wasting his time, not doing his job as a Christian minister because he was 'letting these people go to hell' and Norman said 'they see me as a traitor to the cause'.
The question of whether or not the church locally and generally was supportive received a mixed response. Yasmin said 'I don't think the church, the diocese or the local vicars know what we do' and 'it's up to us to educate them'. Steven said that support was 'Pretty woeful really'. Several interviewees were irked by the parish-

[164] She had met ministers who could not understand how she, a woman, could be a hospice chaplain.

focus of the Anglican church, and there were comments to the effect that the church of any denomination is not generally very good at supporting any clergy. Beth was the exception, describing her diocese as supportive but acknowledging that she was unusual. Two chaplains felt that the understanding of healthcare chaplaincy amongst the hierarchy had improved but awareness at the grassroots level was varied.

Chaplains' clothing and how they introduce themselves

I focus here on the Christian chaplains and particularly those who are ordained and therefore might wear a dog collar.

Several interviewees spoke of the pre-conceptions of certain items of clothing. One, who is not ordained, felt that a black shirt and dog collar received a different response from an open collar. He said that if he was taking a funeral or giving the Eucharist (reserved sacrament) in the chapel he might 'put togs on' but he did not need props to do his work. In contrast six ordained chaplains said they wore their dog collars in order to be completely upfront with patients and staff. Beth felt that the collar was a symbol of authority and responsibility for the sacraments but at the same time she recognized that some people needed informality so she tried to meld formality and informality with a collar on a bright informal shirt. She stressed that, whilst she wore black for funerals, she never wore all black in the hospice.

Ian estimated that his collar had been a barrier half a dozen times in his extensive hospice career but he has a diverse team of ordained and lay chaplains and believes that the patient chooses who they talk to. Norman felt that a collar definitely was a barrier and Keith said 'not clerical gear' quite firmly but then admitted to wearing it quite a lot because of having a lot of official commitments. Twelve ordained chaplains wore the collar when doing something official like a funeral. Doreen contrasted those for whom the collar is helpful, when they have met lots of new people, and those for whom the collar is a turn off because of their past experience with church. She observed that she did not think it did any harm as it is a reminder that she, like nurses, has a uniform. In contrast Steven made the point that his hospice was not a uniformed organization so he wore an open-necked shirt – but the picture on his badge showed him wearing a collar! Patricia wore her collar all the time saying it is part of the uniform.[165]

[165] At that time the website showed her as chaplain, wearing her collar, with a patient. However the website now shows a Spiritual Care Co-ordinator without a collar and without any indication as to whether she is ordained or the nature of her training.

Charles only wears his collar if going to wards where he is not known. He felt that the open neck is a better indication that he is not representing just religion but religion and spirituality. A survey conducted in Larry's hospice found that 98% of staff preferred him without the collar but he stressed that he does not engage in subterfuge but is always open about his position. John explained that he normally wore an open-necked shirt when in the hospice but if he was wearing his collar for an official function and came into the hospice he then took the white bit out. William always wore his collar but when upstairs in the office area he took the white bit out.[166] Two of the free-church chaplains had rarely worn collars in congregational ministry and asked the family if they would like the collar for funerals. However, one had been asked by staff to wear it more as they thought it good to see his 'official role'.

All interviewees introduced themselves by their first name. Some are concerned to counteract any perceived pomposity, some to demythologise any pre-conceptions. Most identify themselves as the chaplain but a few explain that they are a member of the Patient and Family Support Team. Several are concerned to establish immediately that they are not there to do anything – John says 'I'm just here to chat'. If the patient says that they are not religious Charles says: 'I'm not just here to talk about religion. I'm here to listen to your story, wondering how you're making sense of this…' Tracy explained that some of the fear which patients might feel is removed by the staff who 'do a really good job of preparing the way. They do a very good job talking about me…' Valerie also recognized possible fear saying:

> 'I'm the chaplain – don't worry, I'm not the grim reaper, there's nothing suspicious about me calling – I just like to get to know my patients and have a little chat.' I try to keep it short but sometimes when I ask 'how were you last night? Did you get a good night's sleep?' they want to tell you everything and that's fine. You can go in and be there for two minutes or an hour or somewhere in between.

Chaplains' perceptions of patients' expectations.

Larry observed that patients expected the chaplain to have all the answers (but were disappointed) and Ian recognized patients' preconceptions of the chaplain's style. Alan and Tracy spoke of preconceptions which were corrected or eased by the nursing staff. Several chaplains felt that patients expect a religious role and some patients still anticipated that the chaplain would want to do something to them – convert them or judge them. In contrast a patient greeted Ian with the words 'when you come in I know you are not going to *do* anything to me.' The chaplain was the

[166] He did so when I interviewed him.

one person who would not administer drugs, give a treatment, make her do exercises, take blood pressure…

Norman said that there was sometimes a defensiveness because patients saw him as the guardian of all matters religious and therefore he had come to check up on them: are they behaving? and are they saying their prayers? Some appear to test the chaplain - Ian recounted experiences with patients who take delight in telling the most vile and disgusting jokes just to see if he reacts and others who tell him a bit of the story each time he visits so that on the first occasion he hears about their children, then he hears that their son is not married but lives with someone and then on the third visit he learns that it's a same sex partner. This testing was in marked contrast to the quiet acceptance also described by Ian when he visited a hospice patient who had been admitted to the hospital:

> When I arrived her vicar, who had never visited her in the hospice, had just left. She said 'I'm so glad you're here.' I held her hand and she fell asleep. When she woke up she said 'that was so nice'. She felt comfortable falling asleep with me… She said 'the whole time he's here you know he can't wait to get away. With you I don't have to speak.'

Ian was at pains to say that he and the patient held her vicar in high regard: he was a great preacher, wonderful pastor, did wonderful things in the parish including a project with drug addicts and alcoholics which Ian felt he could not do.

A patient who says that she does not wish to see the chaplain may witness her visiting another patient and then change her mind. Ian reported one such experience with an atheist patient who having observed Ian in action felt that he could be trusted as a 'safe repository' for his issues.

Many patients raise existential questions such as:

What happens when I die?
Where do I go?
What are the mechanics of dying – do I die and stop breathing or stop breathing and die?
Will it hurt?
How will I know when I am dead?
Is there heaven? Is there hell?
Will I see my loved ones?[167]

Whilst some chaplains indicated that some patients asked 'Why me?' Larry was adamant that patients did not ask 'What have I done to deserve this?' Practical issues raised included:

[167] How the chaplain handles these questions depends on the nature of the question and the relationship between chaplain and patient. Questions on the mechanics of dying may be explained but other questions may be played back to the patient: 'what do you think?' 'Do you believe in heaven and hell?'

How do I live with the knowledge that I will die in three months?
How will my family cope?
How do I arrange my funeral?
What happens to my body?

Lying in bed or sitting in the bedside chair a patient has time to think, often about things not addressed previously. Several chaplains described helping the patient to look at the issues in different ways, to change perspective. Others described looking at photos with a patient, listening to the patient's life story as they examined their life and assessed its worth. Expressions of regret and confessions – usually informal – were mentioned by only a few interviewees.

Bearing in mind that half the patients in any hospice are there for symptom management or respite care there are also anxiety issues about returning home and the provision of appropriate facilities, about going for a treatment not previously experienced, about role in the family unit. Beth felt that issues of role and identity were particularly difficult for male patients, but only Greta described an issue of identity related to appearance, of a female patient who wore a mask because of her face cancer.

I close this section with a story from Alan, which illustrates that he was expected to know the answer but also a story that he has used subsequently with other patients:

> …I remember a time when I was in a room with a young man who was dying and his wife and his seven year old child and the child said to me 'why are there two daddies in this room?' I asked: 'what do you mean' and she said 'well I can see daddy lying on the bed but I can also see daddy standing by the door'. And it was clear to me that she could see into two dimensions and my helping was to explain that to her: there's daddy's worn out earthly body and I think this is daddy's new spiritual body.

Alan has found this story helpful for other people, including those who say that they do not believe that the Bible has any relevance or value for them.

Training and life experience

Half of the interviewees had come into ministry later in life, usually as a second or third career. Most expressed the opinion that life experience was helpful if not necessary:

> you need to experience that pain of life to be effective in alleviating the pain of life (Alan)

> you have to have a bit of a broad outlook on life, you have to have years under your belt as it were, and life experience as well (Beth)

> it's actually expected that they will have had a certain amount of previous experience before going in to this sort of a role so I'd like to think that it's something to do with experience, including life

> experience and having reflected on that rather than the fact that we're just a load of old fogeys (Doreen)
>
> a chaplain needs to experience life's knocks in order to identify with others who are experiencing life's knocks (Fred)
>
> you have to have been around the block a bit to have had some difficult experiences, to see what life can throw at you, to be in that better place to be alongside people…it isn't the sort of thing you go into in your twenties (Queenie)
>
> Occasionally you will meet someone who has had that life experience incredibly early and will do it, feels drawn in for one reason or another but I think on the whole you need the life experience. Maybe you also need the ability to have the space to reflect, to consider, to pray and if you haven't got that because you have small children, busy life-style, maybe that makes it more hard, more difficult. (Xelda)

Ian said that when you have life experience you are less sharp edged and more able to reflect and extrapolate from your own life to help another. Like Charles he did not feel he could have done this work in his thirties as he lacked the depth or gravitas of spirituality, but neither Ian nor Charles wanted to rule out younger people. Rowena also questioned whether she would have felt confidant doing it when she was younger. Only one interviewee had started in hospice chaplaincy in her twenties but thirty years ago the hospice was very much part of the church role whereas now the chaplain belongs to the hospice rather than the church. Two of the interviewees were in their thirties, one saying chaplaincy is about experience and personality and:

> Maybe younger people don't want to think about death all the time – maybe I'm just a bit weird…and I've always been a bit of an old fart (Steven)

The other drew on his experience in America where Clinical Pastoral Education (CPE) is included in clergy training and in hospitals. He believed that younger people were able to be hospice chaplains advocating a mandatory year of CPE early on in life or early in ministry. Beth and Steven felt strongly that clergy training was poor. She came into ministry after many years in nursing and from her perspective of training on a course which was not just theology but about living the faith, other clergy appeared poorly trained in death, palliative care, bereavement and healthcare chaplaincy. Steven was critical of his theological training :

> at my theological college we did an intensive week on death, dying and bereavement. One week of a two or three year course and then think how much time you then spend dealing with bereavement or bereaved people.

He pointed out that in the Church of England the training incumbent was supposed to provide practical training but even instruction in churchyard administration did not

always happen. Greta commented that there needs to be another model of training for healthcare chaplaincy which might help address her complaint that any vicar or minister is presumed to be automatically equipped for the role of hospice chaplain. Eric, John and Norman each referred to the misconception that chaplains are people who are escaping congregational ministry or whose personal lives are at odds with the values of their institutional church. Norman referred to the observation that chaplains were often 'refugees' from congregational ministry.[168]

Hospice Chaplains' understanding of spirituality and spiritual care[169]

Whether descriptions were spontaneous or prompted, the concepts of spirituality and spiritual care were rarely defined formally or in religious terms. This section presents the ways in which interviewees spoke of these concepts in relation to their work, then presents findings on their understanding of their own spirituality and its relation to their work.

Spirituality

In Chapter One Cicely Saunders' development of the hospice vision in the light of her personal spiritual development was presented and I referred to Walter's criticism of her connection of spirituality with the search for meaning (Walter, 2002:134). He argues that this way of speaking about spirituality indicates a desire to separate it from religion. My research data certainly indicates the use of different language, that is everyday rather than religious, but it is not clear that distance from religion is the motive. What comes through clearly is the desire to find a language that enables the patient, who in the round of appointments, treatments, investigations has lost sight of who he is, to tell his story and in so doing to re-engage with his own spirituality. Asked to define spirituality many of the interviewees took time to respond. Chaplains felt that the language of the many definitions of spirituality, including terms such as 'transcendent meaning and aspiration to life'[170] is appropriate to the academic world and possibly to hospice management but it does not express the actual experience of the patient. Beth said:

> talking about spirituality is talking about what animates a person, their passions, what feeds them when they are down, what resources them, where they find love, what's important to them, it might be their dog – so bring the dog in,…

[168] Hancocks et al (2008).
[169] Some of the material in this section was presented at the Conference of the British Association for the Study of Spirituality (BASS) and subsequently published in the BASS Journal (Thomas, 2015).
[170] Association of Hospice & Palliative Care Chaplains Guidelines 2012

Spirituality was described as 'what floats their boat', 'what makes them who they are', 'what makes you tick', 'your engine', 'what makes me me and you you'. I offered the AHPCC definition of spirituality (text box) to some interviewees for comment[171].

> **Spirituality** gives transcendent meaning and aspiration to a person's life, and may or may not include God. Spirituality concerns all that makes for an individual's existence as a person and our capacity as human beings for self-transcendence, relationship, love, desire, creativity, altruism, self-sacrifice, faith and belief.

Beth picked out 'may or may not include God' saying that it was really interesting to explore what people understand by God. She separates out the letters G-O-D to ask what they mean and the answers vary from 'good old dad' to 'great omniscient deity'. She finds it helps establish the level of their relationship with what they understand to be God. If they think of God as the three persons of the Trinity she can explore how they understand God as father or mother[172]. She is at pains not to put God in a box and to encourage the patient to explore the scope of God. Charles felt that the act of definition killed the essence of spirituality and spiritual care and as he had little time to train nursing staff he thought that explaining spirituality was not the way forward. Rather he was trying to model spiritual care and one of the ways of doing that was to help the staff with difficult deaths.

Generic spirituality was an issue raised spontaneously by Doreen because it caused problems for and with the Multi-faith Group for Healthcare Chaplaincy (MFGHC)[173]. Doreen made the point that generic chaplaincy safeguards those who do not have a particular religious faith: 'just because people don't have a particular religious faith it doesn't mean that they don't have spiritual needs.' Furthermore if there is not an understanding that 'the chaplain supports people in their spiritual journey *whether or not* they are religious' then there is a real danger that the chaplain will be seen as only concerned with religious needs. She felt that from there it is an easy step to saying that the hospice does not need to employ a chaplain but can just get in a vicar for Church of England patients, a Rabbi for Jewish patients:

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[171] There was no attribution attached to the definition. Some chaplains recognized and acknowledged the source (see Appendix G).

[172] Sometimes she tells them about the book 'The Shack' (Young, 2007) which she personally found enlightening on the dynamic relationship among the members of the Trinity and which she felt challenged ideas of the solidity and immobility of God.

[173] MFGHC understood generic chaplaincy to mean that one chaplain would meet the religious needs of patients from any faith. It is of interest that apart from the AHPCC representative none of the other members of MFGHC were/are chaplains. In 2014 the group evolved into the Healthcare Chaplaincy Faith & Belief Group (HCFBG).

> entirely forgetting the fact that the vast majority of patients, with whom chaplains spend a lot of their time, are people who are not card-carrying religious people at all. That's what I've always understood the term 'generic chaplaincy' to safeguard. It's saying that we need to realize that there are people with a huge raft of spiritual issues and needs…

Spiritual care

Describing the practice of spiritual care, the encounter between chaplain and patient, was generally easier than defining spirituality, although two chaplains were wary of using either term as they had experienced confusion with spiritualism, in one case by a patient and the other by a senior manager. Several chaplains spoke of presence (Alan, Eric, Greta, Norman) and 'being a presence for God' (Beth). Norman said that in comparison with congregational ministry hospice work has no tasks and that it's more about presence, a much broader engagement than actually coming in to '*do something.'* William told the story of an old rough ex-stoker from the Royal Navy. He was in his eighties, dying, and a smoker who loved to show William his risqué jokes on his i-player, man-to-man. I know from the way William says this that such jokes are not to his taste but he makes it clear that he never showed disapproval and he coped with the smoke as well so that 'this gentleman has learnt to trust me.' Then the man was rushed in to hospital with breathing problems and demanded in his inimitable style that a nurse let the hospice chaplain know he was there. William popped in to see him – 'and he wept. He's seen a lot of experience in his time in the navy. What a privilege.'

Larry spoke of addressing the fear encountered in a patient with brain metastases by saying that he visits everybody, they could talk about anything and if she was happy to talk with him as a human being he would visit. Larry also described spiritual care as enabling people to discover and cherish the strawberries in life, using the story attributed to a Buddhist monk:

> a man walking across a field realizes a lion is following him. He sees a fence at the side of the field so he jumps over it and finds that he's at the top of a cliff. There are rocks at the bottom of the cliff but there is a creeper to climb down on. Half-way down the cliff he looks down to see there is another lion at the bottom. With a lion at the top and a lion at the bottom he then sees a mouse gnawing at the creeper he is holding on to. At that moment he spies a wild strawberry in a crevice. He picks it, smells it, puts it in his mouth - the juices fill his mouth and his very being. The lions and the mouse are still present but he cherished the strawberry.

Alan and Xelda both spoke of meeting the patient where he is, not where they thought he should be. Alan told the story of the Jewish patient for whom the hospice chef, who was also Jewish, obtained kosher food. The patient wanted pork

sausages! The son, who'd come from London to visit, was very devout and wanted to do the right thing for his father, so he rang his rabbi to ask what Psalms he should read and what prayers he should say. His father did not want any of that fuss, he just wanted his son to be there and Alan's role was to enable them to let go of their own agendas and meet half-way. Xelda said that in serving the patient's need she was always willing to be with the person while they work out where they are going in spiritual or religious terms and to offer whatever they need at that time. One of her ways of helping that process was using the analogy of a globe artichoke, enabling the patient to work his way to the centre, to the bit that actually supports and holds. Doreen spoke of simply being there with the patient, family member or member of staff in whatever it is that they're going through, not providing answers, not having anything to do but 'simply there as people'. She had been invited by a Jewish patient's family to be with them as they lit their Hanukkah candles which she said was lovely and 'I was just able to be there as another human being'. John said that each profession goes to the patient with the tools of her trade, and prayer and anointing are the tools of the chaplain's trade but 'in actual fact mostly I just sit with the patient, I've got nothing to bring. I don't know what they are going to say, there is no way you can prepare and you just sit…we just bring our humanity.'

Beth spoke of being truly human, sitting with a dying patient over a period of several days. His face was eaten away by cancer and he had no visitors. He could not speak but nodded when she asked if he would like her to sit with him and nodded again when she asked if he would like prayer. She said it was about having 'the humanity to love somebody who doesn't look beautiful who really is anathema to most of society…'

Greta spoke of the need to affirm the humanity of a woman whose cancer was growing out of her mouth. Her speech was impeded, the cancer was fungating, the appearance was ugly but eye contact was absolutely essential in order to affirm 'the essence of who she is, as a human being'. Eric also spoke of being an affirming presence, encouraging the patient to tell his story and identify those achievements which will empower him to cope with the present situation.

Keith observed that when he sits with a dying patient he is first and foremost a human being. To think of himself as a Christian at that point would involve expectations which would be inconsistent with his understanding:

> I can simply go in and be who I am in that space just as they are being who they are in that space. And there is a kind of connectedness and I am accompanying them, not in official relationship but we share a common humanity.

That sense of accompaniment was also expressed by Alan:

> (they) need you to be there, a calming reassuring presence, someone to be with them on the long and lonely road, that's not going to abandon them, that will take them all the way up to the gate

Tracy spoke of accompaniment as being a companion on the journey, being 'alongside rather than above' and 'offering insight and skills and knowledge and understanding of faith and spirituality which sometimes people have never thought about or explored for themselves.' Norman also spoke of spiritual accompaniment and companionship, saying he did not come to 'do' anything and 'it's much more about presence'. Queenie compared chaplaincy with other disciplines such as physiotherapy, occupational therapy, who visited the patient in order to do something, observing: 'If we have an 'in order to' it is simply to show God's love to them.' Doreen saw her role as accompanying in such a way that the patient will feel comfortable talking through difficult things. She also said that when you are 'just with somebody' you don't have anything to *do* (her stress) and referred to this as 'enacting' her belief in 'the God who is with us whether we recognize that or not'. Her presence was representative:

> I'm not here to be *this* and a social worker, I'm not here to be *this* and a something else, I'm here almost like a visible reminder of the spiritual. We are the visible reminder of that. Somebody said to me once that she saw me as the visible reminder of all the things that can't be quantified.

Such enacting was particularly relevant with staff as it is not always appropriate to speak about her spirituality but she hopes that she is seen as someone who staff can talk to. Greta said that the chaplain is there to 'be with' the patient, to be a presence, and Larry thought that whilst patients expected chaplains to have all the answers they also expected a presence, just to be around.

A story by Rabbi Harold Kushner[174], (text box), was Patricia's illustration of her understanding of presence, saying that we can actually help people to cry, we can be with them in their suffering – she said that it may not be pleasant or easy and it is challenging.

A little boy went out to play and returned home late. His mum asked where he'd been as she'd been worried and he replied that he'd stopped because his three year old friend fell off his trike and his trike had broken. His mum asked 'you didn't try to fix his trike did you?' He replied 'no, I stopped to help him to cry'.

Patricia loved people and enjoyed relationships, recognizing that they were fundamental to spiritual care. Valerie, Doreen and Yasmin also stressed the

[174] Author of *When bad things happen to good people* (1981 New York: Schocken Books).

importance of building relationships - through chatting about the weather, hobbies, family, moving on to life achievements, hopes and fears, planning the funeral and considering what happens when you die. When the relationship has developed, questions of meaning and purpose arise naturally and if they do not Charles feels it is better to ask: 'what is important to you?' or 'how have you got through difficult things before?' than 'where do you find meaning in life?' Oliver, fairly new to the work, had learnt that a relationship often depended on being the right person at the right time:

> (I) witnessed conversations between the chef just coming in to decide what they want for their meal that day, and seeing how far-ranging that conversation can become, the level of rapport between chef and patient well over and above what I manage to achieve as chaplain.

Larry recounted meeting with a patient whose sense of self-worth had plummeted. The patient was quoting from the funeral service 'dust to dust and ashes to ashes' saying that was all he was. Larry used what the man's wife had told him to say 'Ah, but I understand from your wife that you are gold dust', thus affirming his value. Larry spoke of a picture coming to him during the course of a conversation - other pictures involved gems, roller-coasters, and train journeys.

Tracy uses pictures a lot, observing that they do not always work but giving the example of one that did, working with a lady who was:

> talking about having to re-arrange her life and not knowing where things fitted and I had this image which I gave her straight away of moving house, you have the same furniture to put in a new setting. One of the things you think is 'where's the Christmas tree going to go this year?' In a new setting how do things fit together and she really worked with that for quite a while – it was most interesting that she got it, as a picture it made sense to her, talking about her anxieties about re-arranging her life now this was happening to her.

Two chaplains told stories of using Biblical material: Greta used the dying patient's favourite Psalm with the daughters who did not share their mother's faith. They had however seen the film 'Shadowlands'. Greta linked the film's portrayal of loss with their experience and with the comfort offered by the psalm. John described using the story of the Prodigal Son in his own words, freely describing dad waiting at the garden gate longing to welcome him home, to help patients look at regrets and sorrow for past actions.

Martin made it clear that he was not there to preach or teach, but 'to hold this with you'. He remarked that most hospitals have a team of Chaplains which includes Christian, Jewish, Moslem and other chaplains. In contrast the hospice has only one chaplain who could be of any of these faiths. His response to a patient's question about how he cared for someone of a faith other than his own was: 'I am the

Seelsorger, the one who cares for the soul'. He illustrated this with examples to show his care of souls regardless of faith:

> when the priest left the room the patient asked the nurse to call the chaplain. He then expressed his spiritual distress about something from the past saying 'I could not have had that conversation with the priest'.

On another occasion he found a lady in tears after her priest had visited. The priest had told her she would be fine if she offered her suffering to Jesus. Her response was 'he does not know my pain.' She wanted her church to light a candle for her and a picture of the Virgin Mary with baby, both of which he organized. He finished these illustrations with an expression of exasperation with the offending clergy: 'someone has caused spiritual distress rather than alleviating it.'

Doreen observed that faith-specific chaplains meant that the vast majority of hospice patients were effectively denied specialist spiritual care. Doubtless those patients would still receive loving attention from other staff but those staff are not expected to deal with existential or religious issues and they themselves also need and deserve spiritual care. Tracy observed that nursing staff hesitate to explore spirituality with patients because they lack confidence in their own spirituality but when she recorded that she had used pictures, analogies, metaphors to help the patient talk through her concerns the staff were often interested enough to ask her to tell them more.

William saw his role as enabling and mediating and described how one member of staff had drawn a picture of him with very big ears and a very tightly shut mouth. However, he also said he was there to support other staff who provide spiritual care. Alan said 'a lot of what I do is just pastoral support that crosses faith boundaries'. Larry said 'A lot of conversations are affirming people for their value and sense of worth, for who they are, not for what they can do'.

Affirming people in their spirituality or their belief system, without reference to his own, was an essential aspect of Ian's role and he spoke of leaving his own faith at the door[175]. Whatever way the person is finding comfort Ian's role is to maximise that comfort, no matter whether he agrees with their approach or not, and if they feel that God has failed them his role is to try to find ways to help them work with or around that. He is not there to give them answers or to challenge them but enable them to explore. He explained that part of the role is getting to the place where he can be the person they need him to be, which may mean divesting them of the expectation of an authoritarian or lenient character. He freely admitted that he had

[175] This will be explored in Chapter eight.

first heard the phrase 'be the person they need me to be' used by a Moslem chaplain.

Laying one's own beliefs on one side was also mentioned by Greta who described arriving at the door of the building and being the chaplain from that point: 'it's not about me in the job, it's about the patients and the families and their needs.' Norman also took his shoes off at the door of the hospice because the last thing the patients need is a proselytising minister. However:

> To say that they don't need to hear the words of the gospel is a completely different issue and I suppose that there's a quote that I keep falling back on, that comes from St Francis, that means so much in this context to me. St Francis exhorted his followers to preach the gospel as often as they could and sometimes they could even use words.

Charles portrayed spiritual care as an act of witness, defining the witness as somebody who 'stands back from their own issues in order to witness somebody else's truth, somebody else's struggle.' For Valerie spiritual care was helping people discover what floats their boat but she also expressed a concern that a lot of the ways she might demonstrate spiritual care are also used by other disciplines – for example complementary therapists play quiet music, use poetry.

Doreen also made the point that all staff and volunteers are involved in spiritual care to a greater or lesser degree. The nurse bathing the patient may hear far more than the chaplain about the spiritual issues troubling them - but nurse and chaplain are part of the same team, working together for the benefit of the patient. Beth described the patient who refused to see anyone with a collar but connected well with a chaplaincy volunteer who shared her interest in cross-stitch. Speaking the patient's language led John, who knew nothing about football, to brief a volunteer to provide spiritual accompaniment for a football fanatic. He also told how, at his informal licensing, he pointed out to the Bishop the inappropriateness of promising to do the liturgies 'as specified' when the patient is drawing his last breath. The promise was adapted and the bishop trusted him to do and say what would be appropriate, which John said gave him a freedom to explore and be creative with language with patients. However, he admitted that he still was not creative enough when recording encounters in the notes.

There were a couple of examples of specific requests for help as the patient approached the end of life. Despite saying that spiritual care was about listening with all the senses in order to hear the patient's spirituality and 'meet him where he's at and love him', love him regardless of whether he has a belief system or what that belief system might be, love him using his language and respecting his culture,

Beth also said that her job was to move the patient on spiritually and help him understand and overcome his fear.

Another specific request was the patient who wanted to be sure that they are ok 'for the next part of the journey', but Alan expressed concern that there were times when religion got in the way of a person's relationship with God, even becoming 'a god in itself'. He told the story of the Hindus and the elephant:

> one man holding the tail and the other holding the trunk and they both swear blind they've got the elephant and the truth is they've only got part of it. I think religion can be a bit like that…

and then continued with the story of the Church Commissioner who had done what she thought were all the right things:

> all my life I've done religion, I've said prayers, I've sung hymns, I've done all the offices and things but I don't have a deep relationship with God,…

He observed that she did not have even a tail or a trunk – she was standing underneath thinking 'where's the elephant?' - and his role was to help her recognize and reconnect. Both Moslem and Jewish chaplains also spoke of reconnecting patients with their own spiritual language and religious symbols.

Chaplains speaking about their own spirituality

I have already noted that some chaplains spoke of leaving their spirituality at the door, but finding the language to speak about it, even everyday language, did not come easily and the spontaneous connection with sustaining their work was rarely made. Descriptions of their spirituality and whether it was adequate to sustain the role were varied in content and in the ease of response. Several chaplains mentioned mystery and 'broader than church'. After his immediate response of 'A Mars a day helps you work, rest and pray' Alan spoke easily of God as mystery and his own spirituality as 'broader than church' which sustained his work: sitting in silence 'I am fed at a level beyond words'. He suggested that we may limit God when we use words and it may be better to just sit:

> I liken it to lovers, lovers sit by a river together, they don't need to say anything to each other, they are happy to be in each other's presence. My time-out time in chapel is where I am lover and beloved together, not needing to use words.

Beth is still working on what she understands as God and therefore lives with a mystery, a mystery about being and simply being a presence. However, later she summed up her sense of God as the life-energy in the universe, the creator of all, 'working in me and through me' as 'God is the ground of my being'. She admitted to working from 8 in the morning until 10 at night as she was responsible for a parish

as well as the hospice but on her one day off 'I get on a horse and ride round the countryside which feeds my soul'. The ease with which she spoke was in marked contrast to Charles' struggle. He said that being asked to describe his own spirituality was a horrible question as spirituality is vast, mysterious and 'not capable of being reduced to a few words.' He described two parts of himself, one of which 'says the creed and goes along with Christian doctrine in a fairly traditional form' and the other part that says that this is only part of the truth and 'there is mystery that we just do not understand.' Despite the difference he felt that these two parts sit quite comfortably together these days. The heart of his spirituality is engaging with his own soul by himself and in community with others but this is a work in progress and there are times when his spirituality is not sufficient to sustain him in his work. Keith described his spirituality in terms of his experience of the mystery of life and death. He cannot 'grapple with or grasp' that mystery, which encompasses the transformation of a watershed experience into a source of creative energy to sustain him in his work[176], but he is now in a place where he is comfortable that there are no answers. Believing in the mystery of God was at the very heart of Fred's spirituality and it was about:

> the great wonder of what lies ahead and of what is in the here and now, that mystery that questions the why, that engages with the what if and hopes in the joyful forever after.

He was clear that his spiritual nourishment and strength came from many different sources including his partner and being able to stand at the top of the downs and look out over the sea and 'have the sea-wind in your face and the sky above and see the beauty of all that even on the darkest of winter days gives a different perspective on life and of the fragility of life.' His spiritual development is an increasing sense of liberation from oppressions, from feeling weighed down by a body, from a church that oppresses, that doesn't liberate. He felt that profound sadness in his own life enabled him to empathise with a person who is feeling profound sadness and that his spirituality was massively important for the work he did because:

> my own spiritual life has brought me to a place of letting go, of letting go of fear of what might happen if I just *happen* to be me…I *have* let go of the fear of just simply being me.

Speaking of life after death Eric said:

[176] Keith did not spontaneously mention the transformation but when asked answered in the affirmative.

> What I believe works for me but it is still a mystery, I am comfortable having an attitude of faith in that I'm trusting in something I don't fully understand.

He commented that some patients take comfort from the fact that he, the chaplain, is happy to live with the mystery.

In my initial interview with Greta she spoke of her sense of God's presence and her experience of the Holy Spirit but did not use the word 'mystery'. A follow-up telephone conversation elicited a spontaneous description of a calm, inner peace, not out of her depth but comfortable with silence and 'I'm happy to sit with the mystery.' Some patients experience something of her inner peace, experience God's presence through her and that is mystery. She summed up mystery in the words of Hebrews 11:1: 'Now faith is confidence in what we hope for and assurance about what we do not see.'

Spirituality for Ian is about challenging who he is in the light of the gospel. 'You know you're a bigot when God hates all the same idiots you do' was a challenge to his aspiration to be 'a disciple of Jesus of Nazareth.' Using formal prayers and communicating with God whilst walking in the countryside are sources of spiritual nourishment but both slipped when he was under pressure. Saying the office of the Northumbria Community was mentioned by several chaplains and others mentioned Celtic, Franciscan, Benedictine and Ignatian influences. One interviewee had spent time as a member of the Scargill Community, a resident community of many Christian traditions, committed to a common rule of life and service. Another interviewee described the pressure of theology college where his 'quite strident conservative doctrine and theology' were not just challenged but dismantled and later replaced by what he described as the lighter but nevertheless authentic touch of the Franciscans and the Othona community. Change was also a feature for Tracy who observed that she had gone 'wider' in her spiritual search and traditionalists might regard her spirituality as off the wall, heretical, not rooted in anything concrete. William also acknowledged that his sense of the spiritual had broadened, demonstrated by facilitating a spirituality day with speakers from nine different faiths.

Recognizing that her personal experience – all the 'things that happen which you have to make sense of and interpret and live with in the light of what you believe' – has informed her spirituality Doreen said that her work, regularly being with people who are dying, has also changed her, changed her in ways that she did not always realize until later when looking back and reflecting. When younger she was more confident and the answers seemed clearer but with age she feels more deeply and strongly. Both she and Larry described their spirituality in terms of what they

believed in relation to Jesus and said: 'as I get older I find that the things that I find it necessary to believe as a Christian get fewer and fewer but the things that I do believe I believe more strongly'[177]. Larry also made the point that he was happy to speak of his spirituality using his own language but would not use what he called 'religious' language.

Norman described his spirituality in terms of his practice of prayer and meditation saying it was essential for his work. Martin spoke of his spirituality as a relationship with God through music, art, nature, religious observance but he also likened it to a butterfly landing here and there, being open to whatever is going to meet his need at that point in time. Some mentioned prayer, the office, sometimes honoured more in the breach than in the saying, some mentioned a rule of life. John admitted he was not disciplined in prayer or bible reading so appreciated having to prepare to lead worship and preach in local churches.

Oliver described his own spirituality as orthodox and Trinitarian and he was very open about his struggle to work out his frame of reference. When interviewed he was fairly new to the job and had moved from being a denominational minister to a leader in one of the new streams of church with a commitment to mission. He felt that his church would struggle not only with the non-proselytising, and the multi-cultural, multi-faith aspects of the job but also with the encouraging of folk in their own perception of spirituality. He was still on the journey to discover how he could be at peace with himself on these issues. He also spoke of being the only person to visit a patient and not do anything to them but he also spoke several times of 'what I have to offer' and offering time.

Where it was not spontaneously mentioned I asked interviewees how they took care of themselves. Doreen replied that regular supervision and reflective practice is important because sometimes 'you're just carrying stuff that you don't realize you're carrying.' She compared the experience to that of miners when they come up from underground. She remembered the disputes about whether miners could actually have paid time to have baths at the pithead. She described it as getting rid of the grime and all the stuff accumulated during the working day and as a chaplain needing time, during that day, to have a good wash. She thought the pithead bath a good image for supervision, saying that you accumulate stuff, inside and on your skin, and sometimes you don't even realize but think 'gosh I feel weighed down', 'God I feel messy'. However, she also commented how easy it is to postpone supervision and reflection because she has so much to do:

[177] According to Cicely Saunders' brother she herself said 'I don't believe as much as I used to believe, though what I do believe I believe more deeply.' (Saunders, 2014)

> I went to see my supervisor yesterday and I had only come back from holiday the previous day and I came back to 70+ emails and various things and there was a bit of a temptation to postpone supervision because I just have so much to do here. Then I stopped and rethought 'what am I saying if I say I haven't got time just to sit down with somebody who will help me reflect on my work?' so I kept the supervision appointment. But it is tempting sometimes - the *very* things that you need in order not to rush, not to feel oppressed and not to feel stressed out of your brain or burnt out or tired – those are the very things that you neglect even though you need them.

Several chaplains mentioned work-life balance and others identified specific hobbies or sports as spiritually nourishing - Beth has already been mentioned. John had just started an outdoor sport but admitted that he was not engaging enough with home and personal life and needed to make an effort to attend concerts. Music – listening, singing in a choir - was mentioned by several, as were walking, nature, family and friends. William cycled: 'it's wonderful for self care because I can swear at some of the drivers - and offload in the air.' Xelda sails and sings in a choir. Queenie's Job Description includes paying 'regard to my own spiritual health and well being and refreshment. ' She has recently started to find gardening therapeutic but she also consciously plans family time, as does Yasmin. Ian acknowledged that he had not paid enough attention to his own spiritual care and had come close to a breakdown and Valerie admitted that she needed to get her own life back on track in order to help others find their way.

Describing their spiritual development two chaplains (Tracy and Greta) spontaneously made the connection between their spirituality and being sustained in their work. Greta's passionate concern for spiritual self-care has already been noted and she was one of several chaplains who mentioned the importance of putting their own spirituality on one side, leaving it at the hospice door, in order to meet the patient where he is. Ian illustrated this with the lady who after a long chat thanked him for helping her to become a pagan. He commented that, based on his understanding of who she was and where she was in her life, it was a good choice.

One of the first interviewees (Fred) spoke of the transformation of a difficult experience or personal tragedy into a creative force which sustained him. In subsequent interviews I listened for similar experiences and on some occasions specifically explored this issue. A further ten interviewees (Larry, Keith, Xelda, William, Valerie, Unwin, Steven, Rowena, Beth, Doreen) recognized that their spirituality had been affected in this way, mentioning personal incidents and events which had had an initial negative impact. However the transformation into a sustaining energy and into the sustenance for their work was not spontaneously

recognized. Keith referred to his difficult experience as a watershed in his spiritual development:

> Up to that point God was a marionette in the sky, pulling the strings, making things happen. All you have to do is find out what his will is and then things will fall into place… well-meaning Christian friends said 'It's all part of God's plan'. I thought 'what kind of bastard has a plan like that?'

Other friends suggested that God was trying to teach him something but he thought:

> if I want to teach my children do I put them on the most excruciating rack in order to do it? Such an entity would not be worthy of my worship.

He rejected that version of God but had no clear idea of a replacement except the God of the last verse of Vanstone's hymn *Morning glory starlit sky*:

> This is God: no monarch he,
> throned in easy state to reign,
> this is God, whose arms of love
> aching, spent, the world sustain[178].

Rather than God being a great all-powerful being in the sky, God is underneath all his creation, bearing and carrying the weight of responsibility. The watershed experience shaped Keith's ministry but he did not spontaneously describe it as a source of sustenance for his hospice work. Rather, asked whether it energised him he responded 'yes'.

The childhood death of a sibling was the start of Xelda's spiritual journey to discover where God was, to find her own heart of the artichoke. Beth described the start of her journey in a healing experience at the age of eleven. She admitted that she had bargained with God: 'if you help me…I'll go to church' but she had not expected a collar! Laughingly, she said she was a little wary of Him. Whilst Tracy did not speak of any negative experience she did acknowledge that her work had affected her spirituality, saying that her faith looked quite different from ten years ago and wondering whether other chaplains have the same experience. She thought she might try to research this and write a paper on it.

The data about the hospice

In this section I present data on the chaplains' understanding of the ethos of the hospice, issues of evidence, recording in patients' notes and spiritual assessment tools.

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[178] W.H.Vanstone (1923-1999) was ordained in 1950. Intellectually brilliant he eschewed academia and promotion in the church devoting himself to parish ministry on housing estates. He is best known for his published books which he wrote based on his own spiritual journey.

The hospice ethos

In most interviews it was necessary to ask the question 'What is the ethos of the hospice?' A few interviewees answered promptly and precisely: 'Absolutely patient centred so choice, whatever they need in body, mind and spirit is provided' (Beth) and 'Very genuinely puts individuals at the heart of what we do' (Queenie). Several chaplains observed that ethos depended on management but several interviewees seemed uncertain how to answer, responding with answers not related to ethos, which they acknowledged before trying again to describe the ethos. The most common descriptions were: patient-centered, caring, for all, with some chaplains making the point that the context was secular. Three interviewees had described themselves as mavericks, referencing the Keynote speaker Ann Morisy at the 2010 AHPCC conference. Eric explained maverick as 'not a loose cannon', but accountable with the freedom to cross boundaries, accessing all areas, modeling and expressing the concept of hospice so that everyone feels connected – like the oil travelling through the engine. For Norman there was no problem but Fred and Eric were finding that whilst they had been allowed to permeate the entire organization it was becoming more difficult since management personnel had changed and the ethos was changing. When he later left the hospice Fred stated:

> during my six years at the hospice I saw the management style change from 'collaboration and cooperation' to 'absolute control'! They became totally disconnected from the gifted professionals who provide patient care, and have set themselves up as an elitist group, making decisions that cause so much unhappiness and have led to low morale and job satisfaction, very high sickness levels and staff turnover.[179]

Tracy described the ethos as very caring to patients but not to staff[180]. She was the only interviewee to speak in depth about the shadow side of hospice and the two aspects of the ethos. She did not doubt the sincere desire to provide the best care for patients with life-threatening illness but the means of promoting and funding such care caused her anxiety. She spoke her thoughts on why the hospice does not practice what it preaches, listing hierarchies and silos[181] and a failure to work together – except in the clinical team, which has direct contact with patients and their families. She raised the possibility of jealousy amongst administrative staff who may feel inferior to clinical staff.

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[179] From an email received in response to a follow-up question on the nature of the management structure.

[180] My own experience was similar – those of us who were aware of this and the effect on and between staff used to say 'our hospice has cancer'.

[181] A term taken up by the healthcare sector from industry where it indicates that information is not shared.

In some of the other interviews I felt there was an undefined spectre hovering but the interviewee did not speak of a shadow side nor acknowledge or articulate anything other than the more business-like ethos. Steven observed that the new CEO was from the business world and questioned whether he understood the concept of hospice. Steven commented that his hospice was a Christian foundation but he felt that financial concern for the provision of palliative care had superseded Christian values such that staff no longer felt valued. Long-standing members of staff who in the past would fund-raise, work overtime unpaid, take work home, now say that they arrive on time, leave on time and don't raise money any more. It means he has a huge role in staff support but at the same time finds it demoralizing that he too feels undervalued and now takes time off in lieu when he has worked outside his contracted hours.

Valerie said that when she joined the hospice a year ago the mission statement conveyed the ethos of treating everybody equally, working for the best interest of patients and their families and helping people find peace in their own way. The current mission statement is about providing the best possible care. She felt the wording was more business-like and less person-centered but was not sure whether this was due to the new CEO. Other chaplains also commented on an increased hierarchy and greater stress on business.

Fred wondered whether the newer members of the management team had any concept of spiritual care and the 'heart for hospice'. He felt that coming from industry they would have little idea of day-to-day contact with hospice patients. Rather than holistic care enveloping all aspects of a patients' life, seeing them as a person - with a family, with a history, complex and beautiful - the hospice was moving towards a medical, clinical model, providing evidence for fear of litigation.

Greta observed that the ethos emanated from the management whereas the original ethos of St Christopher's was rooted in Cicely Saunders' vision which was informed by her faith. However, today's management rarely have the vision or the faith. Nevertheless she felt that the chaplain should reflect the ethos of the hospice to the patient. Doreen felt that management did not understand what it is to be part of a faith community and tended to approach spiritual care from the angle of Diversity and Equality which overlooked those who do not belong to a faith group.

There were a few positive comments about management: Alan said that the management was good. Xelda stated that she thought that she was immensely valued whilst Yasmin commented that whilst she was not under threat with the current management it might be different if the CEO were to change.

Interestingly Larry described a hospice under new management with the ethos 'riding a storm'. He found it challenging, as continuity had flown out of the window due to the financial crisis and the retirement of various key senior managers and the CEO. He described the previous management as paternalistic whereas the new managers are very professional people with experience from different fields. However he is aware that some groups of staff are as yet not inspired by the lack of palliative care experience amongst the new managers. Despite the change in personnel he had not experienced any change in his role as chaplain to the institution, and still felt immensely valued.

Whilst several chaplains mentioned being Chaplain to the institution, Patricia described the process of change she had experienced from treating hospice visiting like parish visiting to being much more involved, a member of the team, chaplain to the whole hospice and on terms set by the institution. Steven commented that he did not feel that management understood the concept of chaplain to the institution or if they did understand they did not like it. He was expressing a perception of management as uncomfortable with the chaplain's role in staff support. Tracy described this as management struggling with the fact that she honoured confidentiality and the staff knew this. Furthermore management did not like staff speaking to her – which meant she knew that the hospice does not practice what it preaches.

Two of the chaplains interviewed described their organisation's structure as flat rather than hierarchical. In one case the interviewee was aware of this because he had experience of both and as chaplain was at the bottom of the food chain in the hierarchical hospice. Despite representation to management he did not feel that the chaplain's role was understood as other than being for the patients and allowing the hospice to tick the box of spiritual care. There was a marked contrast with the other hospice where he felt valued as chaplain to the whole institution. He, like about half the chaplains interviewed, reported to a Board level or senior manager. Only one chaplain reported to the CEO, and the remainder reported to a middle manager.

I am told that in the early years of hospice the chaplain often reported to the CEO and in some cases was actually on the Hospice Board. That reporting line has changed over the years and three of the chaplains interviewed (Patricia, Valerie and Steven) had experienced the downward shift of line manager from senior to middle management. All three expressed a feeling that there was also a change in the hospice ethos.

The need for evidence and recording in patient notes

In today's financial climate the necessary hard-headed approach to the future of hospices means that there has to be a reason for every service offered (Help the Hospices 2013a), every service has to represent an added value. At the time (2013) of conducting the interviews evidence-based practice was a matter of increasing disquiet as hospice chaplains became aware that a management concerned with financial stability found spiritual care hard to understand[182]. Given this concern it was interesting that the need for evidence was raised spontaneously by only five interviewees. Therefore the quotation on evidence-based practice (text box and Appendix G) was introduced to elicit opinion[183].

> Chaplaincy needs to be evidence based and evidence led….My only caution is that we are careful that our right and proper attempts to meet the criteria laid down by the healthcare system do not blind us to the obvious: often it is that which cannot be seen or measured that proves to be vital. In our movement towards technical excellence we must be careful not to lose our soul.

Commenting that there was a lot of material on evidence-based practice from the United States, Charles expressed his concern:

> I'm not against trying to raise standards and trying to work out what it is that we are doing…it's just something about working with relationship and spirit that is jolly difficult to measure because of the mystery of what's happening

He felt that the work might look the same as that of other disciplines but there was something about spiritual formation that has a subtly different flavour – which was hard to describe and really hard to argue. Doreen hoped that it would be possible to combine rigorous professional standards and competence, gathering evidence, with an absolute respect for that which cannot be measured or even talked about.
Eric felt that evidence required objectives, which a chaplain does not have. He is there to 'be' and support through his presence. He may just sit with the patient. He may be asked to take the funeral but the patient will not be alive to assess it. He asked:

> if the patient dies peacefully is that a sign of the chaplain's success? What if the patient does not die peacefully? Has the chaplain failed?

He felt that the problem lay with the nature of the recording system and what is to be recorded. He spoke of the difficulty of recording conversations about existential

[182] It was much discussed at conference and at executive meetings.
[183] There was no attribution attached to the definition. It was not recognized by any interviewees (see Appendix G).

issues such as: 'how will I know when I'm dead?' or 'what is heaven like?' pointing out that other professions follow the medical model: diagnose a problem, decide a course of action and report on success or failure. In spiritual care it *may* be possible to 'diagnose' a problem but the chaplain can only advise an approach or suggest a change of attitude. The chaplain does not prescribe treatment (doctor) or instruct in appropriate exercises (physiotherapist) or arrange for Social Services to provide carers (Social Worker) or help bring about change and improve wellbeing (counsellor). The shortcomings of an electronic system were also highlighted by Martin. He acknowledged that the system needs to allow for multiple combinations of culture and faith but the chaplain sees the person, not the categories and what do you do when the system has no facility to record 'lapsed'?

Fred, Greta and Norman also spoke of the medical model of recording evidence. Two chaplains (Fred, Keith) told stories of sitting with dying patients as examples of the difficulty of turning these encounters into interventions that could be recorded as evidence: 'that person can't come back and write in the notes "I was really happy that you were there".' Valerie explained that in her hospice evidence is defined as intervention and, in the absence of an accepted and recognized chaplaincy audit framework, the level of intervention is defined according to the practitioner's psychological qualifications. As she does not have any such qualifications all her interventions are at level one. She also raised the issue of permission to visit a patient:

> we go on the verbals – CQC[184] would like written. That's never going to work in a hospice. How am I going to go in to a semi-conscious patient with no movement in their hands and say 'would you sign this form for me love?'

The best she can do is record in the notes that the patient is happy for her to visit again, but then there is the issue of the nature of the intervention. A lot of roles in the hospice overlap and she asked: 'What happens when the other professionals have taken the touchy-feely connect with yourself stuff? what do we do then?' She said she did not mind that other people are providing spiritual care but she wanted to be involved too. She was concerned that the chaplain's religious role was diminishing and there was a danger that her spiritual interventions were regarded as naïve and very small and the consequence would be a loss of her role.

Tracy stated that she did not shy away from recording the patient's experience, whether or not religious language was appropriate, but other interviewees were less clear perhaps due to the variety of understanding amongst those who will read the

[184] Care Quality Commission, the independent regulator of all health and social care services in England.

notes. Tracy had been involved in the design of the electronic system and using it had made her concise, helping focus on the essence of any conversation. A few other interviewees also mentioned electronic recording systems. John suggested that in recording: 'we are not thinking creatively enough'. He had not written 'a special moment watching the cygnets on the lake' in the notes but when he later read the previous nursing entry 'had a rough night, awake at three in the morning, needed a tablet' he realized that he could have written 'had a fabulous moment with Alf just now looking at the swans' to signify that the patient's equilibrium was restored. Norman recorded the impact that an ice-cream had on a particular patient – it was the most wonderful thing that happened to them all day! – and observed that nobody asked 'what's all this twaddle?'

A note indicating a conversation about death and dying, or relationships, or regrets and forgiveness is relatively straightforward but a conversation about sport? One patient stated that his religion was the local rugby team, another came alive talking about the television programme 'Strictly come dancing'. Some hospices have stickers saying 'significant conversation' to put in the notes but this is not appropriate if the patient is in a coma. Keith said that in the hours sitting by the bedside of someone in a coma he is 'conscious of something happening in that space but I cannot prove it to the person who pays my wages.' Fred stated early in the interview that the last few years had seen 'a move towards a medical, clinical model, towards recording, towards evidencing - for fear of litigation'. He observed that the patient whose hand he held in silence, and who was able to be welcomed by his maker peacefully, cannot come back to express his appreciation. Fred also asked how he could turn relatives' thank-you letters into acceptable evidence, indicating that he thought it impossible to give any quantitative measurement to the nature of the ministry of hospice. Robust structures of clinical evidencing were the opposite of his understanding of 'the heart of hospice'. He was not sure how long he could go on. William also felt that, whilst not disputing the need for accountability, evidencing was not part of his perception of the role of chaplaincy which necessitated availability and approachability. At the time of interview he had not been asked to provide evidence other than the number of patients visited and number of conversations held. In contrast Yasmin was comfortable with having to provide evidence, pointing out that the nursing profession had already struggled with the issue. However, she was cautious about the language used, saying that recording a conversation about 'regrets' is not high-powered enough for management.

In the description of spiritual care given earlier I have indicated that chaplains understand themselves as 'being' rather than 'doing' and in connection with evidence

several stated that the chaplain does not have objectives, she is not there to 'do' anything. Norman asked: 'in so far as we aren't actually doing anything how do you actually measure 'not doing anything'?'

If the patient expresses feelings about existential issues such as 'what happens when I die?' or 'how will I know when I'm dead?' or 'what is heaven like?' what degree of detail is appropriate for the chaplain to write in the notes? Reluctantly Steven thought he would go down the evidence route. He commented that he disliked his own cynicism when he observed that downstairs on the ward it matters that he visits but upstairs in the offices what matters is recording the visit – not the content which might appropriately be shared with other members of the MDT – because that affects 'the stats for the commissioning rounds.' John said 'If it's not evidence-based and evidence-led we shouldn't complain if we don't get recognized or accredited by others. So with regret…' he would be recording evidence. Ian said that a good scientist knows that all our theories are 'just one observation away from being totally trashed.' However, it was important not to invalidate the intuitive but seek to understand it. He also mentioned recording the physiological changes when praying for the dying patient, commenting that the family noticed those changes when he prayed that the patient would let go, saying that the response to prayer is more immediate than the response to chemical drug dispersal.

Spiritual assessment tools

Three interviewees work in hospices which use SystmOne to record notes[185] but all three described a limited facility on which the chaplain could record that a visit had been made but with little detail. One of the three made it clear that the nurses obtained information on religious affiliation for the record whilst he carried out 'a narrative assessment that might not take place at just one point in time.' Several interviewees said that the admitting doctor or nurse will seek to establish the patient's source of inner strength or coping strategy, look for signs of spiritual pain and enquire about religious or spiritual connections but that their assessment would be on-going.

Beth explained that any of the staff she had taught (housekeepers, volunteers, nursing staff, medical staff) might use the spiritual assessment tool based on the

[185] **SystmOne** is a clinical computer system developed by TPP (The Phoenix Partnership), used by healthcare professionals in the UK predominantly in Primary Care, though its use in Secondary Care settings is growing. It is being deployed as one of the accredited systems in the government's programme of revolutionising IT in the NHS. SystmOne is available as a number of different modules designed for different care settings. TPP are involved in the development of electronic patient record systems converting large numbers of paper records into digital form.

mnemonic HEALER[186]. Queenie described three approaches to spiritual assessment: a form filled in by the patient, an assessment guide for the practitioner, and narrative, this last being the one most used in her hospice: 'we've just had a very free form way of keeping our notes.' However her chaplaincy team was looking at whether they could use the electronic system to give them a template or some structure that would help ensure they had covered all the basics and not forgotten anything.

When asked if a spiritual assessment tool was used Charles was amongst those interviewees whose tone of voice in saying 'no' indicated that he did not value such a tool - and yet he admitted to feeling guilty about it. He suspected that 'in the States the doctor who clerks somebody will ask those questions' but it doesn't happen here unless the doctor is doing an holistic assessment. He felt that assessment 'comes out of a relationship that builds gradually…'. Norman was politely dismissive:

> for me spiritual assessment does not actually have a role to play. It's not my role to come in and assess someone's spirituality and then put a whole programme of care and solutions and treatments. This is very much a medical model……we do not see ourselves as people who provide interventions.

Ian had spoken clearly about not pushing his own agenda but accepting people where they are so I asked whether he was doing spiritual assessment as he went along, to which he replied firmly 'Yes.' He is 'quite uncomfortable' with trying to formalize:

> I think there are things you can recognize. I'm getting to the point where I feel I've done enough hours, got a breadth of experience to be able to classify…

but he would be horrified at any suggestion of stages to use in assessment because it implied fitting people into boxes. He was of the opinion that such an approach was liable to exclude rather than allow for 'and, and'. As a scientist by training he appreciated the value of the demonstrable, the observable and repeatable but 'you have to be very clear about what you are measuring.' He was concerned to point out that the absence of check boxes does not mean that he is not assessing, and that intuitive assessment is valid – but he felt that he should be able to understand the intuition.

[186]HEALER - hope, explore feelings, adjustment to loss and change, looking back, existential questions, religious beliefs.

Conclusions

The data from the interviews produced a thick description in the form of hospice chaplains' stories of how they came to be in hospice ministry, the differences between hospice and congregational ministry, and their perceptions of the relationship between church and chaplaincy. There was also plenty of information on how they introduced themselves to patients, what they wore, their perception of patients' expectations, and their thoughts on training and the importance of life experience. Whilst the concept of spirituality was not easily defined the understanding of spiritual care was well-described by examples from their work. However their understanding of their own spirituality was not easily articulated and the connection with sustaining them in their work was rarely made. Being asked to describe the ethos of the institution in which they worked appeared to surprise some interviewees and the majority focused on the ethos in relation to patients and their families. Opinions on the requirements for record-keeping, evidence-based practice and spiritual assessment were readily expressed but little was said about the theology underlying their work, and the chaplain's unique contribution to spiritual care was not obvious.

The rich data reveals that hospice chaplains are pre-dominantly patient-focused but there is little description of exactly how a chaplain works – details of the process are not obvious. There is no mention of reflection, embodied or otherwise, and only one interviewee (Ian) mentioned intuition, but several interviewees used 'presence' to describe the nature of their work. The process by which I am drawn to this concept is not obvious but it involves reflection and intuition, perhaps an example of 'the Spirit at work drawing the student into a particular field of enquiry' (Flanagan, 2014:126). My reflection on the data suggests the possibility that chaplains' working processes are contributing to and occurring in the practice of presence. To illuminate this concept of presence I propose to analyse the data in terms of ministerial formation, which then leads me to explore the role of *kenosis* for the interviewees. However, further reflection in the light of my own experience, both personal and professional, prompts me to begin with an examination of the effects of the chaplain's presence: is it transformative for the patient and the hospice? Does it facilitate a different way of seeing things or a re-framing of perception? Is it counter-cultural in any way: to hospice management's ethos, to the accepted attitudes of society (towards death and dying)? Therefore I need a model of analysis which applies to both individual and institution. On the individual level it will reveal the chaplain's role in releasing the patient from dominant thought patterns. At the

institutional level it will identify the similarities and differences between the hospice chaplain's presence and the dominant culture within which she works.

Section Three: Interpreting the data

The purpose of this section is to use my own understanding of spirituality and the work of other writers on spirituality and spiritual/pastoral care to explore and analyse the spiritual voiced by the interviewees. It is also anticipated that data from the interviews will throw light on the wider hospice situation especially in view of recent developments such as changes in funding arrangements and the Report on the Future of Hospices (Help the Hospices, 2013a).

As I conducted the interviews and typed up the transcripts various themes began to emerge. Whilst interviewees acknowledged that change was happening, there was nevertheless an assumption that hospices would continue – not unlike the way we take for granted that our natural world will continue to function as it always has, that is until the unseen tectonic plates shift resulting in a tsunami. In the hospice various tectonic plates have co-existed peacefully - and in some cases still do. However, the management model of financial problems to be solved and the friction with the pastoral model of care is manifesting in the need to measure, justify, and prove the worth of every salary. In addition there is friction, not always acknowledged, between the medical and pastoral models of care. The medical model is rooted in scientific method, regards the body as the object of medical attention and illness as a problem to be solved. The pastoral model makes no claim to be scientific, but accepts the person as they are, seeks to be with, listen, support, guide as appropriate.

The data shows that interviewees are concerned about the need to prove their worth, but express concern as to how to measure the effectiveness of spiritual care, how to prove the value of 'presence'. Some, like Tracy and Steven, demonstrated an awareness of the friction between patient-facing and organisation-facing cultures. Others, Larry, Valerie and Fred, spoke of culture change in the hospice whilst still others, Xelda and Ian, focused only on the patient-facing caring culture appearing to suggest that there was no friction - as yet. To me the possible transformative and counter-cultural aspects of the chaplain's role suggest a comparison with the Old Testament prophets, which I present in Chapter six. I then examine the formation of presence in Chapter seven, which reveals that the chaplain's experience of 'being who the patient needs me to be' may include *kenosis*, which is then explored in Chapter Eight. The final chapter describes some of the boundaries that have been revealed, both in what was said and what was not said, in the interviews. Given the themes examined in these chapters the data used is predominantly from the twenty-two Christian chaplains interviewed.

Chapter Six: The Prophetic Role

Introduction

In my conclusion to the previous chapter I focused on the interviewees' use of 'presence', wanting to explore this concept further. To establish whether the chaplain's presence is transformative, encouraging a re-framing of perception, and counter-cultural I am making a comparison with the Old Testament prophets - effectively I am assessing the prophetic nature of the chaplain's presence. For the purposes of this research a prophet is understood as a spokesperson:

> I will put my words in the mouth of the prophet, who shall speak to them everything that I command (Deuteronomy 18:18).

He does not announce the future[187] but sees the world as God sees and speaks in God's name (Charpentier, 1981: 43). In such speaking he may be pointing to that which has been lost or forgotten, or perhaps not acknowledged. A prophet such as Hosea sees the presence of God in his own life and in the life of the community and by his words and actions shows the community how to do likewise. The hospice chaplain also sees the presence of God in her own life and in the lives of those to whom she ministers. She hopes to demonstrate God's presence through her own presence and her own actions but she must choose her words carefully so as not to proselytise. Considering the Old Testament prophets Walter Brueggemann[188] states:

> The task of prophetic ministry is to nurture, nourish, and evoke a consciousness and perception alternative to the consciousness and perception of the dominant culture around us. (Brueggemann, 1978:13)

Like Brueggemann I do not believe that a prophet is a social activist or a reformer (1978:28; 1982:52) and it is the evoking of an alternative perception, which I believe to be common ground, that prompts me to explore the hospice chaplaincy in the light of the Old Testament prophet. I am aware that Brueggemann has his critics[189], but I am not convinced that the arguments have a bearing on my use of his work (Brueggemann, 1968, 1978, 1982) to establish an understanding of the term 'prophet' with which to assess the prophetic nature of the hospice chaplain's

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[187] Visions such as may be found in Ezekiel and Daniel are understood not as predicted events but as encouragement to believe that the future is in God's hands.
[188] Walter Brueggeman, born in 1933, is Professor Emeritus at Columbia Theological Seminary. A prolific writer, he is ordained in the United Church of Christ and widely considered one of the most influential Old Testament scholars of the last fifty years.
[189] Anderson (2009) recounts Waltke's criitique of Brueggemann shifting the authority of the text away from the Holy Spirit to the interpreter and the willingness of the community to engage with the text. Like Anderson I find no challenge to the authority of the text but encouragement to faith communities to wrestle with the complexities of both text and God. Neither do I find that Brueggemann's handling of the Exodus reduces the significance of the cross (Vandervalk, 2010).

presence. Therefore I shall consider and compare Brueggemann's prophet with the characteristics of the hospice chaplain as suggested by the research[190].

The prophet and the chaplain

In his early work on the role of the prophet Brueggemann (1968) drew attention to the nature of previous scholarship which had tended to focus either on what he called the crisis without attending to the tradition in which the prophet was grounded or on the 'form and substance' of the tradition, giving scant attention to the context and the prophet's handling of the situation. Brueggemann argued the case for a more balanced approach which in today's healthcare language might be described as 'holistic'. I therefore consider and compare prophet and hospice chaplain in terms of gender, calling, faith community, tradition, context or dominant culture in which they operated, the nature of the language used and its purpose.

Gender and calling

The Old Testament prophet was a male[191] member of a marginal faith community (Brueggemann, 1982:50). A hospice chaplain is as likely to be female as male and a member of a declining faith community (Profile Survey: Chapter four and Appendix P). Regardless of gender neither the Old Testament prophet nor the hospice chaplain viewed their role as part of a career plan, both believing the call to be part of God's plan. The prophet's calling is recorded as from God, it is not planned by Isaiah, Jeremiah, or any of the prophets:

> In the year that King Uzziah died, I saw the Lord sitting on a throne, high and lofty; and the hem of his robe filled the temple… Then I heard the voice of the Lord saying, "Whom shall I send, and who will go for us?" And I said, "Here am I; send me!" (Isaiah 6:1 & 8)

> Now the word of the Lord came to me saying, "Before I formed you in the womb I knew you, and before you were born I consecrated you; I appointed you a prophet to the nations." Then I said, "Ah, Lord God! Truly I do not know how to speak, for I am only a boy." (Jeremiah 1:4-6)

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[190] The data is from the original interviews and follow-up telephone conversations.

[191] Although Miriam, Deborah, Huldah and Isaiah's wife are identified as prophets they do not appear to have performed publicly, as did the male prophets. Deborah's public actions relate not to being a prophet but to her role as a Judge:

> At that time Deborah, a prophetess, wife of Lappidoth, was judging Israel. She used to sit under the palm of Deborah between Ramah and Bethel in the hill country of Ephraim; and the Israelites came up to her for judgment. (Judges 4: 4-5)

It is of interest that in the Jewish tradition, the Tanakh, the books of Joshua, Judges, 1& 2 Samuel, 1 & 2Kings are all included in the section on Neviim – the prophets. My thanks to Tarcisius Mukuka for this last point.

but in the chaplain's case the call is mainly spoken of in terms of chance and serendipity[192] .

Faith Community and Tradition: the prophet

The prophet modelled what he believed within and for a faith community (Brueggemann, 1968:125). His task was to hold and critique the tradition (Torah) of that faith community so that by analysing and evaluating it for the current context its relevance was demonstrated to the community (Brueggemann, 1982:51). Brueggemann argues that traditions are not just memories but tools or weapons, they have a purpose and in this case they reminded the community of their identity, found in the history of their covenant relationship with God recorded in the Torah[193]:

> you shall make this response before the Lord your God: "A wandering Aramean was my ancestor; he went down into Egypt and lived there as an alien, few in number, and there he became a great nation, mighty and populous. When the Egyptians treated us harshly and afflicted us, by imposing hard labor on us, we cried to the Lord, the God of our ancestors; the Lord heard our voice and saw our affliction, our toil, and our oppression. The Lord brought us out of Egypt with a mighty hand and an outstretched arm, with a terrifying display of power, and with signs and wonders; and he brought us into this place and gave us this land, a land flowing with milk and honey." (Deuteronomy 26:5-9)

Thus, for the prophet community and tradition are well-defined, interconnected and mutually dependent. Using this model I examined the data in order to establish the nature of the faith community and the tradition for the hospice chaplain.

Faith Community and Tradition: the hospice chaplain

I began by examining the data for evidence that chaplains, like prophets, lived in and worked for a faith community.

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[192] See Chapter Five

[193] Also found in Psalm 136 which records God's action in their history including the exodus story:

> **10** who struck Egypt through their firstborn,
> for his steadfast love endures forever;
> **11** and brought Israel out from among them,
> for his steadfast love endures forever;
> **12** with a strong hand and an outstretched arm,
> for his steadfast love endures forever;
> **13** who divided the Red Sea in two,
> for his steadfast love endures forever;
> **14** and made Israel pass through the midst of it,
> for his steadfast love endures forever;
> **15** but overthrew Pharaoh and his army in the Red Sea,
> for his steadfast love endures forever;

Most hospices still follow the original AHPCC recommendation of requiring the chaplain to be authorized by his faith community, although one interviewee reported that since his hospice had its own philosophy, to which staff and volunteers were expected to conform, 'we are the authorizing community'. This interviewee commented that AHPCC Guidelines had softened:

> A chaplain can be ordained or lay with an acknowledged status within a mainstream faith community (AHPCC, 2013:2)

but stated that it was an area of contention at AHPCC conferences especially for those who 'follow the religious route.' Another interviewee was a member of what he referred to as 'a new stream of church', not mainstream, and he felt that attitudes were changing such that healthcare institutions no longer assumed that chaplains were Anglicans.

Compared with the interviewees' ambivalence towards the church faith community their appreciation of the support of the AHPCC community was noticeable, with highly rated area meetings as well as the well supported Annual Conference. However, it could be argued that this was a different kind of community since it was not confined to one specific denomination or faith.

Each chaplain interviewed was a member of a denominational faith community and in some cases that community licensed the chaplain to work in the hospice but the data showed that the sense of involvement with and support from that faith community was variable. Doreen felt that the church was beginning to move on from the role of benign but absent parent, realizing that chaplains were worth listening to, but John said: 'Structurally I don't feel that there is a great deal of support or understanding.' Of the twenty two Christian chaplains interviewed, eight held additional responsibility in a congregational community and four were regular members of a congregation, but ten had little contact - although five of these filled in for local clergy as and when need arose. However, some of the churches needing help expected the chaplain to promote the hospice. In fairness I should point out that some of those with little contact with a church chose to be in the hospice on a Sunday[194] and two of these had found alternative spiritual succour, one in a weekday Christian meditation group and the other in the communion service of another denomination, but there is nothing to suggest that either of these functioned as the chaplain's faith community. Greta spoke of searching for a place to worship that would be her faith community, providing support and spiritual nourishment.

[194] Interviewees were asked about connections with a local church. Limiting such connections to a Sunday was the response of the interviewees, not suggested by the interviewer.

Further complicating the identification of the chaplain's faith community is the nature of her work, with and for an individual – patient, family member or staff - rather than for a community as such. As proselytising is forbidden, that work is at a level of spiritual awareness rather than religious commitment. Not only is this not as yet an approach openly acknowledged by the church but some chaplains reported being told by congregational ministers that they were 'not doing the proper work' or that they have 'copped out', perhaps contributing to their ambivalent attitude towards the faith community in the local church.

Hospice as community

In Chapter One I described how St Christopher's was founded in 1967 rooted in Christianity (Bradshaw, 1996:411). Saunders' original vision was for the hospice to be a community in which all who came would feel at home and staff would be united by their common aims and Christian beliefs (du Boulay, 2007:72). However, as early as 1960, still in the planning stage, Saunders had to acknowledge that to expect: 'a secular group of people without any rule to be able to hold together and give the feeling of security which I want so much to help our patients' was asking the impossible (104). Nevertheless, even though it had no rule, no oath of commitment, no sharing of possessions it did have a playgroup for children of staff, accommodation for retired staff and a common sense of purpose – and in reality it was a community (104). Saunders referred to it as 'a village' and 'a reaction against the impersonal medical city.' Feedback from patients' families described it as 'a family' and it still had that feeling when I attended a short course there in 2000, but that year also marked a downturn in economic conditions and the retirement accommodation was closed. The nursery survived until 2005 and at that point Saunders had to let go of her vision of the hospice as a community (203).

The idea of community may have died but the concept of teamwork survived and thrived and is one of the hallmarks of hospice care. Therefore I used the sense of being part of the team, embedded (Charles, Larry), as an indication of community, albeit not a faith community. Several interviewees (Alan, Fred, Norman) described being part of a team, all working to the same end of trying to give the best care. The team was usually multi-disciplinary, although some also mentioned being part of a chaplaincy team or the Patient & Family Services Team. Doreen described herself as fortunate to have always been part of a supportive team, previously in congregational ministry with other Christian ministers and now in the hospice with people of different professions. Whilst Tracy and Steven alluded to the difference between teams in the patient-facing area of hospice and those in management the

overall feeling I gained from the data was of belonging, being part of the hospice community[195].

Chaplains and the wider faith community

However, the data also indicates that Christian chaplains relate to the wider Christian faith community and regard themselves as part of the Christian tradition but unlike the Old Testament prophet a chaplain is contractually bound not to promote her tradition[196], which has to be put on one side or 'left at the hospice door.' Greta explained that it is not about her but about the patients and their families and Ian said:

> My role is to affirm people, support people in their spirituality, their understanding, their belief system, their faith system without any regard to mine. I've got to leave all of that at the door…

He spoke of maximizing the person's spiritual comfort whatever the source, something which Oliver admitted he found difficult.

Several chaplains spoke of their grounding in their own faith tradition: 'I believe my feet are firmly rooted in a faith that sustains me' (Tracy) and John described having a 'deep grounding in one's own faith, having a position on which to stand' but at the same time recognized that everyone else had their beliefs. Such grounding was in marked contrast to the people with whom they worked who generally had little or no knowledge of spiritual or religious tradition (Doreen). Despite the grounding the data yielded only a few Biblical references and examples of the use of aspects of the Christian tradition were conspicuous by their absence[197]. However, John spoke of the need for 'a sense of liturgy' at the memorial 'Lights of Love' services or when a member of staff died. He gave the emotions form, expressed them as 'what we as an institution feel' so that those present could identify and acknowledge their emotions[198].

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[195] Whether that is the entire hospice or just the patient-facing area is not clear.

[196] Yet some ordained chaplains wear a dog-collar at least some of the time and apparently not in contravention of the contract.

[197] Larry recognized the patient's reference to being dust as a reference to the words used in the Funeral Service and used the analogy in a positive way by suggesting that the man was gold dust; Greta did not want to just read Psalm 23 to the deceased's relatives but wanted to 'tap into something that they could relate to'; John reported adapting the story of the Prodigal Son to convey a sense of worth to various patients; Valerie had told the story of the thief on the cross to a patient struggling with whether she was good enough to go to heaven.

[198] The 'Lights of Love' service uses the symbolism of candles. At time of writing there was a serious stabbing incident involving teenagers in the Benefice to which I am attached. The vicar devised a simple outdoor service using candles saying 'We use symbolism when it's too awful for the words.'

The data also suggests a broadening of the tradition amongst Christian chaplains from church membership to shared humanity. Alan expressed the need to be broader than church in order not to limit God and to be able to embrace the mystery. Keith explained that his background experience with the church was like baggage which would interfere with his chaplaincy role, but he could:

> …be a human being in that space with them and there is some sort of energy and grace with that… And there is a kind of connectedness and I am accompanying them, not in an official relationship but we share a common humanity.

For Beth broadening the tradition to being human was not incompatible with God: 'in being very human there is something very loving and divine.' Greta spoke of the disfigured patient needing affirmation as a human being. John and Doreen were there as a human being and Larry described talking to a patient 'as a human being.' With no common religious ground the interviewees meet patients 'where they are at,' saying that they would 'be the person they need me to be' (Ian, Unwin) and offer whatever the patient needed at the time (Alan, Xelda, Ian). John indicated that it was in his humanity that he hoped 'to give a human face to God.' Consequently Biblical, religious or liturgical language from the tradition was not used because 'it's such a foreign language' (Tracy). Understanding the tradition as human rather than religious aligns with Saunders' statement that what the dying need is 'someone who will come to this meeting not bearing any kind of technique, be it therapeutic, pastoral or evangelistic, but just as another person' (Saunders, 1965a:4).
The role of both prophet and chaplain was to help the recovery or establishment of the tradition, but whereas the prophet used the actual tradition of the relationship between God and the people the chaplain has to establish what tradition, if any, is held by the patient. Encouraging the patient to tell their story (Ian, Beth, Valerie, Oliver) and questions such as: 'How have you coped in the past?' (Patricia), 'How are you feeling about where you are?' (Eric), 'How do you feel about your future?' (Eric), 'How are you making sense of this?' (Charles) might reveal that tradition, religious or otherwise.

Thus far there is a marked difference in the nature of the community and tradition of prophet and chaplain. Whilst the prophet's community is well-defined the chaplain's is hard to locate. The prophet's tradition is clearly stated whereas the chaplain's own tradition is of necessity hidden and the tradition against whose backdrop she works has to be explored with each patient. There is also the possibility that hospices have their own patient-facing tradition based on Saunders' original vision of:

> …a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end (Saunders, 1958:11)

However, this tradition was formed when Christianity was still the dominant culture in England and Saunders' charismatic personality was a strong influence on the hospice culture, the context in which the chaplain worked[199]. Before considering the context for prophet and chaplain in more detail I want to draw attention to societal developments in England in the sixties and briefly visit the work of Alister Hardy[200] and David Hay[201] on the nature of spiritual awareness.

Context and dominant culture: background

Alister Hardy founded the Religious Experience Research Unit in Manchester College, Oxford, in 1969. Hardy argued that spirituality is a natural form of awareness, refusing to accept that an academic argument could dismiss his (Hardy's) experience of God in nature. This was the period when secularists and Christian conservatives were thinking that if Darwin's theory of evolution was correct the existence of God was no longer credible. Hardy's response to the dismissal of his experience was to dismiss Darwin as irrelevant (Hay, 2006:35-36). He was the first person to explore the universal nature of spiritual awareness in biological terms (Hay, 2007:2), pointing to its important positive function of enabling individuals to survive (Hay & Nye, 2006:22). It is this sense of spiritual awareness contributing to the ability to survive that chaplains are concerned with. Beth, Fred and Keith spoke of their personal spiritual nourishment in terms of God in nature but only John gave an example relating to a patient.

Like Hardy, Hay argues that spirituality is a natural awareness, a primordial human experience, a bodily awareness or 'felt sense' that is there before words or thinking (Hay, 2006:31). Hay does not accept that human beings are born as atheists who are socialised into acquiring religious beliefs but the opposite:

> We are born with a vivid awareness of a transcendent dimension to our experience and we learn how to interpret it via the local religious

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[199] The decline of Christianity as the dominant culture in healthcare was explored in Chapter One. On a wider stage Charles Taylor explores the changing nature and place of religion in the western world in *A Secular Age* (Taylor, C. (2007) Harvard University Press).

[200] Alister Hardy (1896-1985) was head of the Zoology Department at Oxford University.

[201] David Hay (1935-2014) worked with Hardy's Religious Experience Research Unit, taking over as director in 1985 when Hardy died. He subsequently held posts at the universities of Nottingham, Lampeter and Aberdeen, publishing numerous articles and books on religious experience.

> culture, thus integrating it into the pattern of our lives (Hay, 2007:41).

Hay maintains that socialisation causes the loss of that awareness and is particularly critical of the role education plays in depriving children of their spiritual birthright (Hay & Nye, 2006:144). He argues that there is a tendency to treat education as a commodity to be distributed and measured, resulting in objective knowledge being privileged over subjective (144) with the consequent loss of spirituality or relational consciousness, as Hay calls it. However, Hay also cites 'the threadbare texture of community in many parts of our society' (146) as a cause of the loss of spirituality/relational consciousness pointing to events such as the Bulger case in 1993 in which two ten-year-old children forgot who they were, or perhaps never understood what it is to be human, and murdered a two-year-old.

If Hay is right, that identity is rooted in relational consciousness/spirituality, perhaps it is not surprising that many adults flounder when faced with a terminal diagnosis or the unexpected death of a loved one[202]. Whilst acknowledging that for some people relational consciousness results in religious belief Hay does not seek to promote religion but wants, like the hospice chaplain, to nurture humanity (148). Such nurturing releases people from the need to conform in order to survive[203] (147) and frees people from 'historically created social pressures' that prevent or harm wholeness (149). The role of both prophet and chaplain includes identifying those social pressures and enabling people to imagine an alternative, and it is to that context that I now turn.

The context or dominant culture: the prophet

As a marginal people the value of the Israelites to the dominant culture, whether that culture was Egypt under Pharaoh or royal under Solomon, was economic. To maintain the economic status quo it was necessary to exercise social and political control without acknowledging responsibility for the people's welfare. To that end the Pharaohs subjugated the gods. They did not annihilate or defeat the gods for they understood that the gods were a tool for social control (Brueggemann, 1978:36). The Israelites understood that the gods were not free or independent but under Pharaoh's control and for this reason Pharaoh could not be criticized or challenged. However, when Pharaoh died (Exodus 2: 23-5) the Israelites were able

[202] In my experience many adults whose diagnosis meant loss of job and /or loss of appearance had little or no sense of self-worth and no resources to help them navigate their terminal illness.

[203] Hay gives the example of a boy joining a gang in order to survive, but to be accepted he has to forget who he is and create a false self (Hay & Nye, 2006:147).

to express their anguish[204] to 'the God of Abraham, the God of Isaac, and the God of Jacob' (Exodus 3:6) who was not answerable to Pharaoh but free to act as he wished.

It is arguable that a hostile dominant culture, external and threatening to the survival of a faith community, is easier to recognize than a home-grown dominant culture established by King Solomon. We might think that a divinely appointed king did not need to subjugate God, as the Pharaohs subjugated the Egyptian gods, but Brueggemann shows how Solomon domesticated God so that God would serve Solomon's purposes rather than the other way round (1978:34). Again the issue was one of social and political control: the common people were oppressed and exploited and those who managed the exploitation became affluent and apathetic to ideas of justice[205]. Affluence inures to the suffering of others (41) and there was no reason to think that God might be suffering with his oppressed people. The affluent might dismiss the cries of the suffering as a betrayal of God (41), who was on their side, not realizing that they themselves had relegated God to the role of maintainer of the status quo (42). In these circumstances:

> It is the vocation of the prophet to keep alive the ministry of imagination, to keep on conjuring and proposing alternative futures to the single one the king wants to urge as the only thinkable one (45).

Brueggemann suggests Jeremiah as the best model of a prophet using imagination to embody an alternative perception to the dominant royal culture (51). The role of the prophet was to enable oppressed people to engage with their suffering and release it in words of grief[206] which Brueggemann refers to as 'the language of lament'.

The context or dominant culture: the hospice chaplain

I have gone into some detail on the recognition of the dominant culture and its effect on the people because Brueggemann argues (45) that 'the same realities are at work in every family and every marriage and every community.' I therefore explore the data for signs of those realities, enabling people to grasp an alternative future and be released from oppression, in the work of the hospice chaplain with individuals and

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[204] Brueggemann calls this expression of anguish a 'primal scream' – a concept which I shall explore further. It is the first stage in seeing reality differently and essential for the reframing of view and attitude.

[205] Considering feminism as a prophetic alternative to patriarchy Ruether argues that the prophet opposes the established religion which is part of the dominant social order. She refers to religion as the 'handmaiden' of the ruling class (Ruether, 1994: 58-73)

[206] An example of 'hearing to speech', to borrow Nelle Morton's phrase (Morton, 1985:127-8). The nature of the listening necessary is explored in Chapter seven.

in relation to the hospice as an institution. Part of this process is about recognizing, owning and expressing feelings and the prophet uses poetic expression to take us inside the life experience which the dominant culture has suppressed (1982:53). Brueggemann argues that poetry has the time and patience as well as the impatience to pay attention to the textures and nuances of experience (53). I contend that hospice chaplains also have the time and patience, as well as the impatience, to pay attention to the textures and nuances of experience and that in enabling the patient to explore and claim his experience it may well be that dominant thoughts and perceptions which restrict and oppress are identified and grappled with to set him free[207].

In my experience the patient's world has been reduced, sometimes just to the room he is in, sometimes to the horizon of the family. Therefore his dominant culture may be a need for forgiveness (Alan, Yasmin), or how to cope (Valerie), or a perception of poor self-worth (Larry). Valerie described a patient whose world was reduced to the question 'will I go to heaven?' Valerie told her the story of the thief on the cross and prayed using the patient's words 'I'm sorry if I've messed up. Please forgive me and have me in heaven.' The patient's family reported that after her chat with the chaplain she was a different person, much more peaceful. Beth spoke of helping people to think differently, to 'see in new dimensions'. The dominant culture was a one-dimensional way of thinking which stifled imagination. By encouraging imagination the patient thought about death in a different way. In the absence of further examples from the data I observe that from my own experience the most common form of alternative perception was enabling patients to live life to the full, albeit with limitations, rather than withdrawing and waiting to die. Some made 'bucket lists' which often included travel – Anne went to see the penguins at the south pole – others had changes made in home or garden so that hobbies might continue.

Listening is crucial to identifying this kind of oppression, hearing what is not said as much as what is. Ralston (2014a) describes it as 'listening in colour rather than in black and white' and argues that the secular hunger to be heard is the equivalent of spiritual hunger[208]. This kind of listening is as important in relation to the dominant culture of the hospice itself.

[207] The latter half of the twentieth century was a time when the patient 'began to be remolded from a passive participant in treatment and care to an active collaborator' thanks to the work of Saunders, Houde, and Bonica (Seymour et al 2005:2)

[208] A point which I shall explore further in the next chapter.

Hospice culture today

This research has been carried out amongst hospice chaplains in England where, as I argued earlier, the dominant culture is no longer Christian and a secular society prevails. Pockets of Christian culture still exist in organisations such as charities like Tearfund and Cafod and there are educational institutions and commercial organisations which declare themselves Christian. In the early years of development many hospices followed St Christopher's example reflecting a Christian culture – and some still do reflect that culture[209]. However, developments at St Christopher's were shown in Chapter One to demonstrate the decline of Christianity as the dominant discourse. The overall culture in England is no longer predominantly Christian.

To consider the culture operating in hospices today I used the data from the question: 'what is the ethos of the hospice?' Interviewees' body language suggested that this question took some by surprise (Eric, Charles, Patricia) and their initial response was not related to the question (Charles). However, whilst there seemed to be a general feeling of care and compassion, especially in the patient-facing area of the hospice, there was also an awareness of change. It was reported that management had changed, both in personnel and in style, and a more business-like approach was manifest (Valerie, Fred). Patricia observed that whilst the hospice had never set out to be a Christian organization there had been more Christians, staff and volunteers, in the past than there were now. Steven commented that the introduction of management hierarchies had all but obliterated the Christian foundation of the hospice as managers claimed and protected their territory. When these staff spoke of not forgetting their roots they were not referring to the Christian foundation but to palliative care – as opposed to care of heart disease, Chronic Obstructive Pulmonary Disease or Alzheimer's Disease. When speaking of the need for liturgy at times of memorial John indicated that the normal hospice culture was not one in which emotions were openly expressed. Several interviewees felt that management no longer understood or appreciated the original concept of hospice and this resulted in unhappiness amongst the clinical and patient-facing staff (Fred, Tracy, Steven). These chaplains then found themselves supporting those staff but at the same time were aware that management were not happy with the chaplain having knowledge and power over which they (management) had no control and which might threaten their supremacy (Tracy, Steven).

Whilst the prophet identified the oppressive dominant culture, helped the people to recognize that culture and envisage an alternative the hospice chaplain has to

[209] Keith described the location of his hospice as demographically white and therefore culturally Christian.

contend with different dominant cultures: that which affects the patient, the culture in the patient-facing area of the hospice and the management culture.
With patients, their families and with staff the chaplain aims to provide spiritual care and support which results in a reframing of attitudes and the realization of alternative perceptions. For the patient and family this might mean recognizing and expressing feelings, like anger and grief, previously suppressed. They might also look at the situation differently, not letting the illness get the better of them, not unlike Jeremiah with the people of Judah:

> …this enabled people to endure the exile in faith and hope, not being overwhelmed by their misfortunes, but rather discovering a new meaning in life (Charpentier, 1981:62)

However, patients and families have little reason to challenge hospice culture as their experience is limited to the wonderful clinical care and contact with management is minimal. The chaplain's role with clinical staff has the potential to result not just in alternative perception but empowering them to express dissatisfaction and criticism, thus challenging management. In reality, disaffected nursing staff are more likely to suffer in silence than challenge management, using the chaplain to let off steam, ceasing their fund raising activities and then finding another job! (Steven). This leaves the chaplain as the one person who, given time and opportunity, might be able to facilitate management to an alternative perspective. However, this would only be possible if the chaplain was accepted, in reality as well as on paper, as Chaplain to the Institution. Of those interviewed only Queenie described being treated as an equal by her line manager, who was a Board member[210]. Other interviewees said that they were Chaplain to the Institution or chaplain to all but none conveyed the degree of acceptance conveyed by Queenie. However, Brueggemann warns 'situations of cultural acceptance breed accommodating complacency' (Brueggemann 1978:29) and chaplains need to consider whether the price of acceptance is loss of an otherwise counter-cultural role. Perhaps the already-mentioned dis-ease experienced by Tracy and Steven is a necessary 'living with chaos' not unlike that described by Larry who found the process of change, 'riding a storm', exciting.

The patient focus

Overall the data indicates that in describing the ethos of the hospice interviewees focused on the patient-facing work. The chaplain's role in supporting staff was rarely mentioned spontaneously suggesting it was not a frequent occurrence. Where it was

[210] I should also point out that Queenie was the only interviewee with extensive NHS management experience.

mentioned the interviewee also spoke of management's displeasure, supporting the view that there are two cultures operating in the hospice. In the patient-facing area or clinical side there is a predominantly caring culture that seeks to focus on the patient and his needs. The chaplain is part of this culture, being used to working with the unpredictable, whatever emerges and without planning or control, described by Greta as 'just about being, sitting with, holding a hand, no plan, no direction but not directionless.' This is in marked contrast to the management culture which needs predictability, planning and control in order to ensure that the hospice continues to exist. Despite the fact that the hospice is in the business of care the management culture struggles to acknowledge care of patients or staff. Whilst still describing the hospice ethos as caring some chaplains felt that management had little understanding of what Fred called 'the heart of hospice' and change was occurring such that the management ethos of financial survival was beginning to dominate. I suggest that these two cultures are like the tectonic plates spoken of in the Section Introduction.

Similarities and differences of prophet and chaplain

Whilst the prophet's character, his call, his faith community, the tradition, the way he worked and the context or dominant culture in which he lived and worked were interdependent the same cannot be said of the chaplain whose community is not uniform but varies from chaplain to chaplain, and whose tradition is a necessary but hidden ground that enables him to work with the tradition appropriate for the patient. Prophet and chaplain have in common the skill to enable alternative perceptions and the skill to hear into speech both of which threaten a controlling dominant culture. However only the prophet demonstrates these skills publicly – there is no equivalent of a 'Thus saith the Lord' speech for chaplains and even if there was I suspect the chaplain would think of the security of his job before using it. This highlights a major difference between prophet and chaplain – the prophet is not paid by the dominant culture. He might be harmed by it in other ways such as threatened, as Jezebel threatened Elijah (1Kings 19:1-2), or imprisoned as Jeremiah was thrown into the pit:

> Now Shephatiah son of Mattan, Gedaliah son of Pashhur, Jucal son of Shelemiah, and Pashhur son of Malchiah heard the words that Jeremiah was saying to all the people, Thus says the Lord, Those who stay in this city shall die by the sword, by famine, and by pestilence; but those who go out to the Chaldeans shall live; they shall have their lives as a prize of war, and live. Thus says the Lord, This city shall surely be handed over to the army of the king of Babylon and be taken. Then the officials said to the king, "This man ought to be put to death, because he is discouraging the soldiers who are left in this

> city, and all the people, by speaking such words to them. For this man is not seeking the welfare of this people, but their harm." King Zedekiah said, "Here he is; he is in your hands; for the king is powerless against you." So they took Jeremiah and threw him into the cistern of Malchiah, the king's son, which was in the court of the guard, letting Jeremiah down by ropes. Now there was no water in the cistern, but only mud, and Jeremiah sank in the mud. (Jeremiah 38:1- 6)

Jeremiah challenged the dominant culture's status quo of staying in the city by listing the consequences, and describing the alternative perception of leaving and staying alive. The data does not provide a hospice equivalent of this situation, nor are there many examples of alternative perception with an individual. Larry's reframing of dust as gold-dust has already been mentioned. Another example might be Beth's attempts to change the perception of the evangelical ordinands so that they see patients as people who need and deserve love and care rather than as objects of mission. Norman recognized the significance of the ice-cream for his patient. John realized that watching the cygnets on the lake was a significant experience for the patient but he also pointed out that that 'special moment' did not answer any of the questions on the spiritual care form. However he went on to admit that he had not been thinking creatively enough and was of the opinion that chaplains hold back from writing such moments in patient notes because they lack creative imagination[211]. He also expressed concern that chaplains not 'lose the capacity to allow those moments' which Brueggemann describes as 'open to the spirit' (Brueggemann, 1982:47).

Poetry and imagination in prophet and chaplain

Such moments of openness to the spirit were characteristic of the prophets who refused to be constrained but were receptive to experience and non-conventional discernment and for whom imagination was crucial (Brueggemann, 1982:47). According to Brueggemann a prophet refused to let life be quantified, generalized, summarized, but took time to notice and express pain and healing (47,53). Brueggemann also comments that if the prophet's poetic message with its pictures and metaphors was reduced to prose this would be like explaining music or reducing art to technique (1982:52), which seems to match the concern expressed by John Swinton (2013:68-69) in relation to chaplaincy evidence. The text box contains the extract from his paper shown to most interviewees, all of whom agreed with his sentiments[212].

[211] As I write I ask myself whether embarrassment is a factor.
[212] The interviewees were shown the extract without the attribution.

Chaplaincy needs to be evidence based and evidence led….My only caution is that we are careful that our right and proper attempts to meet the criteria laid down by the healthcare system do not blind us to the obvious: often it is that which cannot be seen or measured that proves to be vital. In our movement towards technical excellence we must be careful not to lose our soul (Swinton, 2013:68-69).

Whilst acknowledging 'If it's not evidence-based and evidence-led we shouldn't complain if we don't get recognized or accredited by others' (John) chaplains are wary of trying to quantify and summarize spiritual care. Greta echoed Swinton describing evidence-based practice as the medical model whereas:

> Chaplaincy is in the realms of the metaphysical. We need to be cautious. I believe in the rigour of academic training, accountability, supervision but if we lean too far towards the medical model we will lose our soul.

She went on to say that if chaplains relied on technical excellence they were 'no better than scientists of spiritual and religious care' and asked 'How caring is that?' Brueggemann warns that the 'managerial mentality' of the dominant culture does not believe that there are any mysteries to honour but only problems to be solved (Brueggemann, 1978:42). I have already mentioned that some interviewees indicated the more business-like approach which seeks to solve the financial problem of keeping the hospice afloat. Brueggemann's claim that the dominant culture will reduce the prophet's poetry to prose, which can then be turned into a programme, appears to be a good description of what might happen in the hospice: spiritual care becomes a tick box exercise. Just as the poetry's power to inspire (Brueggemann, 1982:52) is removed so the chaplain's care is removed from spiritual care reducing it to a function and neither prophet nor chaplain are able to convey belief in people. In its original form the prophet's poetry energizes people by nurturing hope rather than optimism (Brueggemann, 1978:96)[213] and hope asks 'is this really all there is?' (67), turning the people to look to the future – a future with the God who has done so much for them in the past.

Hope

Brueggemann argues that hope releases amazement to counteract despair and grief to remove the numbness endured by and under the dominant culture (1978:69)[214]. Hope hears the oppressed into speech or rather, for Brueggemann, into song! (72).

[213] Brueggemann draws attention to the connection between belief and energy commenting that where there was no belief Jesus could not energise, as shown in Mark 6:5-6 (1978: 100)

[214] A similar discussion of the role of hope in energizing resistance is found in Grey (2000:32-28).

However, in comparison with its importance in prophetic poetry hope is a word conspicuous by its absence from the research data. In the Gospel of Luke we learn that when John the Baptist appeared, preaching a baptism of repentance for the forgiveness of sins, the people flocked to hear him and understood his message (Luke 1:76-79). They then confessed their sins and were baptized in the River Jordan (Mark 1:5). Like hope the word sin was conspicuous by its absence from the interviews. I used the word search facility on my computer but found that all of the twenty appearances of 'sin' were actually part of words like since, business and nursing. Redemption was mentioned only once, by Larry who said that hope and redemption were both religious words.

Two interviewees mentioned hope in connection with their personal faith but only Patricia spoke about being a symbol of hope for patients. She included hope in her definition of spirituality: 'What gives your life meaning and purpose and hope and makes life worth living' and was of the opinion that meaning and hope were essential and that to lose hope was to lose everything. She spoke of helping people to readjust their levels of hope especially those who say there is no light at the end of the tunnel and struggle to maintain hope. She described how when they received bad news they felt as though they were walking on a tightrope. They unbalanced easily and may even fall off and she described her job as helping them think about how they've coped in the past, what helped them, who's there for them, what support they've got, what love, what care, so that they can get back on the tightrope and be steady enough to enjoy life a bit…until the next blow. In using the metaphor of the tightrope Patricia empathically expressed the reality of the situation and exposed what had been suppressed - not unlike Brueggemann's prophet who presented the situation as 'seen from the perspective of the passion of God' (Brueggemann, 1978:50). However, she was one of the chaplains who had experienced a loss of status in who she reported to – not that she saw it in that way. If Brueggemann is right that hope is counter-cultural (13) perhaps the change in reporting line was an attempt to subjugate a symbol of hope:

> Those symbols that will release experience and let it be redemptive bring to expression precisely those dimensions of reality which the king[215] fears and cannot subjugate (Brueggemann, 1978: 48).

Queenie commented that there are different kinds of hope and 'for people of faith there is hope of a life beyond.' Greta quoted from Hebrews: 'Now faith is the assurance of things hoped for, the conviction of things not seen' (Hebrews 11:1).

[215] For 'king' read hospice management which I suggest feared the reality of the original hospice vision of patient-centred care which appeared incompatible with financial survival.

For those with a Christian faith hope is an aspect of purpose:

> For to this end we toil and struggle, because we have our hope set on the living God, who is the Saviour of all people, especially of those who believe (1 Timothy 4:10).

Saunders' original vision, quoted earlier, included bringing 'hope and consolation to the end' but it would seem that Saunders' understanding of Christian hope has either been ignored or domesticated by the dominant culture to limit hope to the present, as in hoping for relief from pain, rather than future hope of heaven. Nolan's research (2012) supports this and he quotes a patient saying:

> There is a lot of hope about, but it's not the sort of hope that you're thinking of. Like a lot of cancer patients, I hope that there will be a breakthrough, that they will find some new treatment. I hope that I will die in here and I hope that my friends will be around for me. I hope for these kinds of things. But that's not hope in the way that you're thinking (Nolan, 2012:93).

Nolan admits that he was shocked by this[216] and went on to 'reconfigure' hope to mean 'hope in the present' with reference to the future no longer implicit or relevant. His interviews with chaplains established that 'presence' or 'being-with' was fundamental to the practice of spiritual care and he discovered that hope-fostering was often an outcome of that presence. Whilst hope received little mention in the data from this study 'presence' and 'being with' received many mentions and will be further explored in the next chapter. However, before moving on there is one further comparison to make relating to Brueggemann's expressed admiration for the prophetic use of 'the language of lament' (Brueggemann, 1978:51).

The language of lament

Brueggemann references Jeremiah (Brueggemann, 1978:53) as a prophet who articulated in lament the grief that was present in the community, acknowledged or not:

> Even the stork in the heavens knows its times; and the turtle dove, swallow, and crane observe the time of their coming: but my people do not know the ordinance of the Lord. (Jeremiah 8:7)

and the grief that the king/dominant culture was trying to deny:

> My anguish, my anguish! I writhe in pain! Oh, the walls of my heart!
> My heart is beating wildly; I cannot keep silent;
> for I hear the sound of the trumpet, the alarm of war.
> Disaster overtakes disaster, the whole land is laid waste.

[216] When I read the proofs of his book I was surprised that he was shocked. Then I realized that whilst he is a hospice chaplain Nolan is not a member of AHPCC and therefore had not been present at Conferences at which the nature of hope and the concept of presence had been discussed.

> Suddenly my tents are destroyed, my curtains in a moment.
> (Jeremiah 4:19-20)

Jeremiah sees community and king as Gods sees them, and the grief he expresses is God's grief (Brueggemann, 1978:58). Anguished and yearning for a way to avoid what had become the necessary death of king and community, Jeremiah knew that grief was the only way to new life: 'only grievers can experience their experiences and move on.'(60)

Although in my hospice experience I was involved in the practice of the expression of grief/sadness and the use of lament where appropriate[217], I could not find any such in the data. However there were references to crying and tears, two of which suggest an ambivalence to the expression of grief. Patricia recalled being told by her training incumbent never to cry with anyone because tears would stop her helping them and they needed her to be strong. In contrast Ian spoke of professional distance: he knew doctors and nurses in NHS institutions who had been taken to task for weeping with a patient, whereas in the hospice he and the nurses did not restrain themselves:

> I've wept – it's part of being human. I wasn't any less professional. If you show tears because of the distressing situation someone is in what a wonderful gift! No amount of words can say better 'I am moved by your situation' 'I feel your pain'.

Beth spoke of the positive effect of expressing her own tears after taking the funeral of a patient she had known for a long time. The family had not expected her to be upset but she felt that this evidence of her humanity was good, especially when they saw both how she was affected and how she recovered (because of her faith). She felt that such an expression only made her stronger and increased her empathy. If it is true that many of the new managers in hospice have NHS or industry backgrounds their attitude and therefore their culture is not likely to embrace the expression of grief in the workplace. The absence of the expression of grief may lead to the loss of the ability to grieve, especially if there is no-one to counter the culture and facilitate its expression. I believe this is an aspect of the chaplain's role, to hear the patient into the expression of grief by listening, and the nature of that listening will be explored in the next chapter.

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[217] Those patients who had a sense of God or of a greater being could be encouraged to express their feelings. More often than not I supplied the lament, which I called a modern-day psalm. Invariably it began 'God, it is not fair.' Twelve years ago I read one of my psalm-laments in the Resource Sharing Session at AHPCC Conference. It was met with a mixture of appreciation, requesting copies, and bewilderment.

Conclusion

According to Brueggemann (1968:124-125) prophets are not called to give a new message but they do need to be imaginative and creative in their identification and presentation of the tradition; the prophetic and the pastoral are not incompatible or mutually exclusive; the prophet is not alone using his private faith and force of personality but has support and resources from the tradition and the community 'that has gone before and has yet to come' (Hebrews 12:1); prophetic ministry is not grounded in feelings/hopes/needs of the individual but in something outside the self; the prophet does not predict but discerns God's presence and actions; prophetic ministry is not limited to words but is embodied in the whole person, his behaviour and his presence so that his investment of himself in the prophetic ministry is a sign of God's investment in people.

On the basis of the comparison made in this chapter I submit that the equivalent statement for the chaplain reads:

Chaplains are not called to give a new message but they do need to be imaginative and creative in their identification and presentation of the relevant tradition; the chaplain is not alone using her private faith and force of personality but has support and resources from her tradition; chaplaincy is not grounded in the feelings/hopes/needs of the chaplain but in something outside the self; chaplaincy is not limited to words but is embodied in the whole person, her behaviour and her presence so that her investment of herself in the chaplaincy is a sign of God's investment in people.

Having explored the prophetic aspect of the chaplain's concept of presence I now focus on how it is developed or formed.

Chapter Seven: Presence

Stay with me, remain here with me, watch and pray… (Taize Ostinato Chorale based on Matthew 26:38)

Introduction

At the end of Chapter Six I noted that the work of both prophet and chaplain is embodied in the whole person, behaviour and presence[218]. Some chaplains used the term presence to indicate that the role was more than the absence of tasks (Queenie, Larry, Eric, Beth). Norman said: 'it's more about presence, a much broader engagement than actually coming in to *do something* (his italics)*'.* Those who spoke of 'being there' or 'being with' (Greta, Xelda) also said it was not functional, not doing something but 'staying with the stuff that is difficult, painful and can't be changed' (Doreen).

To explore the chaplain's concept of presence, what it entails and how it is formed, this chapter uses the work of various writers including Henri Nouwen[219], whose model of the wounded healer provides the starting point.

The Wounded Healer

The concept of the wounded healer may have roots in Greek mythology (Williams, 2010) but many people today associate the term with Christianity and a few working in healthcare will name Henri Nouwen. I have already described how Cicely Saunders herself referred to Nouwen's work and over the years his book *The Wounded Healer* has been much referred to by hospice chaplains and by those exploring the nature of pastoral care, seeking to establish the necessary characteristics of Christian leaders.

Nouwen's book, *The Wounded Healer,* was first published in 1979 and is based on the premise that ministry requires the minister to 'make his own wounds available as

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[218] Presence is most commonly understood as 'being present' (Guiver, 1996:76). For example a school register establishes physical presence but gives no indication of the ability to interact, socially, intellectually, emotionally, spiritually with others. However, presence may also be understood to indicate mien, the quality or manner of a person's bearing and it may also be understood to mean that a divine or incorporeal being is present.

[219] Nouwen (1932-1996) wrote over forty books on the spiritual life, many of which include his personal experiences. Ordained priest in 1957 his varied career included teaching psychology, army chaplaincy, becoming Professor of Pastoral Theology at Yale Divinity School, spending time at Genesee Abbey, and living with Jean Vainer at the L'Arche community in France. He spent the last ten years of his life at L'Arche Daybreak, Ontario.

a source of healing' (Nouwen, 2014:xxii). Nouwen (97) contends that 'A minister is not a doctor whose primary task is to take away pain. Rather he deepens the pain to a level where it can be shared.'[220] The renowned pastoral theologian Alastair Campbell[221] states that pastoral care is not about competence or specialist skills or giving answers and advice but is embodied care, grounded in the reality of a mutual relationship (Campbell, 1986:37). He also observes that the wounded healer helps others by refusing to collude with their desire to avoid pain (1986:43). Bellamy acknowledges Nouwen's influence, arguing that a mutual relationship between any carer and care-receiver is more healthy and beneficial than a subject-object relationship:

> Modern pastoral theology reflects this in terms of Nouwen's 'wounded healer' whose acknowledgement of weakness and vulnerability becomes a source of healing. (Bellamy, 1998:195)

More recently Ewan Kelly[222] (2012:5) observes 'the greatest asset which any of us offers to another in caring relationships is ourselves, the self we have reflected upon.' One of the interviewees, Xelda, said that she could not believe that there are many hospice chaplains who are not wounded healers and several interviewees commented on the mutuality of their ministry (Beth, Fred, Greta, Patricia, Tracy). According to Nouwen a wounded healer minister uses his own wounds by being competent at articulating 'inner events', and is compassionate and contemplative (Nouwen, 2014:39). Although Nouwen does not use the term 'presence' in his ministerial formation it is hoped that analysing the data in terms of his three criteria will illuminate what the interviewees mean by presence and how it is formed.

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[220] Nouwen is described as something of a boundary figure in the world of contemporary spirituality (Ford 2006:227) which may have resonated with hospice chaplains who regard themselves as working on the boundaries (Blake 2002). In the early years of my chaplaincy experience I found Nouwen's work immensely helpful, only later coming to appreciate the complexity of his character which both enabled the expression of some of his inner conflict and blinded him to his limited response to the love of God and humans which he so craved (Ford 2006:176ff, 226).

[221] Alastair Campbell is Director of the Centre for Biomedical Ethics and Professor in Medical Ethics in the National University of Singapore. He was previously Professor of Ethics in Medicine at the University of Bristol and prior to that Professor in Christian Ethics and Practical Theology in the University of Edinburgh. A prolific writer, he is Honorary Vice-President of the Institute of Medical Ethics, UK.

[222] Ewan Kelly was Programme Director for Healthcare Chaplaincy and Spiritual Care, NHS Education for Scotland until 2015 when he moved to NHS Dumfires & Galloway as Lead for Spiritual Care. He is also part-time senior lecturer in Pastoral Theology at the University of Edinburgh, UK.

The articulation of 'inner events'

Introduction

Nouwen argues that ministers have become used to 'running the show as a circus director' and they have forgotten, 'become unfamiliar with, and even somewhat afraid of, the deep and significant movements of the spirit' (Nouwen 2014:40). Perhaps this explains some of the antagonism from parish clergy felt by hospice chaplains (Doreen, Larry, Norman, Tracy). Nouwen argues that familiarity with his[223] own inner life is essential for any minister in order to recognize and name his own experience, and then be able to use it to help others (40-41). He writes of the minister being 'the first to tell those who are afraid what he has seen, heard and touched' (41) and goes on to show how this may be used in preaching so that the listener may recognize that the preacher is expressing what he 'vaguely felt' or 'fearfully kept in the back of my mind' (42). Although Nouwen's context is a Christian community and the hospice chaplain's context is secular, the concept of expressing what the other has not managed to express – perhaps speaking the unspeakable[224] - is relevant. Unfortunately Nouwen does not give examples of 'inner events' in *The Wounded Healer* but another of his books, *The Return of the Prodigal Son,* is the story of his own inner events whilst meditating on the Rembrandt painting of that name[225]. Two interviewees stated that this book was very influential in their own spiritual development. Greta spoke of learning about the nature of forgiveness and acceptance from Nouwen's portrayal of the Father based on the Rembrandt painting. Tracy said:

> the poster of Rembrandt's prodigal son had a profound impact on me, more than I can put into words. The exploration of that painting through Henri Nouwen's book was a life-changing event for me, a faith-changing event. I can't overestimate the effect of that.[226]

Pain and suffering as 'inner events'

Both Campbell and Nouwen stress the use of the carer's own experience of pain as the source of the care offered to others. Nouwen is direct in stating 'only he who is

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[223] Nouwen refers to ministers as male throughout *The Wounded Healer*.
[224] Tyler referred to Thomas Merton's use of this phrase (Tyler, 2014b).
[225] See Appendix J
[226] Neither Greta nor Tracy had seen the Batoni painting (Appendix K) so I sent them each a copy with my thank you for the interview email. Greta's response when she saw it was 'I was stunned…absolutely BEAUTIFUL.' Both paintings show us how God (the father in the story) accepts us as we are. Nouwen argues that such unconditional acceptance asks nothing but demonstrates true compassion, and I shall return to this when considering compassion as an aspect of presence.

able to articulate his own experience can offer himself to others as a source of clarification' (Nouwen, 2014:41)[227]. Campbell is a little more cautious:

> Wounded healers heal because they, to some degree at least, have entered the depths of their own experience of loss and in those depths found hope again (Campbell, 1986:43).

Saunders expressed the need for our own journey in her paper *Spiritual Pain*:

> …unless we are occupied in our own search for meaning we may not create the climate in which patients can be helped to make their own journeys of growth through loss (Saunders, 1988).

Kelly asks how we are to help others if we do not recognize what has helped us through previous painful experiences, what nourishes and energizes ourselves:

> If we are to enable healing and restoration in others, how aware are we of what soothes our soul and aids us in our journey towards wholeness? (Kelly, 2012:155)

That sentiment was echoed by some interviewees:

> …if a chaplain loses sight of his own spirituality how dare he sit by the bedside of others to encourage them to discover their own spirituality? (Greta)

and William observed that a speaker at Conference had said 'how dare we go and invite someone to share their soul if we haven't actually owned our own'. Whilst it was important to be able to own and articulate inner events interviewees also spoke of putting the self, their beliefs, on one side – not offering actual personal experience as a source of clarification in the way Nouwen appears to imply, unless asked to do so[228]. Campbell (1986:101) argues that self-knowledge requires a discipline which not only does not come naturally but is not necessarily encouraged by church communities wanting to appear to be good Christians. Self-examination means not running away from God's light, not running away from my own pain and suffering. To run away from myself is to turn away from the inward journey which all must undertake 'to meet God dwelling within the depths of their souls' (de Hueck Doherty, 1975:23). Jean Vanier[229] also cautions against running away because Jesus is in the pain and God's power can enter and transform through our wounds:

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[227] Staff on the Southern Theological Education and Training Scheme, Diocese of Salisbury Ordained Local Ministry Scheme and Ridley Hall, Cambridge, use this quotation in their book on priestly identity (Cocksworth, C. & Brown, R., 2002:147).
[228] This may be due to the non-proselytising nature of the employment contract.
[229] Jean Vanier is a Canadian Catholic philosopher and theologian best known as the founder of L'Arche, an international network of communities where people with and without intellectual disabilities experience life together as human beings. A prolific writer and friend to Henri Nouwen he has also won many awards, including the Templeton Prize in 2015.

> And do not turn aside from your own pain,
> your anguish and brokenness,
> your loneliness and emptiness,
> by pretending you are strong.
> Go within yourself.
> Go down the ladder of your own being
> until you discover –
> like a seed
> buried in the broken, ploughed earth
> of your own vulnerability –
> the presence of Jesus,
> the light shining in the darkness. (Vanier, 1988:63)

In Chapter Five I reported that only two interviewees (Tracy and Greta) spontaneously made the connection between their spirituality and being sustained in their work. I also noted interviewees who had experienced negative events which I considered may have been transformed into sustaining energy. However, only a few (Keith, Fred, Greta) gave any detail of the 'inner events' related to their negative experience. Furthermore only Fred recognized the transformation himself, and at the other extreme, Patricia had not thought to connect her personal pain with her spirituality or her ministry. Fred spoke of being liberated from personal pain and his conviction that the experience of profound sadness enabled empathy for another person's profound sadness. Furthermore he described how his spiritual journey had enabled him to 'let go of the fear of just simply being me.' He stressed 'the letting go is really crucial'[230] but there will be no letting go without the recognition and acknowledgement of the pain. Fred had not only recognized his personal pain but he stayed with it in order to discover its root of fear. Fred's description and body language conveyed sadness and a degree of anguish. He did not indicate whether he let out a 'primal scream' (Brueggemann, 1978:21) when he realized that life did not need to be that way but there was energy in his glimpse of an alternative reality.

The primal scream

At this point I want to step sideways to consider the primal scream as an inner event and how that scream is heard[231]. Swinton observes that in a context of faith and compassion 'Lament gives a voice to suffering and releases rage' (Swinton,

[230] I shall return to 'letting go' in Chapter Eight.

[231] December 1987 to June 1988 was a a period of personal anguish for Nouwen of which he says: 'Within me there was one long scream coming from a place I didn't know existed, a place full of demons' (Nouwen 1997:x). He describes his spiritual journey coming through the anguish but does not write further of the scream.

2007a:105), but what of the secular context of the hospice?[232] To explore the expression of suffering Swinton uses Munch's painting *The Scream*[233]:

> The silent scream reflects the voicelessness imposed by suffering, a silent, disorienting entrapment that defies language but remains, nonetheless, meaningful (95).

Arguing that the character in the painting has no language to express her feelings he asks 'Where can she find a language that will enable her to articulate her pain and sadness?' (95). In my experience listening to my own screams and inner events heightened my ability to 'hear' the screams or inner events of those to whom I ministered. Such listening is a necessary characteristic of intentional reflexivity or embodied reflection which Schon called 'knowing-in-action' (Schon, 1983:49). Examples of embodied reflection are found in judging a distance when playing golf or tennis, recognizing faces, an accountant summarizing significance from a glance at a set of figures (52), and the chaplain recognizing when speech is not necessary[234]. There are no easily identifiable criteria, little or no physical sign of reflection taking place for the skill is internalized – perhaps operating subliminally. Describing informal spiritual assessment Ian referred to the skill as intuition, associating it with breadth of experience and hours of practice. Kelly (2012:36) describes it as the combination of wisdom and practical experience, observing that the Greeks termed it *phronesis*, which is

> …more than a gift we are given, but requires on-going reflection on our practice of caring as well as the ability to discerningly refer to that accumulated pool of comparative practical examples which each of us carries with us (36).

Whether we call it intentional reflexivity or embodied reflection it can appear effortless. In reality it is hard work, requiring a constantly reflexive attitude and a commitment to regular reflective practice (36).

Having 'heard' the scream the chaplain knows that for the sufferer to move on he needs to be heard into speech (Swinton, 2007a:103) but facilitating the expression of pain may not always be appropriate. As Swinton argues, there are times when 'we must learn the practice of listening to silences' (101). For the chaplain the patient's feeling of alienation is authenticated by Jesus's alienation on the cross and the belief that God is ever-present, but what about the patient? Can the chaplain's

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[232] Much of Swinton's work is in the area of mental health but as a practical theologian and founding editor of the *Scottish Journal of Health Care Chaplaincy* he has contributed significantly to issues in healthcare chaplaincy.

[233] See Appendix L.

[234] There is an argument that technological advances are leading to the loss of embodied reflection. One example is in golf where wrist watches which calculate distance are now popular.

presence authenticate the patient's suffering? Swinton quotes Nouwen[235] when he observes that the people who mean the most to us are not those who proffer advice but those who share our pain and touch our wounds, 'who can tolerate not-knowing, not-curing, not-healing and face with us the reality of our powerlessness, that is the friend who cares' (101). Keith, sitting with a patient who was in a coma, described being conscious of something happening … but there were no words to describe. Keith also described his personal conviction that there are no definitive answers and spoke of the frustration he feels when anyone tries to close or narrow down an experience to an explanation. His body language was such that it felt like horror rather than frustration and I asked if he was like the character in Munch's painting *The Scream.* He replied:

> Yes, so I have to be very careful when I am with patients because some patients do see or interpret experience like that and I have to make sure I allow them to do their own exploring at their own pace rather than tearing it all down. *laughter*

His laughter at his strong feelings defused the situation but he went on to describe a situation where a visiting pastor had encouraged a patient to believe that she would be healed. She was not healed and she disappeared 'into a black existential hole from which she never came back.' Again his body language suggested he was screaming inside – but I do not know whether he was screaming on behalf of the patient or screaming his own frustration. Either way the point is made that the scream – even when it is silent, even when there is no indicative body language – is an inner event which needs to be heard and acknowledged. A chaplain needs to hear her own scream and articulate it and she has at her disposal biblical words of grief and lament:

> The act of lament is radical because it refuses to acknowledge the hopelessness and nihilism through which western culture views evil, suffering and death (Swinton 2007a:131)

Soelle[236] (1975:70) argues that such language is no longer commonplace because institutions and rituals no longer provide the individual with a language from beyond

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[235] *Out of Solitude* (1974:34)

[236] Born to a middle-class Protestant family in West Germany Dorothee Soelle (1929-2003) studied philology, philosophy, theology and German literature at the universities of Cologne, Freiburg and Göttingen. She lectured at the University of Mainz but, unable to secure a permanent position because of her political activities, became a Visiting Professor at Union Theological Seminary in New York. She divided her time between the USA and Germany, where she continued to speak out against nuclear proliferation, capitalism and oppressive regimes in South America and South Africa.

himself[237]. She argues that at one time liturgy and prayer provided such language but criticizes religion (74) for colluding with the dominant culture claiming to provide stability but no longer enabling people to speak, echoing the prophetic situation explored in the previous chapter. Soelle maintains that the sufferer must speak his suffering himself: 'it is not sufficient to have someone speak on his behalf' (76). However, she does allow the 'nonverbal possibilities of expression.' Indeed the patient's own expression of his suffering is the ideal but it is not always possible. In my experience a patient more often than not shared his story but without verbalising the suffering. On some occasions when I 'heard' the patient's scream I expressed the suffering in poetic form or in prayer, depending on my understanding of his beliefs. Invariably this was met with tears - a nonverbal form of expression. The text box gives an example of a prayer-poem, based on what little information was gleaned by the nurses and me, written for a man whose brain tumour was reducing his ability to communicate.

Almighty God,
I don't know if you're real
I've seen no sign of your presence.
You may have created the world
But my wife destroyed my world by walking away.
They say all hearts are open to you
Well you've made me feel vulnerable and worthless
They say all desires are known to you
But there was no desiring
Only rejection and the absence of love
And they say no secrets are hidden from you
But there were secrets – every family has them
I know I'm not perfect but I did my best for them
And now they won't visit so I cannot say 'sorry'.
I long for their love, my wife's especially
And there's nothing I can do
I'm shattered and filled with despair

But if you are real
If you are there
Please help her to know
That I care.
Before I move on
I need peace of mind
Don't let it be long - please be kind –
the tumour is changing me
Give me peace whilst I still have my mind.

[237] Soelle argues that a phrase like 'Believe me folks!' is psalmic language grappling to express pain, and it is the equivalent of 'Hear me, O God; hear my supplication' as found in the psalms (1975: 71 -72).

When I read it to him he cried. Thus it was possible to facilitate the expression of the suffering, but the difficulty in the secular hospice setting was finding or adapting the words to avoid (being accused of) proselytisation.

There may be an additional problem if the hospice management culture echoes that of society's dominant culture in the attitude to death, dying, bereavement and mourning. Despite the efforts of the Dying Matters Coalition[238] to help people talk more openly about dying, death, bereavement and plans for the end of life, these are still not mainstream topics of conversation and neither are they accepted as part of everybody's life. Where such attitudes prevail the role of the chaplain is counter-cultural but has the church colluded with the dominant culture to maintain the status quo? Swinton (2007a) focuses on the bombing in Omagh in 1998, arguing that the church should have responded with redemption, forgiveness, thoughtfulness and hospitality, but it failed to do so. I maintain that these responses are just as appropriate for suffering hospice patients, outside the context of the Christian church. Furthermore they are necessary responses if we as a society wish to value what it is to be human per se – without reference to cognitive or physical ability, without reference to independence or contribution. In addition another factor, not mentioned by Swinton, which may have contributed to the church's failure, may be the loss, during the 1970s, of the regular use of the Psalms of Lament and Imprecation. Therefore my earlier statement that the chaplain has biblical words at her disposal may not be accurate, and may mean that she does not articulate her own 'inner events'[239].

The articulation of 'inner events': reprise

Using the data on spirituality as an indicator of 'inner events' interviewees found it hard to define the term spirituality, using everyday expressions like 'whatever floats your boat', 'what makes me me and you you.' Even using such language the descriptions of their own spirituality varied in ease of expression, content and depth. Some, like Charles, said that speaking of his own spirituality was hard and he was then amazed that despite his protestations of difficulty he did so. He commented on the vastness of the word spirituality against his attempt to convey the essence of who he is in just a few words. He still finds organized religion 'quite difficult' and

[238] Set up by the National Council for Palliative Care and made up of organisations from NHS, Voluntary and independent health and care sectors, social care and housing sectors, community organisations, schools and colleges, academic bodies, trade unions, the legal profession and the funeral sector. Further information may be found at http://www.dyingmatters.org/ and http://www.ncpc.org.uk/

[239] In Chapter Six I indicated the mixture of appreciation and bewilderment with which my version of a Psalm of Lament was met at the AHPCC conference.

struggles to see traditional doctrine compatible with mystery. He said 'my job is to listen, not try to cheer her up, not try to change that but to be a witness,' but he finds he gets filled up with distress from other people and his own distress and his spirituality 'just isn't enough.' He said that the only thing to do is go through it and try to work out what is actually going on, try to embrace the distress, reflect, go deeper into the pit…'it's a bit like Jacob wrestling at Peniel, struggling with the stranger who might also be God.' Charles said that if he is with a patient when this struggle happens he brackets it for a later date.

Unlike Nouwen's Christian minister the hospice chaplain cannot offer his inner events to the other person for clarification of his situation, but they are still a resource for the care offered, the potential energy source for that care and contributing to the formation of presence. Given the transformation of Jesus's death to resurrection, the transformation of pain and suffering into ministry-sustaining energy deserves further comment and will now be explored.

The transformation of the painful 'inner event'

The cross stands at the centre of the Christian faith – a cross holding the crucified body of Jesus and an empty cross signifying his resurrection. The crucifixion shows the reality of God's suffering because 'God so loved the world that he gave his only Son, so that everyone who believes in him may not perish but may have eternal life' (John 3:16). Soelle argues (2001:138) that this incomprehensible love freely accepts suffering and leads disciples to likewise follow the way of passion, thus 'completing what is lacking in Christ's afflictions' (Colossians 1:24). This does not mean that Jesus death was not sufficient but rather that his death has made it possible for us to become who God made us to be, made in God's image, and to share in the redemption of all creation:

> 'For the creation waits with eager longing for the revealing of the children of God…and will be set free from its bondage to decay and will obtain the freedom of the glory of the children of God.' (Romans 8:19 & 21)

Or as Vanier expressed it:

> That is why Jesus had to leave this world.
> He had to go
> so that we could become Jesus,
> continuing his work (Vanier, 1988:68)

Christ's crucifixion and resurrection had to happen for Christ to be ever-present in the world: 'And remember, I am with you always, to the end of the age' (Matthew 28:20b). Without his suffering there would be no presence of which we could be a

part. Without his suffering we would not experience God sharing our suffering. Mursell (2005:602) argues that Christians pray the Psalms in the light of the crucifixion believing that only a God who enters the depth of their suffering can help them find meaning, and that in the process they discover a living God who shares their suffering. Interestingly only two interviewees, Greta and Keith, spoke of using the Psalms with patients and only one (Fred) spontaneously mentioned the transformation of personal suffering. Christ's suffering was transformed and we too need not only to own and offer our suffering for transformation but to take up our cross for the redemption of creation. We cannot become God's image without Christ – there is no pain-free way. The data revealed that many interviewees had experienced tragedy - death of a child or relative, murder of a relative, suicide of a relative, divorce, serious illness, redundancy, collapse of a project, - but only one mentioned transformation and some, like Patricia, had not considered such transformation.

If interviewees are indeed concerned to 'be whatever the patient needs me to be' then concern with their own 'inner events' and their own relationship with God is to be expected, as is self-examination for that which might obstruct that union. Such obstructions might be memories of past hurts, painful experience of present attitudes, awareness of wrongs not owned, and all that is entailed in failing to love my neighbour as myself[240]. The point is that whatever the source of the wound or suffering it can be transformed by God if it is handed over. Campbell quotes Richard Shannon's poem *The Peacock and the Phoenix,* (Campbell, 1986:37) to illustrate the point:

> Wounded oysters build out of gory wounds a pearl.
> And create within the gap of pain a jewel.
> May we be so wise.

Without the grit there would be no pearl: 'Then he began to teach them that the Son of Man must undergo great suffering, and be rejected' (Mark 8: 31). Does this mean that without suffering there would be no ministry? Nouwen states that 'The great illusion of leadership is to think that man can be led out of the desert by someone who has never been there' (Nouwen, 2014:76).

Thus far the articulation of inner events has focused on the acknowledgement and expression of the experience of pain and on the transformation of that pain to

[240] When asked which was the greatest commandment Jesus replied 'you shall love the Lord your God with all your heart, and with all your soul, and with all your mind, and with all your strength.' The second is this, 'You shall love your neighbor as yourself.' There is no other commandment greater than these. (Mark 12: 30-31)

sustain ministry. Another important benefit of the transformation of pain is the space that is created when the pain is released. If I am to minister to another, I must make room for them.

'Inner events', and space for the other

Nouwen connects the ability to articulate inner events, which enable the removal of 'the obstacles that prevent the spirit from entering', with the creation of space for 'Him whose heart is greater than his, whose eyes see more than his, and whose hands can heal more than his' (Nouwen, 2014:41).

Volf (1994:141) uses the terms exclusion and embrace, pointing out that the self that is 'full of itself' cannot receive the other, nor make a genuine movement toward the other[241]. The self has to make room for the other[242]. Charles spoke of the need for space in himself in order to reflect with another human being: 'if I'm full-up with my own unreflected stuff there's no space to be the witness.' Greta spoke of 'not getting in God's way'. Beth used the word 'conduit' many times, to convey that she is a channel for the transmission of God's love.

For the embrace to take place mutually Volf states that a soft touch is necessary (Volf, 1994:143). Too strong an embrace becomes an assertion of power which dominates and excludes the possibility of relationship. Equally each party needs boundaries that preserve the sense of self and prevent self-destruction. The identity of both is preserved and yet both are transformed by the relationship. Neither seeks to absorb the other, and neither seeks to understand the other, for such claim to understanding again slips into a power-play. Volf quotes Gurevitch's argument that the ability of not understanding, or the ability to recognize and behold the other as an other, is essential for the embrace to be genuine (144) and is exemplified in Keith's description of allowing patients to see and explore at their own pace. However the ability of the chaplain to see the other as other may be marred by her

[241] Miroslav Volf is Henry B Wright Professor of Systematic Theology, and Founding Director, Yale Center for Faith & Culture. A Croatian protestant he writes out of personal experience. Active in ecumenical and interfaith dialogues he teaches and lectures internationally.

[242] To make room for the other entails dying to self. Sophrony (1977:59) described the effect of being 'caught up ' in the sphere of prayer and then returning to earth 'dead' to worldly matters, with a new life or as Paul wrote: …it is no longer I who live, but it is Christ who lives in me (Galatians 2:20). Thus Christ living in me welcomes the other, a quality in my experience as true of the research interviewer as of the chaplain visiting a patient. In both situations my understanding is irrelevant to the interview – it was necessary and appropriate for me to put my views aside, to allow the interviewee to express his understanding and perspective.

own need for self-worth, security and significance. Crabb[243] (1977: 56-57) argues that these are basic personal needs of all human beings. Should the chaplain or any personal carer, consciously or unconsciously, view the embrace or the person being embraced as fulfilling those needs the embrace is not genuine. Not only is the chaplain's need likely to clog the channel but it may take from the other, causing diminishment, or it may create a false self which will also block the channel. Rooted in God/Christ the essence of significance, security and self-worth is transformed. As concepts they are empty of substance but in Christ they are creatively full and free to give birth to the true God-given self. Letting go of an identity[244] rooted in the function of the congregational pastor with specific tasks to fulfil and finding and accepting an identity rooted in being is a necessary process for understanding the chaplain's concept of presence[245].

Having created the space for the other I now consider the nature of the listening which takes place in this interaction.

Listening

The nature of listening

From her experience in healthcare chaplaincy and in Spiritual Direction Margaret Guenther[246] observes that 'not to be heard is not to be' (1992:148) and this is often the plight of the very young, the very old, the very sick, the confused and the dying[247]. She notes that people no longer have the time or patience to listen, some are frightened of what they might hear and some dismiss the other as not worth listening to. The hospice chaplain, like the spiritual director, is a 'holy listener' who does not classify or dismiss another person, but as Charles expressed it 'witnesses somebody else's truth.' Even in a secular situation, with an atheist patient, the chaplain listens for the presence of God in the patient's story. She may not refer to God but she can encourage the patient to listen more deeply, to pay more attention to their own inner activity as they tell their story. Ian described listening and,

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[243] Lawrence Crabb is a well-respected Christian counselor, Bible teacher, seminar speaker and author of many books.

[244] This will be explored further in Chapter Eight.

[245] I believe I was privileged to observe this process in Oliver who had only been in post for a short time. His background meant that the non-proseltyising nature of the hospice culture was a steep learning curve. He conveyed a sense of spiritual struggle to hold Jesus' Great Commission (Matthew 28:19) and the requirement of his job, to encourage folk in their own perception of spirituality.

[246] Margaret Guenther is an Episcopalian priest, spiritual director, Emeritus Professor at General Theological Seminary, New York, where she taught Ascetical Theology. She was also the Director of the Centre for Christian Spirituality.

[247] Guenther observes that listeners may also be agents of healing (Guenther 1996:85).

regardless of the patient's belief, being open to the power of the Holy Spirit to help him identify spiritual strengths and weaknesses and to help him enable the patient to recognize those strengths and weaknesses.

Anne Long says that in the Christian counselling context the listener:

> will need to have made friends with the colourful spectrum of his own emotions if he is to become open and available to those of others. (Long, 1990:48)[248]

Helen Ralston (2014a) goes a stage further referring to listening with the whole being, perceiving with the inner eye, listening with the inner ear and feeling with the spiritual heart[249]. She calls it listening 'in full colour', rather than in black and white. The text box gives her account of her first experience of this type of listening which she describes as 'at a deeper level,' listening not just to the words but to the person.

I was at a conference which began with an 'ice-breaker' or 'warm-up' exercise.
The facilitator asked us to work, in pairs, with someone we had never met. We were invited to talk about our family, and then the other participant would tell us what they had heard.
I was confident that I could listen well. I had worked in people management jobs for some years and had interviewed hundreds. I started: "I have two brothers and a sister. My parents are still alive. They all live in Scotland. We will soon be having a party for my father's 70th birthday. He plays golf …..etc etc. ……."
I then expected my partner to start by saying, "You have two brothers…..," perhaps getting some of the details wrong. (Pause) In fact, she began quite differently: "I am hearing that your family is very important to you. You might be a bit concerned about your father getting older, but he sounds fit - you mentioned golf."
This sent chills up my spine and the hair stood up on the back of my neck. How could she possibly know so much about me? I had never met her before, and she had no access to any information about my background.
At the time, it had not occurred to me that my family were important to me – in fact I had never thought about it. I had never considered what I 'felt' about them.
This was a different kind of listening than any I had encountered before. It was my first conscious experience of listening at a deeper level. Because my fellow participant had listened - not just to the words - but to the person, I was able to hear something *which I had always known* – (my family IS important to me) - but it was as if I was hearing it *for the very first time.* (Ralston, 2014b)

Initially she was thrilled by the experience but later she expressed a note of caution: this type of listening needs handling with care lest it cause distress if the listener

[248] Now retired The Revd Canon Anne Long was on the staff of St John's Theological College, Nottingham before working as pastoral consultant with the Acorn Christian Healing Trust.

[249] Helen Ralston was a delegate at the Conference of the British Association for the Study of Spirituality May 2014. I attended her presentation based on her doctoral thesis and have exchanged emails with her on the subject of listening.

hears more than the person intended to convey, hears feelings which he was trying to conceal, or hears something completely different.

Ralston (2014a) spoke of transcending the confines of everyday listening mentioning Buber's I-Thou relationship in which each accepts the other, is present to the other and creates space for the other to speak in his own language. Gordon (2011:207) makes a similar point examining Buber's concept of embrace in order to understand his concept of listening, which he describes as 'active attentiveness'. Buber argues (1923:62) that the I in the I-Thou relationship is a person, whereas the I in I-It is an individual and the connection is not a relationship but a subject-object connection. The chaplain in an I-Thou relationship addresses the eternal Thou in the patient: 'I was sick and you took care of me' (Matthew 25:36b). This type of listening requires effort, skill and time. Whilst there was some evidence that it is valued - William reported appreciation of listening from a volunteer who drew a picture of him with big ears and tightly closed mouth - I want now to consider whether society's attitude is supportive or dismissive.

Society's attitude to listening

In his comment that for some people being listened to was a very rare experience Norman drew attention to the way in which listening is being devalued. He made the point that he was careful to give such a patient his undivided attention. Beatty (1999:281) argues that good listening is often associated with passivity, a lack of self-assertiveness and even a lack of self-esteem. He claims that when we cannot find anything good to say of someone we say 'He is a good listener'. Yet Queenie observed that five minutes being listened to might make all the difference for a member of staff. Sound consultant Julian Treasure (2011) argues that we are losing the ability to listen partly because our world is so noisy and partly because technical advances in recording equipment mean that accurate, careful listening is no longer appreciated.

Ralston (2014a) argues that listening is a natural process: we listen before we are born[250]. She maintains that in today's society the emphasis is on successful communication and we assume that the meaning we receive is the message the speaker intends to convey. This approach views successful listening as the exchange of information, for example in the hospice the patient needs to convey successfully that the pain is worse in order to receive pain-killers. However, the hospice nurse should not assume that the pain is physical, and neither should she listen for her

[250] When pregnant with my first child I noticed that the baby's movements changed whenever I played in an orchestra. On the several occasions when Saint-Saens's Organ Symphony was performed the baby was most active.

own self-interest so that the patient stops pressing the buzzer (Corradi Fiumara, 1990:115). Beth said that her role was about 'really listening,' and Doreen described just being there with them, listening and supporting. The difficulty is that this kind of listening is not about the successful transmission of information and therefore has 'no remunerative value in our dominant culture' (Corradi Fiumara, 1990:30). As Keith observed: he cannot prove the value of his agenda-free listening to the person who pays his wages.

Spiritual pain manifests in a variety of ways and requires the listener to create a space and an ambience which will encourage the patient to explore her own inner events. Corradi Fiumara (1990:128) asks whether society has come to the point where it sees no point in learning to listen because there is nothing to hear/ no inner voice to pay heed to. If that is so, any sense of identity rooted in the inner self is denied and the individual is forced to find /justify identity in external factors and rules spoken by others[251]. He is thus rendered incapable of sustaining the inner self and letting the inner message spring to life (129). The prophetic situation of the previous chapter is again repeated in the restraint and control of the individual by an outside agent. In contrast, by being whatever the patient needs her to be, the chaplain, like the prophet, believes there is something to hear, listens to enable the patient to find his inner self and allow the spirit to live in freedom. Xelda spoke of listening for what is underneath the superficial talk. However, if hospice management follows the societal line, that there is nothing to be heard, they are challenging the hospice vision, suggesting a clash of tectonic plates.

There is also another potential clash of tectonic plates between the chaplain's practice of listening-in-relation, discussed earlier, and the subject-object attitude of the medical profession who treat the patient as a problem to be solved and mortality as a problem to be treated (Gawande, 2014:Lecture 3; Bellamy 1998:187). Atul Gawande[252] recommends that doctors learn to communicate with their patients – enter into relationship – to establish what their priorities are. He describes how he learnt that in relationship the doctor does not do most of the talking, does not bombard the patient with facts and figures but asks him his goals, his unacceptable outcomes, how he understands his situation, and above all he listens as the patient tells his story, all of his story.

[251]Exploring the Benedictine way of life Vest observes 'speaking is a way of asserting control and avoiding receptivity' (Vest, 1994:21).

[252] Reith Lecturer in 2014 Atul Gawande is a Harvard professor of medicine, surgeon, writer, thinker and political analyst.

The role of story

'Separated from our stories, we lose our identity' (Guenther, 1992:149). Interviewee Eric spoke of encouraging the patient to tell his story as a means of affirmation and empowerment. As the patient tells his story he discovers what he has achieved in life. Charles used the making of a poster to enable the patient to tell his story and in the process discover what he believed. Beth encourages the patient to tell his story so that she can identify what matters to him. Frank (1995:53) argues that stories are not simply descriptions of the self but they are the self, being perpetually recreated according to experience and circumstance. Many people think that they create the stories themselves, not realizing that stories are often offered by or inherited from family[253], friends, literature and the media. Alan spoke of using stories from his own experience to help the patient make sense of the situation. Serious illness necessitates revising the story but it also needs to repair the damage done by the illness, the person's sense of who they are (Frank, 1995:53). Patients lose sight of who they are, becoming instead the cancer-sufferer, the person needing chemo, the person whose hair has fallen out. It is hard for a fit and healthy person to identify roles projected onto her by others, or acknowledge her collusion with such projections in order to avoid confrontation (Thomas, 1999:65-66), but for a hospice patient who is not fit and healthy… Larry took the patient's story of being (worthless) ashes and turned it into a story of gold dust.

Swinton (2013:68) argues that the world of illness is not the same as the world of healthiness. Not only is it a strange and disorienting place but the stories of identity no longer fit, and the coping mechanisms do not work either! Tracy used a story of moving house to help the patient re-form her identity. Oliver spoke of helping the patient to see himself outside the confines of the diagnosis. Swinton (69) argues that the patient needs to create new stories to develop a new identity. Otherwise the patient is vulnerable to the imposition of roles assigned by the various professionals who come to 'do something' to her to ease her pain or manage her symptoms. Her relationship with these professionals is not equal and she is physically, emotionally, spiritually disadvantaged.

Frank (1995:66) argues that medicine gives the patient a diagnostic identity which makes her the subordinate half of a power relationship. Her story changes without her realizing it - the very institution of the hospice puts her on the receiving end of authority (or power), of doctors, physiotherapists, nurses, for which she feels she must be grateful. He further argues that until recently the taking of a medical

[253]I have written elsewhere (Thomas, 1999:65-66) about my own experience of realizing that I was living a life created for me by other people.

history was considered to be *the* story (58), when the process actually curtailed or prevented the patient's story. The taking of a medical history ensured that what might be termed the 'uncomfortable' parts of the story were omitted[254] when in fact the patient needs those parts to be spoken and heard as part of the development of a new, revised story which takes into account, but is not dominated by, the terminal illness.

Unlike other professionals in the hospice the chaplain does not visit to do anything to the patient. She does not identify the patient by his medical diagnosis but by his humanity and furthermore she appreciates the value to the patient of telling his story to someone who listens with their whole being[255]. However, such listening is hard work and tiring and those who carry it out need to tell their story to someone who listens with their whole being. Comments on the value of the research interview included:

> 'rare that I talk in that depth'(Greta, Ian),
> 'good reflective experience' (Eric, John), '
> 'an opportunity to think rather than listen'(Alan, Norman).

Tracy observed that it was really helpful to explore things that 'you know you know but put them into words' and that 'we don't often take time to properly analyse'. All of which suggest that opportunities for chaplains to be listened to in this way have been few and far between.

The context of the society in which we live has changed causing the meaning of words, like hope, redemption, sin, at best to change and at worst to lose their meaning. It appears that the meta-narrative of Christianity has lost its dominance but what has taken its place is not clear. For some there is a hodge-podge of beliefs and values unwittingly collected, some have a deliberate pick-and-mix selection and some, as reported by Tracy, have not thought about it. The relevant point for the chaplain is the consequence that she has to pick her way across what may be a minefield to enable the patient to respond to his suffering in ways that are life-enhancing rather than life-destroying. Just as the patient's life has been turned upside down by a life-limiting or life-changing illness so too the chaplain's role. The guide-lines and maps previously used by the patient no longer apply but the chaplain cannot offer the guidelines and maps of her Christian faith – at least not in a way

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[254] The uncomfortable parts may be personal tragedies, events seemingly unrelated to the illness which the patient deems significant, or lengthy asides when the doctor has other patients to visit.

[255] The chaplain's patient-centred, rather than diagnosis-centred, approach owes a debt of gratitude to Carl Rogers's unconditional positive regard which advocated that clients could be coaxed to identify their problems and decide how to deal with them without being instructed by the therapist. (Kirschenbaum, 2004: 117)

that might be seen as proselytising. However, the values exemplified in incarnational Christianity affirm humanity and affirmation is the starting point for the chaplain, affirmation by being with the patient, affirmation by encouraging the patient to tell his story, affirmation by listening to the patient's story. I have already noted Norman's observation that being listened to is a very rare experience for some patients. Only by listening to the story can the chaplain discern what, if anything, the patient believes. Xelda said she listened for the things that mattered to the patient, for anxieties and fears, and tried to read between the lines. Only by listening to the story can the chaplain discern where God is in the patient's life, regardless of whether or what he believes. That willingness to listen to the other's story is characteristic of Nouwen's second ministerial criteria: compassion.

Compassion

Nouwen regards compassion as 'the fruit of solitude[256] and the basis of all ministry' (Nouwen, 1990:33). It 'is born when we discover in the centre of our own existence not only that God is God and man is man, but also that our neighbour is really our fellow man' (Nouwen, 2014:43-44)[257]. For the compassionate man *(sic)* 'nothing human is alien' (2014:44; 1990:34). Such concern for the alien or stranger – or person not like me – is found throughout the Old Testament where God is described as he 'who executes justice for the orphan and the widow, and who loves the strangers, providing them food and clothing' (Deuteronomy 10:18)[258]. However, for any human being to live a life of such concern or engage in any form of pastoral caring relationship on the basis of sympathy, feeling sorrow for, pity, or even empathy is exhausting. When these feelings are offered to God there is the possibility of transformation which enables compassion without exhaustion because 'it is no longer I who live, but it is Christ who lives in me' (Galatians 2: 20a). By God's grace the emotions are infused with Ignatian indifference resulting not in (professional) detachment but a change of perspective from wanting to do something to acknowledging there is nothing I can do except *be*. Queenie commented that chaplains do not visit 'in order to…,' she has no objective, nothing

[256] Nouwen states that we are each responsible for our own solitude – for creating our own desert where we spend time in the healing presence of our Lord (Nouwen 1990:30). Solitude is its own end and the place of our salvation where Christ remodels us in his own image (32).

[257] The word 'compassion' suggests: 'an active concern for our neighbour, including a willingness to help, even perhaps to put oneself at risk for the sake of another' (Davies 2005:204-205)

[258] Against those who would dismiss compassion as an instinctive, irrational emotion Nussbaum (1996: 28) puts the case for regarding compassion as a particular type of reasoning, a thought process focused on the well-being of others.

to achieve. Alan said 'a calming reassuring presence, someone to be with them on the long and lonely road, that's not going to abandon them…' Ian illustrated compassion with the story of the patient who observed that when her vicar visited she could tell he could not wait to get away but with Ian she did not have to speak, she could even fall asleep and he would still be there when she woke.

Compassion as hard work.

Nouwen stresses that compassion is hard work and there is a danger that ministers who ask for more training in order to be more professional are avoiding the harder work of being compassionate (Nouwen, 2014:44-45). In biblical language this necessitates the heart of stone being turned into a heart of flesh (Nouwen, 1990:34):

> …no one can help anyone without becoming involved, without entering with his whole person into the painful situation, without taking the risk of becoming hurt, wounded or even destroyed in the process (Nouwen, 2014:75).

which seems to contradict his statement that the minister should not let his feelings interfere (75).

By 1992 when he wrote *The Return of the Prodigal Son* Nouwen had evidently thought further about compassion and seeing the world through the eyes of God. He uses his own experience[259] to describe how each of us needs, like the two sons in the story, to discover and acknowledge the lost child within – but we also need to discover within ourselves the compassionate mother and father that is God (1994: 23).[260] Eric believed that he was beginning to see as God sees, and Beth described encounters with patients as 'the divine in me meets the divine in you.' Nouwen goes into some detail on the character of the child within each of the brothers and within himself, showing what needs healing, what it is to be forgiven and the experience of receiving unconditional love so that ultimately each will be like the Father in compassion. It is the receipt of unconditional love that is the source of compassion: 'We love because he first loved us' (1John 4:19). Eventually Nouwen realizes that he has been trying to find God when in reality God has been trying to find him:

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[259] Experience from December 1987 to June 1988 which was eventually published in 1997 as *The Inner Voice of Love*

[260] Nouwen observes that in the Rembrandt painting the father's left hand is very masculine, strong and muscular, but the right hand is refined, soft and tender. The position of the left hand is supportive but the right hand lies gently, comfortingly. Thus, argues Nouwen, Rembrandt shows us that God is both father and mother (Nouwen,1994:99)

> The question is not 'How am I to know God?' but 'How am I to let myself be known by God?' (Nouwen, 1994:106)

Reflecting on looking through God's eyes at himself, seeing God's joy at his own homecoming leads him to the crucial question: 'Can I accept that I am worth looking for?'(107). He identifies this as the core of the spiritual struggle – against self-rejection, self-contempt and self-loathing, all areas which I surmise are wounds and examples of Nouwen's personal 'inner events', and which illustrate that compassion starts with the self. If I believe that God has compassion for me a denial of my compassion for myself would challenge both the understanding of God and the validity of God's compassion. One interviewee had come close to a breakdown, realizing that his care (compassion) for himself had slipped, and another recognized that his self-care was inadequate but struggled to accept that he was worthy. According to Nouwen compassion is expressed in grief, forgiveness and generosity (Nouwen, 1994:128) and I have already mentioned the influence the book and the painting had on Greta's understanding of forgiveness. Nouwen states that these are the three ways in which the compassionate image of the Father grows in the person so that he is no longer the younger or the elder son but is to *be* home, waiting like the Father. However, Nouwen focuses on the joy of welcoming home a lost son, as John did in his use of the story with a patient. Only later does he identify 'a dreadful emptiness' in the Father's role which has 'No power, no success, no popularity, no easy satisfaction' (132)[261] and write of 'the loneliness of the Father, the loneliness of God, the ultimate loneliness of compassion.' Nouwen describes his own struggle of wanting to see rather than be half blind like the father in the painting, of not wanting to wait but wanting to be with, of not wanting to be silent but wanting to ask questions, of not wanting to stretch out his arms when so few are willing to be embraced. Yet he knows he is called to share God's emptiness, loneliness, suffering, and compassion[262].

Nouwen argues that people respond to compassion, consciously or unconsciously acknowledging the source of the minister's authority (Nouwen, 2014:43; 1994:22). For Swinton (2007a:80-84) Christian practices, such as compassion, forgiveness and lament, need to be practised. Informed by scripture and tradition, inspired by the Holy Spirit and learned through participation within a community: 'It is not enough to know about and understand a practice theoretically' (84). Like riding a bike or

[261] However, he also recognizes that it is 'the place of true freedom', which I shall return to in Chapter 8.
[262] To what extent hospice chaplains share this call may be a subject for further research.

walking a tightrope we need to keep working at it – practice becomes habit and then becomes not just what we do but who we are. So as we practice compassion we become compassionate. Beth described her own journey from early in her nursing career when she held a dying sixteen year old in her arms to where she currently stands:

> 'I've come to a place where I can understand faith through suffering, my own and other people's, and how intensely Christ is there dying with them. It's an amazing spiritual journey.'

Compassion and authority for the hospice chaplain

For some hospice chaplains the dog collar can be an issue: its authority gives security for the taking of funerals but at a first meeting may engender deference or antagonism in a patient: 'I find that the clerical collar acts as a magnet and may attract or repel' (Edmeads,[263] 2007:550). In contrast, when God's compassion, visible in Christ, is visible in the chaplain it elicits a response, perhaps of curiosity but often of willingness to engage. Nouwen argues that the compassionate minister is in the world as a human being, which is how Keith described his role[264]. Seeing the world as God sees the minister's response is not pity, which patronizes, nor sympathy[265], which separates (Nouwen, 2014:43), but love which sees Christ in all people and the Kingdom in everyday life. Beth spoke of God as the life-energy in the universe and 'the potential for Christ in everybody.' Eric thought that he was beginning to feel what God feels. He expressed concern that he might sound super-spiritual but went on to explain – possibly justify – that we talk about our heart beating with God's heart. His description brought to mind Dali's painting of Christ of St John of the Cross, in which Christ on the Cross is in the troposphere/ stratosphere looking down at the world[266].

Compassion as a response to suffering

Nouwen observes that the spontaneous response to suffering is either to flee or find a quick cure rather than acknowledging the gift of being able to go with others into their place of vulnerability and brokenness (Nouwen, 1990:34). Queenie and Beth both described thinking that hospice chaplaincy was not for them, but did not flee.

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[263] A hospice chaplain, member of AHPCC, but not one of those interviewed.
[264] Hacking (1990:126) argues that Christians are called to be more human, rather than less, but too often they learn to be religious before they have learnt to be human.
[265] Brene Brown distinguishes between sympathy and empathy in a helpful cartoon: http://www.youtube.com/watch?v=QMzBv35HbLk
[266] Eric knew of the painting and thought he should explore further.

Furthermore Queenie made the point that a barrage of questions such as 'how are you today?' 'did you sleep?' 'how is the pain?' is not compassion – it is harassment! Predicated on an understanding that God suffers with creation for the sake of its completion (Soelle, 1975:146), Soelle argues that for us compassion is one of two possible responses to suffering. She makes it clear that she is not referring to the kind of suffering brought about by self-mortification which she describes as 'the unparalleled demands of ascetism' (Soelle, 2001:139), but says that compassion 'arises in the immediacy of innocent suffering and from solidarity with those who have to bear it' (139). As Patricia said:

> We can actually help people to cry, we can be with them in their suffering, even though it's not pleasant, it's not easy, it's challenging.

Soelle uses Reinhold Schneider's classification of agony and numbness as two possible conflicting responses to suffering (149-150). Numbness is the avoidance of suffering, not seeing and not wanting to see[267], trying to protect the self against suffering through busyness and material goods. Agony is choosing voluntarily to enter the pain of the other, possibly to death. She observes: ' "Numbness" is a metaphor for apathy, "agony" a metaphor for compassion'(150). Is this an echo of the situation described in Chapter 6 of the domestication of God and affluence as an anaesthetic to suffering? Rather than acknowledge God's suffering and the people's suffering, the apathetic society depersonalizes and objectifies prisoners, workers, patients, by giving them numbers (Soelle, 1975:37-38). Soelle observes that Christians have themselves contributed to this situation by maintaining that the divine did not and could not suffer (41) or by excessive glorification of Christ's suffering which claims that he has done all that needs to be done (81-82, 128 -129). Our suffering then becomes irrelevant to this suffering-free salvation. The desire to want to be in God's image without being in Christ's image betrays a lack of understanding of the nature of salvation and a need for instant and easy gratification. Such a salvation has no place for the recognition and transformation of inner events explored earlier and neither does it acknowledge the primal scream. Soelle is working on a broader canvas than that of the hospice chaplain and that of this research, but the principle of 'remaining in inconsolability' (Soelle, 2001:154) or 'holding firmly onto agony against every possibility of escaping into numbness' (152) holds good at every level: we are called to see as God sees, as mentioned by Eric,

[267] Merton recounts de Hueck Doherty's observation that instead of seeing Christ in those who were suffering 'we preferred our own comfort: we averted our eyes from such a spectacle, because it made us feel uneasy: the thought of so much dirt nauseated us – and we never stopped to think that we, perhaps, might be partly responsible for it' Merton (1990:341).

and to share God's suffering through the death of Jesus. Like God we are powerless. Whatever adjective is used: powerless, empty, lonely, it is the Gethsemane element in compassion:

> 'To watch with Jesus, not to fall asleep during the time of his fear of death, which lasts till the end of the world and has in view all the fearful, is an ancient Christian demand that is contrary to every natural response to affliction.' (Soelle, 1975:79)

Christians are called to live life fully as human beings, throwing ourselves into God's arms and participating in his sufferings in the world, watching with Christ in Gethsemane (Bonhoeffer, 1953:125).

Watch with me[268]

For Cicely Saunders Jesus' Gethsemane words: 'Watch with me' (Saunders, 1965b:1615) summed up all the needs of the dying. The word 'watch' meant respect for the patient, paying very close attention to his distress, learning what his pain is like and finding ways of relieving it. It also entailed continually learning and gaining new skills but she learnt from patients that they 'wanted not only skill but compassion also. They needed warmth and friendship as well as good technical care' (1615). Real watching must include the willingness to learn what pain is like, what it feels like to be so ill and know that you will soon be leaving those you love. 'We have to learn how to feel 'with' patients without feeling 'like' them if we are to give the kind of listening and steady support that they need to find their own way through' (1615). Queenie and Norman observed that chaplains have no agenda. Patients do not want pity or indulgence but respect and the expectation of courage. Saunders anticipated supporting patients as they journeyed from a pleading 'I do not *want* to die' to a quietly accepting 'I only want what is right', bringing Gethsemane into today (Saunders, 2005:14) and seeing joy as well as doubt and fear (Saunders, 1965b:1615).

Saunders argues that when first spoken 'Watch with me' did not mean 'understand what is happening'. Nor did it mean 'explain' or 'take away'. It did include the point at which the watcher acknowledges helplessness – but nevertheless stays. 'Watch with me' means 'be there' (Saunders, 1965b:1616). The watcher however is not alone but part of a community each of whom contributes to the care of the patient without being 'overwhelmed by her own responsibilities' (1616). Saunders writes from an ecumenical, nondenominational Christian perspective and argues that we have not begun to see the meaning of 'Watch with me' until:

[268] Matthew 26:38 from the Authorized King James Version

> we have some awareness of Christ's presence both in the patient and in the watcher. We will remember his oneness with all sufferers, for that is true for all time whether they recognise it here or not. As we watch them we know that he has been here, that he still is here and his presence is redemptive (Saunders 1965:1616).

George Handzo[269] (2011:369) argues that on many occasions the patient is only asking for a compassionate presence, someone who will listen to his story, his angst. He is not looking for answers:

> What is spoken as a spiritual question is most often not a question at all but an expression of spiritual pain. The patient is not looking for an "explanation." The patient is looking for another human being to be with them in their spiritual and existential pain. This is a time-consuming and often emotionally demanding task (Handzo, 2011:369).

Kelly makes a similar point:

> Much of what people seek from pastors and chaplains is time and space in which to ask existential questions, to seek to find ways to make life more fulfilling and adjust to altered roles and changes in perceptions of identity (Kelly, 2012:102).

adding that it is important for the chaplain to be aware of her own spiritual wounding in order to avoid projecting her own issues onto the patient. Awareness of her own wounds is also necessary for the recognition of boundaries and issues which make it inadvisable to minister to a particular patient.[270] In other words recognizing when staying with the agony is not feasible and a flight into numbness is imminent. Moltmann (2004:81) argues that in Gethsemane the disciples lost their sense of the nearness of God, felt completely lost and fled to the numbness of sleep, 'a sleep which protects us from what is unendurable.' Ian and his line manager recognized that, after a month of really difficult funerals and various other issues, he 'came close to cracking up', which I interpret as recognizing the imminence of numbness. Three week's leave was arranged and his clinical supervision reviewed and changed.[271]

Edmeads (2007:551) describes the hospice situation as not 'Don't just sit there - do something,' but the reverse 'Don't just do something – sit there.' He observes that in the hospice the superficial is stripped away. Patients will still talk about holidays and allotments and the daughter's wedding – but in the middle of the conversation

[269] George Handzo is Senior Consultant for Chaplaincy Care Leadership and Practice at HealthCare Chaplaincy, New York, USA. He is internationally known as a lecturer, researcher, prolific writer, who argues that professional chaplains are the most cost-effective and underutilized resource for increasing patient satisfaction.
[270] Self-awareness will be explored in Chapter Eight.
[271] Supervision will be discussed in Chapter Nine and in the Conclusion.

they will ask about hymns for their funeral. There are times for words but mostly what people need is for the words to become flesh: 'they might want company, a smile, shared tears, an ability to sit still, the willingness to listen, to watch with them often in silence.' In watching and sharing the pain there is a connectedness in which Christ is present. The Christian answer to the mystery of suffering and death is not an explanation but a Presence (Saunders, 2005:29), and a transforming awareness of divine presence is one way of defining Nouwen's third criteria: contemplation.

Nouwen's contemplation

In his interpretation of contemplation Nouwen (2014:46) stresses that in describing the minister as 'contemplative' he is not advocating a life lived behind walls with little contact with the world. Rather he wishes the Christian leader to practice an active, engaged form of contemplation (46). To do this Nouwen says the minister will need to be a mystic: 'a person whose identity is deeply rooted in God's first love' (Nouwen, 1989:28). The focus is on the discipline of dwelling in the presence of God, the discipline of contemplative prayer. Nouwen argues that meditation and contemplation are precursors of concentration which is a precondition for what he calls 'true hospitality' (Nouwen, 2014:95), which I have referred to as 'making space for the other,' and he does acknowledge that to create space for the other it is necessary to withdraw the self (95). He writes of the need for solitude and silence and the prayer of the heart (Nouwen, 1990) but are these aspects of contemplation?[272] Nouwen quotes the Russian mystic Theophan the Recluse:

> To pray is to descend with the mind into the heart, and there to stand before the face of the Lord, ever-present, all-seeing, within you (Nouwen, 1990:76).

He observes that the prayer of the heart 'pulls us away from our intellectualizing practices, in which God becomes one of the many problems we have to address' (78). He recounts a story of a Russian peasant who wants to learn how to pray without ceasing and observes that continued prayer results in unceasing prayer. Again he mentions discipline: 'we will need a serious discipline to come to a prayer of the heart in which we can listen to the guidance of Him who prays in us' (89). This prayer has a purpose: to help the minister discern the ministry which brings glory to God rather than glory to the self (90). Despite Nouwen's acknowledgement that the prayer of the heart is the way to find rest in God the minister is still the protagonist, searching to find rest (90).

[272] The role of solitude and silence in contemplation will be explored in the next chapter.

Nouwen speaks of the desire for communion with God being present from birth, affirms this desire as sincere and that it comes from God but then instructs 'dare to stop seeking gifts and favours like a petulant child and trust that your deepest longing will be fulfilled,' (Nouwen, 1997:79). It appears that the fulfilment of the minister's longing is dependent on his behaviour, rather than fulfilment being the gift of God. Nouwen says that through the discipline of contemplative prayer ministers learn to listen to the voice of love and find wisdom and courage for whatever issue they are dealing with – suggesting that the purpose of contemplation is not union with God but the successful execution of the minister's job. He speaks of saying 'Yes' to the one who calls us the Beloved, the one who wants a mutual relationship of love with each one of us (Nouwen, 1993:106) but apparently did not personally find rest in such a relationship until the last decade of his life (Yancey, 1996).

Overall Nouwen's approach to contemplation is practical – along with the articulation of inner events and compassion, contemplation is a necessary trait for the minister. The focus is on the characteristics of the minister – that is Nouwen's principal concern – but the minister is responsible for developing them. This is not to deny the value of Nouwen's work but to draw attention to his focus on the congregational minister who does not endure a restriction on proselytising and who does not engage in whole-person listening to the same extent as the hospice minister. Furthermore Nouwen's understanding is different from the traditional understanding in which descriptions of contemplation, or unity with God, fall into two categories. One category, describing a hierarchical means of ascending to unity with God, is exemplified in the incomprehensible unknowing of the *Cloud of Unknowing*[273] (Walsh, 1981:120-121), and the dark night of the senses of John of the Cross[274] (Kavanaugh & Rodriguez, 1979:312). The other category, found in Julian of Norwich[275] or Bonaventure[276] describes stages which are not successive but contemporaneous and present throughout the spiritual journey (Melloni, 2000:38). In both categories contemplation is not a self-activated experience but the gift of God, a sentiment

[273] Written in the fourteenth century by an anonymous English person.
[274] John of the Cross (1542-1591) was a Spanish Carmelite author of The Dark Night of the Soul, The Ascent of Mount Carmel and other writings whom Tyler (2010b) argues is best regarded as a 'practical theologian'.
[275] Julian of Norwich (c1342-c1416) anchorite at Norwich Cathedral recorded her personal spiritual journey in *Showings.*
[276] Bonaventure (1218-1274) 'the premier mystical theologian of the mystical tradition' (McGinn, 2005:22).

echoed by Thomas Merton[277]:

> The whole mystery of simple contemplative prayer is a mystery of divine love, of personal vocation and of free gift. This, and this alone, makes it true 'emptiness' in which there is nothing left of ourselves (Merton, 1973:117).

Despite writing about him Nouwen does not share Merton's view[278]. The fundamental difference between Nouwen and the descriptions of contemplation/unity in all these writers is the identity of the initiator. In Nouwen's writing it is the minister but in the tradition, and in Merton, the protagonist is God, who makes a gift of contemplation to the beloved. This will be explored further in the next chapter.

Conclusion

Several interviewees used the term 'presence' to describe the hospice chaplain's role. However explanation was limited: 'more than the absence of tasks', 'being there' and 'staying with the pain.' Therefore further clarification was sought on the nature and formation of presence. Awareness of the influence of Nouwen in the hospice world, for Saunders and for contemporary chaplains, led me to use his model of the wounded healer to explore and analyse the research data for more information. The exploration suggested a description of the chaplain as a person who chooses to respond to Jesus's 'abide in me' (John 15: 4a) and who therefore focuses on God, wants to do God's will, wants to dwell in God. According to Nouwen this soul is the agent of the activity in all three criteria: the ability to articulate inner events, compassion and his representation of contemplation. The inner events are transformed to produce the fruit of compassion, though this is rarely articulated by interviewees. This fruit, compassion, is the source of the willingness to listen but the listening of the hospice chaplain requires her whole being. Anyone can listen but listening with the whole self means not just hearing the life-story which questions the value of his life but 'being with' as the patient explores his own previously uncharted territory, his own inner events[279]. The listener is then vulnerable, exposed to her own similar territory which has to be laid aside during the pastoral

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[277] Thomas Merton (1915-1968) born in France, educated in France, England and America, converted to Catholicism in 1938 and became a Trappist monk in 1941. An influential thinker and prolific writer on a wide range of topics from spirituality to non-violence, civil rights and nuclear arms. His autobiography *The Seven Storey Mountain* (1948) was a best-seller.

[278] See Chapter Eight.

[279] At an AHPCC conference Tom Gordon, then president of the association, told the story of listening to an old man who was coming to the end of life. At the end of the story the man had one question: 'will it do?'

encounter[280]. Compassion 'suffers with' in a relationship of equals which nevertheless is one-sided since the chaplain, unlike the congregational minister, does not share her story unless requested, and even then will turn the exchange back to the patient as quickly as possible for hospice care is 'patient-centred care'. Nouwen's first two categories therefore throw valuable but limited light on the interviewees' concept of presence.

More importantly Nouwen's model is focused on what it takes to be a minister and is therefore functional: to be a good minister these characteristics are necessary and the development of them the responsibility of the minister. Nouwen's minister is like the souls who 'must explore carefully and scrupulously every means they can find which may lead them to their union with him' (de Caussade, 1989:5)[281]. However, 'when God lives in souls there is nothing of themselves left, save what comes from his inspiration' (5)[282]. These are the souls who recognize God's invitation and offering of the gift of contemplation or union. However, Nouwen's discussion of the third criterion describes the minister as a contemplative in action but does not explore the experience of contemplation. In my view this shortcoming is at least partly due to Nouwen's failure to confront his own deepest wounds (Ford 2006:176) and learn to *be* a person (178), that is until he was working at the Daybreak L'Arche community in the latter part of his life. In other words he sidestepped the point at which contemplation is received as a gift from God, which de Caussade describes as God living in the soul (de Caussade, 1989: 5), and the point at which *kenosis* occurs (50) – again as a gift from God. Therefore in the next chapter I explore the nature and significance of contemplation and its relationship with *kenosis* in the experience of the hospice chaplain. To do this I turn to de Caussade, and other writers, whose work provides details of the processes of contemplation and *kenosis* with which to analyse the interview data.

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[280] I maintain that acknowledging inner events and offering them for transformation is a continuous process.

[281] Jean-Pierre de Caussade (1675-1751) was reputedly a Jesuit priest and author of *The Sacrament of the Present Moment* which was originally published as *Self-Abandonment to Divine Providence.* Supposedly based on the notes of talks which de Caussade gave to the Sisters at Nancy recent scholarship has cast doubt on his authorship (Salin, 2007: 27).

[282] It is possible that the point at which Nouwen realized that God was looking for him and asked himself whether he was worthy is the point at which God was inviting Nouwen to trust, to let go of his concern for the characteristics of Christian leaders, and be inspired to live in a new place beyond emotions, passions and feelings, a place which he had not fully acknowledged as the place where God dwells (Nouwen, 1997:13).

Chapter Eight: *Kenosis*

Let the same mind be in you that was in Christ Jesus, who, though he was in the form of God, did not regard equality with God as something to be exploited, but emptied himself, taking the form of a slave, being born in human likeness. (Philippians 2:5-7)

Introduction

Whilst interviewees used the term 'presence' to describe their role the interview data provided little explanation of their understanding or of the formation of presence. It was therefore necessary to examine the data for aspects of this non-functioning, being-rather-than-doing ministry. Acknowledging Nouwen's significance for the development of hospice chaplains his model from *The Wounded Healer* was used to explore what the ministry of presence might entail. In the previous chapter the development of the characteristics of a Christian minister was shown to be initiated by the minister himself who works to be able to articulate inner events, be compassionate and become a contemplative in action. However Nouwen's representation of the minister attaining contemplation through his own efforts is not supported by scripture or by the tradition, which sees contemplation as the gift of God. Reference was made to Jean-Pierre de Caussade's inspirational work *The Sacrament of the Present Moment* purportedly written for nuns who wanted to discover the secret of belonging to God. De Caussade (1989:5) makes a clear distinction between the soul living in God and the soul in whom God dwells. The former initiates exploration - reading, thinking, praying – trying hard to achieve union with God through her own efforts whereas the latter surrenders to God and receives the gift of contemplative union (5). Souls in union focus on and follow God without question, they are 'content in their unknowing' (69). They see God in everything (84) and have the spiritual quality of being all things to all people (87). They are totally surrendered to and dependent on God, who gives them what they need as and when they need it (6). However, the world thinks such souls are useless (6). Whilst de Caussade's clear distinction may seem unrealistic and his seventeenth century spirituality of passive acceptance may seem dated and inappropriate I believe the movement from the activity of my own efforts, to passivity or quiet receiving, may be helpful as a lens through which to examine the contemplative-type practices described by interviewees. In addition it is hoped that such examination will illuminate their understanding of presence and reveal the relevance of *kenosis.*

To identify the contemplative-type practices it was necessary to listen to the interview recordings in colour rather than in black and white (as described in Chapter Seven) and read the transcripts alert to intuition. In both listening and reading discernment of the transcendent was imperative. Consequently in this chapter the term contemplative-type includes not only experiences described by interviewees as meditation and/or contemplation but also descriptions of needing to still the mind and references to the mystery of God defying understanding. Therefore I also refer to the contemplative-type practice offered by *The Cloud of Unknowing* and the work of Thomas Merton and Dorothee Soelle, both of whom address the use of the intellect and the role of emptiness in contemplation.

Whilst the words meditation and contemplation were used by some interviewees to describe their experience I do not wish to explore the varying uses and meanings of those terms by different writers down the centuries. Neither do I wish to engage with the understanding and role of apophatic and kataphatic prayer. However, I do want to examine the experiences described by interviewees, which I refer to as contemplative-type, and examine the relationship between those experiences and the understanding of presence. Furthermore I wish to explore whether that relationship involves *kenosis.* Therefore my working definition of a contemplative-type experience is broad, covering any experience described by an interviewee which appears to me to relate to her relationship with God. However, before exploring the nature of the contemplative-type experiences described by interviewees I explain my understanding of *kenosis.*

Kenosis

Kenosis, my understanding

Kenosis is a Greek term meaning emptying. In Christianity it refers to the self-emptying of Christ described by Paul in the letter to the Philippians:

> Let the same mind be in you that was in Christ Jesus, who, though he was in the form of God, did not regard equality with God as something to be exploited, but emptied himself, (Philippians 2:5-7a)

Kenosis may be understood as an essential characteristic of the Trinity and Jesus' self-emptying may be seen as a model for all Christians. However, I am arguing that *kenosis* is a gift from God associated with the gift of union or contemplation[283]. The

[283] Contemplation is here understood as union of a person with God, or being aware of being in God's presence, but not by any effort or action of the person. The action of gifting the presence is God's and can happen anywhere and at any time. Meditation is understood as the state – focus, sense of calm, letting go of problems - achieved by the person's efforts. However, interviewees used one or both terms with varying meanings.

articulation and transformation of inner events described in Chapter Seven is not *kenosis*. That this transformation and emptying helps create space for the other is not denied but it is dependent on the ability to articulate that which needs emptying, which is dependent on self-awareness. The emptying is therefore limited. Charles described being so 'full up of my own un-reflected stuff that there's no space to be the witness'. He needed supervision to help him create the space through a self-activated emptying. Whilst differentiating between the emptying which is self-activated and *kenosis* which is God-activated I am not suggesting that they are unrelated for both are part of the journey to union. My personal experience indicates a sequential spiral relationship of my self-activated emptying followed, rarely immediately and usually without my being aware, by God-activated emptying. What I experience is the effect of *kenosis* - the effect of the action of God's grace.

According to de Caussade (1989:50) it is the power of God's love which empties the heart to prepare it for union with God. God does this by reducing his love and his will to the dimensions of the present moment so that he may reach the senses and from there pass to the heart which has been emptied by God ready to receive him (50). Thus *kenosis* or emptying and union, which may be the contemplative-type experience, are connected. This connection is also made by Merton who defines in some detail what contemplation is not: it is not trance, ecstasy or enthusiasm; it is not the gift of prophecy; it is not an escape from conflict, anguish or doubt; it is not complacency, inactivity or anaesthesia (Merton, 1972: 10-13). Rather contemplation is 'a purification of the sanctuary' so that nothing is left in the place which God has commanded to be left empty (13). Even the relationship with God, my own spirituality, is laid on the altar as a sign of my willingness to abandon myself to God's purpose. In the context of the hospice chaplain that purpose is spiritual care or 'being whatever the patient needs me to be,' to which I shall return.
According to de Caussade God empties the heart in order to live in it (de Caussade, 1989:50) and the soul or person is then characterized by a passive submission to divine action and by the grace to be as Paul said 'all things to all men *(sic)*' (87). Today the expression 'passive submission' might be taken to mean giving in to domination or allowing oneself to be oppressed, but such an understanding would be alien to de Caussade. The movement he refers to is from doing to being, from actively seeking God to doing nothing but waiting on God. Just as Jesus' passion was a definite time in his life when he was 'handed over to wait upon and receive the decisions and deeds of men, to become an object in their hands' (Vanstone, 1982:31) so the passive soul waits upon and receives from God, becoming an object in God's hands or, as de Caussade expresses it, passiveiy submitting to divine action.

In waiting upon the patient the chaplain waits on God, receiving whatever the patient offers and responding according to God's guidance. For de Caussade submission is seen in a willingness to respond to God in humble obedience (87) and allow 'the Holy Spirit to act in us regardless of what it is doing, happy, even, to remain in ignorance' (87). By the power of God's grace the submissive soul learns to act on intuition, mentioned by Ian, and faith (38), accepting without question what God ordains (44, 75). Such action may appear impulsive but it is sound because it is initiated by God's grace (de Caussade, 1989: 38-39). Greta spoke of being grounded in faith and guided by the Holy Spirit. Furthermore God nourishes the seed in the heart of the person so that it throws out branches, leaves, flowers, fruit which the person cannot see but which will nourish others (40). Thus the divine purpose works without the soul knowing (43). According to de Caussade, everything conceals God's divine purpose so that 'we are always being taken by surprise and never recognize it until it has been accomplished' (84). Beth remarked that so often she found herself where she was needed *without realizing.* She understands this kind of experience as God working 'in me and through me.' The failure to realize how God is working through her is not a sign of poor self-awareness, but rather a sign that the self-awareness has been sufficiently developed to surrender to God. I will therefore now make a brief exploration of the connection between self-awareness and *kenosis*.

***Kenosis*, self-awareness and identity**

Self-awareness and identity were spoken of by some interviewees (Oliver, Queenie, Yasmin, Xelda, Keith, Tracy) and implied by others (Eric, Fred, Valerie), developing, as Nouwen found, as a result of the work they were doing[284]. For Nouwen the work was his study of Thomas Merton which resulted in the publication in 1972 of the book now entitled *Thomas Merton: Contemplative Critic*[285]. Nouwen relates Merton's point that a real intimate relationship first requires that the person know his own identity (Nouwen, 1991: 41) and finding that identity might involve much pain and suffering which some, but not all, of the interviewees had described. Merton describes 'sacrifice and anguish, risk and many tears' (Merton, 1972:32) which description could certainly be used of Keith's experience. Merton recognizes that 'Not to accept

[284] As they were all over fifty this development may also be an example of the second half of life as described by Richard Rohr (2011). Nouwen was around forty when researching Merton so may also have been entering the second half of life. However, the significance of age for the development of self-awareness is not explored in this study but might be a topic for further research.

[285] Published originally in 1972 with the title *Pray to Live.* The second edition was published as *Thomas Merton: Contemplative Critic* in 1981, twelve years after Merton's death, and reprinted in 1991.

and love and do God's will is to refuse the fullness of my existence' (33). He describes the false self – the one who wants to live apart from God – saying that for most people this is reality. He describes wrapping experiences like bandages around himself in order to substantiate this false self[286] and realizing that underneath there is nothing but nakedness, emptiness and hollowness (35). His existence, peace and happiness depend on discovering himself in discovering God: 'If I find Him I will find myself and if I find my true self I will find Him' (36). Not unlike Merton, Oliver said that he could only engage with the world of the hospice by finding his own solitude, spiritual identity and sense of being. I am arguing that self-awareness was key to letting go of his identity as a congregational minister with specific jobs to do, finding himself in God and being other-aware so that he could *be* a hospice chaplain, without specific jobs.

Tracy was acutely aware of the increase in her self-awareness through encounters with patients, families and staff, resulting in increased confidence to stay with the difficult issues, have the challenging conversation or comment to patients or staff members that an experience 'must have been spiritually refreshing.' She was also aware that her faith had been influenced by her work, saying 'I realize now that I am more contemplative than evangelical.' Consequently her own spiritual refreshment was important and, having found that local churches' services did not fulfill her spiritual need, the discovery of a Meditation Group was timely. She was not the only interviewee to say that she needed 'to disengage the brain' so I will now explore the place of the intellect in the contemplative-type practice and its relevance for kenosis.

***Kenosis*, the intellect and the contemplative-type experience**

De Caussade describes how the soul in search of God explores carefully and scrupulously every possible way to find union with God (de Caussade, 1989:5). The soul is proactive, using the intellect, accumulating knowledge. The path is clearly marked in her reading, her thoughts and ideas, and with God by her side she speaks for herself for she lives in God (5). On the other hand when, by His grace, God lives in the soul there is nothing of herself left 'save what comes from his inspiration.' The path is no longer clear, the only support is God himself (5). The empty soul waits on God who 'himself replaces the books, ideas, self-assurance, advice and wise guidance of which they are deprived' (6).

[286] Reminding me of my own experience of recognizing that I was living a life created for me by other people, like wearing clothes offered by others (Thomas, 1999:65).

As she failed to find spiritual nourishment in church services Tracy turned to a meditation group to 'disengage her brain'. However, each of the meditation sessions attended by Tracy began with listening to a talk on a World Community for Christian Meditation CD, which seems to contradict her aim[287]. Admittedly this was followed by twenty-five minutes of silence but in this she was learning, with diffuclty, to use a mantra. She admitted that the focus on breathing was far more helpful. There was no mention of union with God and her description is not unlike the picture of the soul in search of God given at the start of this section (de Caussade, 1989:5). However, Tracy also observed that the communal practice of meditation generates something special and even when she was struggling to use a mantra she benefitted from the quietness of the other group members. She had learnt to practice meditation when on her own and appeared to have developed what Ignatius calls indifference[288] which enabled her to speak with confidence about her role in the hospice. She also described remaining at peace within herself when she had to attend a disciplinary hearing for refusing to pass confidential information to the Human Resources Manager. According to de Caussade confidence and peace are signs of God dwelling in the soul in contemplative union (57).

Rather than 'disengaging the brain' Ian spoke of stilling the busyness of the mind through formal prayer. He spoke of experiencing an awareness of God's presence, but without any communication taking place. His description of his way of attending to the prayers sounded to me like *lectio divina* but his experience of that was limited, so he preferred to say that it was like the way he might attend to knitting or sewing. Not unlike *lectio divina* Freeman describes a way of reading and absorbing the scriptures (Freeman, 2005:433) in which a verse or a text is prayerfully repeated, initially verbally, until it is repeated silently in the heart as though it was part of the person and then even repeated without the person being aware of it (432). By reducing the meditation to the constant repetition of a single verse the mind is prepared for the grace that leads to contemplation or union with God (Freeman, 2005: 432). Ian described occasions when his mind was not just stilled but liberated so that he and God could be together, saying 'God and I have an agreement that this is when he can get at me!' He also spoke of living in God's presence everyday

[287] The World Community for Christian Meditation is a global contemplative network which teaches meditation as a way to inner and outer peace. It is directed by Laurence Freeman OSB who worked with John Main OSB to establish the first Benedictine lay community in 1975.

[288] Indifference is the maintenance of emotional and spiritual balance and calm in the face of praise and or criticism and all the stages in between. The Russian Orthodox call it 'holy indifference' (de Hueck Doherty, 1975:136).

perhaps suggesting the stirrings of grace mentioned by Freeman (432) and de Caussade (1989: 15).

God's grace was also mentioned by Norman who spoke of clearing his thoughts, his busyness, as a by-product of focusing on the breath in meditation. This helped him to 'engage better in prayer' and sharpened his awareness of God's presence – of God in him, God as accompanier and God as the third person in the relationship with the patient. He observed that a lot of people refer to meditation as mindfulness because it uses a religious tradition but without the faith and spirituality[289]. He stressed the importance of prayer for undergirding his work, giving the example of time spent in the chapel in silent meditation, especially when a meeting with a patient had brought up issues for him. Time to reflect before going on to the next patient was immensely valuable. Asked about the term 'contemplation' Norman stated that it was not a word he ever used as to him it meant 'actively thinking about something,' rather than the disengagement from all we feel and do in order to stay in the present focused on the patient. Such disengagement may be an example of de Caussade's walking with God 'in the duty of the present moment' (de Caussade, 1989:15).

These descriptions indicate that Tracy, Ian and Norman felt that the intellect was getting in the way of the relationship with God. Rather than a hindrance Keith and Alan seem to be saying that the intellect, the ability to reason, is irrelevant. Keith described living with the mystery of God. Explanations are anathema to him. The wonder that accompanies new life is the same wonder that defines death, even when that death is unexpected. For Keith there are no answers, no reasons, but his sense of 'the presence of something' which some days he would call God and other days might not… Alan observed that God cannot be fully understood because a finite mind cannot understand the infinite, and it is only at a level of 'truly moving in the spirit that you have an understanding that is maybe beyond words.' As de Caussade observed: 'Words are no longer necessary to explain what is not based on reason,' (de Caussade, 1989:21). He refers to Romans 8:28: 'We know that all things work together for good for those who love God, who are called according to his purpose' and again explains that a soul who has surrendered to God no longer tries to reach him through reading, endless speculations or inner supplications, nor does he need

[289] In the last ten years mindfulness has become fashionable as a way of handling stress and changing attitudes and thought processes. Williams and Penman (2011:6) say that mindfulness is not a religion but a method of mental training. (Mark Williams founded the Oxford Mindfulness Centre and the Centre for Mindfulness Research at Bangor University).
An AHPCC Executive member undertook some mindfulness training and then ran a workshop at the annual conference in 2012. At the end of the workshop several chaplains observed that mindfulness meditation appeared to be the practice of the presence of God, which they had learnt from Brother Lawrence, albeit without God!

to look for his path because God has marked it (22). He advises the soul to focus on the fulfilment of divine purpose, and do nothing but:

> … meekly comply with God's will, doing everything yet doing nothing, having nothing yet possessing all (de Caussade, 1989: 81)[290]

The irrelevance of reason and the intellect and the focus on obeying the divine will without question is summed up by de Caussade as the 'duty of the present moment' (de Caussade, 1989:22,61) and I shall now explore the relevance of this concept for the hospice chaplain.

The duty of the present moment - without a why or wherefore

Understanding de Caussade's 'duty of the present moment' (de Caussade, 1989: 22,61) as not needing to know why, or the lack of the need for a reason, the chaplain's duty of the present moment is demonstrated in the taking up of the position, not planned as a career move, but by chance, serendipitous and encouraged by others.[291] When working in the hospice the chaplain's duty of the present moment is the person in front of him - patient, family member or staff. The chaplain has no purpose or agenda (Queenie, Norman) save to 'be whatever the person needs me to be' (Ian, Unwin, Doreen, Alan, Xelda) or 'to weep with those who are weeping, to rejoice with those who rejoice, to talk with the simple-minded in their language and to use the most erudite and learned terms with sages' (de Caussade, 1989:31). Beth gave an example of this in having a 'deep and meaty discussion' with an intelligent patient and finding the same depth in 'having a chuckle' with another patient who was 'not an intellectual'[292]. In order to walk with God in the duty of the present moment the soul disengages from everything else (35). Interviewees spoke of leaving the self at the door (Greta, Ian), laying my own beliefs on one side (Greta, Charles), taking my shoes off at the door (Norman)[293]. It pained Beth to think that she might hinder somebody in their spiritual journey, and Greta was also concerned not to get in God's way. By the power of God's love the heart is emptied, redeemed and made ready to receive God (de Caussade, 1989:3).

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[290] According to Paul 'as having nothing, and yet possessing all' was a manifestation of God's grace (2Corinthians 6:10)

[291] See Chapter Five.

[292] Beth also contrasted a theologically deep discussion with an intelligent patient with a conversation with those who are not so intelligent but who get to the point more quickly and are more forthcoming with their emotions. She felt that both were deep discussions but the latter was often more real rather than theoretical.

[293] Alluding to Moses' experience when he saw the burning bush and was instructed 'Remove the sandals from your feet, for the place on which you are standing is holy ground' (Exodus 3: 5).

Because he is in all creatures (19) the chaplain's heart is ready to receive God and the other, in this case the patient who is the duty of the present moment, which Beth expressed as 'the divine in me meets the divine in you.' In order to walk with the patient in the duty of the present moment the chaplain disengages, becoming indifferent to the outcome of the encounter but being a conduit (Beth, Norman), 'totally open to God working through me' (Beth).

The duty of the present moment and *kenosis*

Norman described himself as a conduit but had not considered that his emptiness was self-actuated rather than God-actuated. On reflection he thought they were 'two sides of the same coin.' Beth's understanding of being a conduit was not the result of her acknowledgement of, and work with, inner events but an aspect of her relationship with God. She described herself as grounded in God's love for all, a contemplative for whom prayer is sustenance. *Kenosis,* which is 'not just emptying the self,' has empowered her to be a conduit and to say that her work is where God is with the person, knowing the person as God knows him. She referred to the *mantra* of her hospice, which is the basis of her training for chaplaincy volunteers: 'meet people where they are at and love them.' To do this each person has to lose her own agenda, pour the self out: 'leave the self at the door, if not before.' Neither priestly nor chaplaincy training covered the chaplain's *kenosis* which she believes should reflect the *kenosis* of Christ: pouring out the self in incarnation and on the cross, relinquishing his divinity to be one of us, not just being with us but being one of us. She commented that Nolan's book on the nature of the chaplain's presence as 'being with' did not embrace *kenosis*, which would mean not just being *with* the person in their suffering but being *in* the suffering with the person. However, she did not think that we could empty ourselves - *kenosis* is not self-actuated. God facilitated *kenosis* so that she could work from the patient, as Christ but not Christ, hearing the patient's story, identifying what is of value to him. When her self is put aside her purpose as priest and chaplain is to enable the patient to find his purpose. The starting point is the patient, identifying what he believes is his purpose in life and then exploring what, if anything he understands about God. Her faith enabled her to see 'divine action in everything' (de Caussade, 1989:84). She called this 'bottom-up' ministry in contrast to her Anglican training which she said was 'top-down'. In 'bottom-up' ministry the baseline was, and is, God in all creation though not necessarily recognized or acknowledged. She said that the chaplain works on the assumption that God is present regardless of the patient's belief, and by the grace of God, the power of the Holy Spirit works through the chaplain to enable the

patient to recognize God in their life and in creation. 'Top-down' ministry also has the baseline of God in all creation but such ministry operates by telling people where God is in life and creation. Beth's description of bottom-up ministry is like de Caussade's duty of the present moment, a ministry exercised by a soul in whom God dwells[294], a ministry that responds to the divine purpose without a why or wherefore. Further research is needed to establish whether Beth's description supports Elford's argument (1999:x) that most ministers study theology first and then encounter the pastoral whereas in reality theology develops out of pastoral concern.

Without a why or wherefore – further observations

To live 'without a why' was a crucial aspect of Soelle's mystical resistance. She borrowed the phrase, the original was *sunder warumbe* meaning 'live without a why', from Meister Eckhart who used it to express the innermost ground of life itself (Soelle, 2001:60, Hawkins, 2005:90)[295]. For Soelle a believer should respond to God 'without a why', living in the present rather than needing to see results from prayer (Soelle, 2001:60,294). Whilst most interviewees understood the hospice management's need to see and record results, they were not comfortable with what would effectively be providing a why and wherefore. Spontaneous mention of the need for evidence was rare and feelings on professionalization were mixed. Most agreed that the move towards technical excellence risks the loss of the essence of spiritual care (Charles, Doreen, Keith, Yasmin).[296] Fred asked how to quantify comfort or the effect of words of reassurance, saying that trying to do so inhibited 'the ability to just respond'. He felt that the need to measure was stifling what had been for him a liberating ministry.[297] Larry asked who was benefitting from the quantifying, indicating that it was management who needed the reasons of why and wherefore, rather than patient or chaplain.

For Soelle 'without a why' meant to be without intentions, purposes or power and therefore to be free to respond to God's grace. She felt that to live without a why was particularly important for anyone in ministry as 'The soul that is able to live in this spirit has no need to justify its existence; it simply appreciates the beauty of being alive in the now' (Hawkins, 2005:90). Soelle argues that such a soul is called

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[294] Whether top-down ministry is that of the soul dwelling in God is a subject for further research.

[295] Connolly (2014:3) understand *sunder warumbe* as 'without a why or will' stating that Eckhart was referring to how to live a good life by drawing attention to the attitude or motivation behind actions.

[296] Interviewees were asked to comment on an extract which is shown in Chapter five which may also be found in Appendix G.

[297] He left hospice chaplaincy completely some six months later.

upon by God to give away her own ears and eyes and let herself be given the ears and eyes of God and so live and love as God lives and loves (Soelle, 2001:293-294). The data suggested that some interviewees were experiencing this transformation: Eric thought that he was beginning to see the world as God sees and John described himself as giving a human face to God. Beth spoke of 'being a presence for God' and Greta said that it was not her ministry but the Holy Spirit through her.

Above, below and around these lenses on 'without a why or wherefore' is 'We love because he first loved us.' (1John 4: 19). We do not love in order to receive something in return, or because we are commanded to, but because we recognize and respond to God's love. God alone is the motive for love, the more I love the more I am able to receive love, and the more I receive love the more I love God. Depending on my circumstances this loving relationship may lead me to examine and articulate my inner events, as explored in the previous chapter, perhaps resulting in a self-emptying which, although not the same as the emptying or *kenosis* associated with contemplative union, is nevertheless part of my journey to union.

There is one other subject I need to consider as it was mentioned by some interviewees and may contribute to the understanding of presence, and that is: solitude and silence.

Solitude and silence

In the fourteenth century Julian of Norwich lived the solitary life not for selfish reasons but in solidarity with Christ, having compassion for humanity (Leech, 1985:90). Leech points out that a person enclosed in a false self or a self-absorbed person could not live a solitary life, which only has meaning within the Christian context of the Body of Christ. He further points out that a solitary, contemplative life does not lend itself to assessment of function and efficiency and so appears absurd to management today (89). For hospice chaplains this absurdity has to be handled not only with management: Doreen expressed concern at the absence of the disciplines such as prayer, meditation, contemplation from the professional documents on standards and competencies. Such documents are heavily skills and knowledge-based and need the balance of the contemplative-type experience, prayerful discernment and indifference.

The ability to stay with the painful and difficult (Doreen, Tracy, Beth, Alan, Keith) requires the chaplain to feel the presence and reality of God in the pain. Just as the author of *The Cloud* encourages perseverance in contemplation because he knows how hard it is to suppress thoughts, how easy it is to be distracted (Walsh, 1981:173-4) so the chaplain needs perseverance to stay in the present painful

situation, not letting her thoughts wander, not being distracted, not looking for reasons. Her focus needs to be on God, on the fulfilment of divine purpose (de Caussade, 1989:81).

Just as in contemplation God plays his part, giving his grace to encourage and strengthen – and even sending 'a ray of spiritual light, piercing this cloud of unknowing between you and him' (Walsh, 1981:174) so in the bedside vigil God plays his part: Keith described reading a psalm and saying a prayer and then watching 'as something quite profound happened in the mysteries of that person's soul.' Thus the work of 'beating on the cloud of unknowing' and the 'firing of the dart of love' (131) takes place in the solitariness of the heart when the chaplain is actually with a patient, family, or staff member. Or, to put it another way, the very nature of the work means that a sense of the value, the necessity, of stillness and silence within has been cultivated. Alan and Norman spoke of sitting in silence as a necessary part of ministry. Alan likened his silent prayer to two lovers sitting by a river together – they do not need to speak because they are just happy to be in each others presence. During the course of his day he took time out in the hospice chapel, where he was lover and the beloved and was nourished without the use of words. Alan also spoke of the misunderstanding about action and contemplation saying that people tend to think they are opposites when 'actually they complement each other.' He expressed the opinion that effective action arose out of contemplation and that whilst he was on his own in contemplation the outcome was for the benefit of others. The need for both contemplation and action, rather than one or the other, was stressed by Thomas Aquinas (Woods, 2012:100), and others.[298] McGinn (2012:35-36) tells us that the contemplative life, love of God, always results in activity, love of neighbour, but many mystics believed that contemplation and action could only be practiced in succession. Others, like Ignatius of Loyola, thought that they could be 'active in the state of contemplation' (36). Either way the importance of the contemplative life for apostolic action is clear[299] and this principle gives significant weight to the concern about the absence of spiritual disciplines expressed by Doreen.

Ian described the silent aspect of the morning prayer – even when saying the words because 'part of my mind is liberated so that God and I can be together.' He commented that the sense of God's presence is helped by the natural world. He

[298] The Dominican Albert the Great (1200-1280) consistently stressed the importance of contemplative life expressed in apostolic action (Woods, 2012:99). The Augustinian Thomas of Villanova (1488-1555) regarded contemplation as 'the doorway to apostolic life' (Laird, 2012:63-64).

[299] Contemplation is as necessary for an active preaching ministry as for an apparently inactive anchorite ministry (Laird, 2012:63-64).

gave an example: just as a spouse asks 'Do you like the wonderful meal I have cooked for you?' so God asks ' Do you like the beautiful sunset I have made for you?' Those who respond to God's love learn that God communicates through the Word/Scripture, through people and community, and through creation as expressed by Ian. God's communication in creation is a cause of concern for de Caussade (1989:70) who fears that without silence we shall fail to be 'attuned' to it. The means by which any of us 'attunes' to God warrants a brief mention of the use of metaphor.

Queenie was the only interviewee to spontaneously mention the use of metaphor although other interviewees spoke of using journey. Alan made the point that it would depend on what the patient offered, meeting him where he is rather than where Alan thought he ought to be. In contrast George Guiver (1996:50-51) cautions the use of metaphor saying that God is not a gas to be sniffed, or a radio wave to be picked up by an internal receiver[300] - though Harry reported patients who thought he had a hotline to God. Guiver argues that metaphors are only helpful in the context of community, the Body of Christ. He describes the English way of prayer, 'you are nearer to God in a garden', as sub-Christian (51). For the hospice chaplain a metaphor, like the garden, may be the only means of communicating with a patient who is exploring what she believes. The chaplain has no option but to work with the sub-Christian or non-Christian metaphor - an example of what Beth called 'bottom-up' ministry, referred to earlier.

Returning to the chaplain's 'attuning', her relationship with God will not be found by escaping from the world and all its messiness. As Merton said;

> We do not go into the desert to escape people but learn how to find them; we do not leave them in order to have nothing more to do with them, but to find out the way to do them the most good. But this is only a secondary end. The one end that includes all others is the love of God (Merton, 1972:80).

The desert teaches us to pay attention (Lane, 1994:198) and we learn the indifference of the desert believers who were not affected by scorn or praise and not afraid to stand against the dominant social values of the time (201). Lane states that the desert to which a person withdraws may be literal or metaphorical – either way the journey into the desert is not engineered by the person but is the result of the movement of God's Spirit in the soul. He describes the metaphorical desert as 'the uncharted terrain beyond the edges of the seemingly secure and structured world' (203). However, he points out that the journey into the desert may be

[300] George Guiver is Superior of the Community of the Resurrection and Vice-Principal of the College of the Resurrection, Mirfield, the only Anglican theological college to share its life with a monastic community.

involuntary, caused by external circumstances, such as AIDS, abusive relationships, addiction, divorce, redundancy and as previously mentioned 'the steep cliffs beyond the waiting room of Radiation Oncology' (203)[301]. In order for those pitched involuntarily into the desert to receive compassion and spiritual sustenance it is necessary for there to be people who either enter the desert voluntarily, or who offer their own involuntary desert experience to God for transformation. Either way these are people who say 'yes' to God's invitation - without a why or wherefore - and in so doing are emptied of everything by God (204). However, the term 'desert experience' was not used by interviewees although more than half described an event which could be construed as such. The idea that a desert experience, or tragedy, might be transformed into the energy for accompanying another through the desert was rarely spontaneously acknowledged. However, Keith described his experience as a 'watershed' which shaped, informed and sustained all his ministry. Asked what enabled him to stay with the pain of others Steven described how his experiences had sustained ministry to those experiencing similar problems in both congregation and hospice. Greta recognized how her own unexpected experiences had influenced her support of patients experiencing unexpected life journeys. In contrast Patricia had not thought about connecting her own pain to her ministry but on reflection recognized that some experiences had fed her.

The desire to love and serve God is expressed in various ways, as the willingness to do his will, *The Cloud*'s dart of love, de Caussade's commitment to the duty of the present moment or self-abandonment to divine providence. It appears that this is all that is needed to facilitate the gift of contemplation and *kenosis*. Isaiah described it as: 'a spirit from on high is poured out on us, and the wilderness becomes a fruitful field, and the fruitful field is deemed a forest' (Isaiah 32:15). In the process the transforming awareness of the intensity and extent of God's love (Egan, 2005:211) is increased to inspire a similarly fierce love for others: the desert thus does its job of afflicting the comfortable and comforting the afflicted (Lane, 1994:203 -204). In the case of the hospice chaplain: his comfort has to be afflicted, emptied, to make room for the afflicted patient to be comforted. As Isaiah expressed it: 'For waters shall break forth in the wilderness, and streams in the desert' (Isaiah 35:6b).

God is the initiator for contemplative practice or union, offering the gift when the person is willing to abandon herself totally to God. She need do nothing except accept the gift – by the power of God's love she is empty and ready to receive God (de Caussade, 1989:50-51). In abandonment the wings of the intellect are tied back, there is no reason, no why or wherefore. The focus is solely on doing what

[301] Noted in Chapter Two.

God wants. Soelle understands this union as transformation: 'What really happens in mystical union is not a new vision of God but a different relationship to the world – one that has borrowed the eyes of God' (Soelle, 2001:293). She is now ready to fulfil God's purpose for her – generally to be all things to all people and in the case of the hospice chaplain the spiritual care of all whom she meets in the hospice expressed as 'being who the person needs me to be.'

Kenosis and hospice management

Just as de Caussade observed that the world thought souls in whom God dwells are useless (1989:6) some interviewees seem to feel that they too are regarded as useless by hospice management. Hospice management and hospice chaplains are like two tectonic plates – a task-oriented goal-centred rationality prohibits any form of existence for which there is no purpose (Soelle, 2001:60). It is essential that the chaplain personally operates without a why or wherefore but management needs evidence. Unfortunately for the chaplain management does not appreciate the value of (apparently) doing nothing. Keith and Fred both observed that they could not prove the value of sitting with the dying and John observed 'mostly I just sit with the patient.' Doreen expressed the feeling that it would be good to have something 'to do' but at the same time acknowledged that the hospice chaplain's role is 'to be' rather than 'to do'. Out of this 'being' springs the fruit, often invisible to the person, by which others are encouraged and loved (de Caussade, 1989:38-39). Mark Clayton, chaplain in a children's hospice, refers to the chaplain's perspective as a 'contemplative stance' of attentiveness and presence which grows out of his personal faith and experience of divine presence. In practice it not only enables the chaplain to stay in the present moment with the patient and family but also empowers them to stay and experience their own attentiveness or contemplation (Clayton, 2013:35,40).

Management requires hard data on defined activities such as patient visits, phone calls and the categorisation of soft data such as: family issues, existential questions, funeral arrangements. As Tracy said 'what is the essence of that conversation that you want to capture to pass on to someone reading it?' The ambivalence of interviewees to these issues may lie in the reason behind the requirement. To pass the information on to other members of the multi-disciplinary team is to the benefit of the patient but to pass the information on to justify the chaplain's pay-cheque is not consistent with her integrity. To do the latter is to support the assumption that there is always a result of some kind, whereas the nature of any kind of ministry is to sow seeds and not know whether the plant grows.

Conclusion

Jesus set an example of withdrawing to deserted places to pray (Luke 5: 16, Matthew 14:23, Mark 6:31) but the evidence of chaplains doing likewise was limited, possibly due to a culture which does not speak of such things, or to management attitudes or to the skills and knowledge-based emphasis of chaplaincy professional documents.

By its very nature Christian contemplation must engage with the world (Tyler, 2012:389) but equally Christians, like hospice chaplains, who are engaged with the world must be contemplatives. The contemplative attitude is living life in the context of the relationship with God. It is focused on doing God's will, fulfilling God's purpose, and indifferent to the success or otherwise of the endeavour. Despite the patient-centred description of all hospice work the chaplain needs to be focused on God in order to be indifferent to the outcome of the encounter (de Caussade, 1989:50) and to be indifferent to the machinations of management. Only then will the contemplative chaplain be the conduit for the love and relationality of the Trinity. Only then will the contemplative chaplain be comfortable balancing the requirements of the job with her ministerial integrity.

Whilst faith-specific disciplines such as prayer, meditation, contemplation, communal worship and non-faith-specific mindfulness continue to be absent from guidelines on what it is to be a chaplain there is a risk that his desire to focus on God will be challenged by the patient-focused ethos of the hospice environment and by the need to keep the job through the provision of evidence of the value of spiritual care. The pull of the demand for evidence may encourage the desire to be like other hospice employees and the satisfaction of providing evidence may become a substitute for the desire to fulfil God's purposes.

In the past the chaplain's role was not examined too closely by management – in Norman's words 'they had no appetite for it' and it was generally accepted that it was good and necessary work. The economic climate is bringing about change so that every discipline is put under the microscope to justify its existence and value. Management is aware that chaplaincy is not easily categorized but stands on various boundaries such as that between life and death, professional and untrained, patient's wish and doctor's need for a clinical outcome. There may also be ignorance of the concept of spiritual care and exactly who the chaplain is caring for – management may think the provision of spiritual care for all staff is rightfully part of the job description until it comes to themselves. In addition the chaplain may be uneasy about boundaries, of profession and training, evidence and integrity. Whilst education may be of some help for both management and chaplain, time and

expenditure have to be justified for clarifying what are essentially unclear or blurred boundaries. Some of these boundaries will be discussed in the final chapter.

Chapter Nine: Boundaries

Introduction

The examination of the understanding of the chaplain as prophet and presence in the previous chapters drew attention to various boundaries. Before drawing my conclusions on the role of English hospice chaplains I want to consider some of these boundaries in the light not only of what the data revealed but also what was not revealed. I also want to convey the hospice world of the future as conceived by the Help the Hospices Commission into the Future of Hospice Care[302]. Therefore this chapter acts as a series of stepping-stones facilitating the linking of the interpretation with the conclusions, and in the process allowing me to make some observations about what is hidden under the stones. The first part of the chapter is concerned with the shifting boundaries of the present situation, focusing on the chaplain. I begin by examining the chaplain's boundary position. Consideration is then given to the boundary between life and death before examining the boundaries of Cicely Saunders' original vision. The blurred boundaries of knowledge, professionalism and evidence are then described, followed by an observation on the implications of wellness and well-being for spiritual care. The theology underlying the practice of chaplaincy is followed by a comment on the role of 'chaplain to the institution'. I then present my case for the chaplain as the bearer of dangerous memory. The second part of the chapter focuses on the hospice, summarizing the work of the Commission into the Future of Hospice Care in order to set the context for my final conclusions and recommendations.

The chaplain

Chaplains on the boundary

Chaplaincy in general occurs in marginal places (Threlfall-Holmes & Newitt, 2011:xiii-xvii), that is places that are not part of, but outside the boundary of, normal everyday life[303]. In addition, because it is also outside the boundary of 'normal' church life, chaplaincy may be viewed as marginal and therefore irrelevant. And yet chaplains are located where 90 per cent of the non-church-going population are to be found (xv). Furthermore, whether church-goers or not, the topics of death and

[302] Help the Hospices (2013a) *Future ambitions for hospice care – our mission and our opportunity*. The final report of the Commission into the Future of Hospice Care. There are also contributory reports.
[303] See chapters Three and Six.

dying are outside the boundary of normal conversation for most people[304]. As already argued in Chapter Six the chaplain symbolizes an alternative reality and hospice chaplains, working on the boundaries of recognized religion, referred to in Chapter Three, symbolize an alternative reality for both living and dying. A terminal diagnosis challenges the boundaries which aid our sense of security - we are fearful of what we cannot see, what we cannot control. We do not like a lack of control especially when it is due to failing physical and mental fitness. The boundary between life and death is particularly problematic, not in the sense of being heart-beating alive or heart-not-beating dead but in its unpredictability and in the decline which most people experience from life to death. Cicely Saunders worked in the area between life and death experienced by those diagnosed with a terminal illness, principally cancer sufferers. Despite her work and the more recent government work on end of life care aimed at promoting the acceptance of the declining phase of life, whatever the cause, and treating the person with dignity, the process of dying is still not an acceptable topic of conversation in our society. Dying is outside the boundaries.

The boundary of life and death

The demise of Christianity as the dominant culture has resulted in a decline in understanding of the continuity of life through death and an increase in the number of people who do not believe in life after death. The significance of such a belief is deemed irrelevant and life is lived on the understanding that 'this is all there is.' The data supports this showing that only three interviewees (Alan, Doreen, Ian) reported that patients asked questions about death and dying and Oliver said that such questions did not occur regularly. In addition assisted suicide was not mentioned at all and only one interviewee (Alan) mentioned euthanasia, saying he was interested in the debate which keeps coming round and wondering how he would feel if he had motor neurone disease.

Furthermore, not only has the boundary of life and death been solidified but the movements for euthanasia and assisted suicide, are seeking to control and bring it forward. Uncertainty is feared but 'this is where and when it ends' gives certainty, supposedly resulting in security and the removal of fear. Further research would be needed to establish whether euthanasia and assisted suicide did not feature in the interviews because they are not topics raised by patients or they are raised but not encouraged by other staff.

[304] In Chapter Two the Victorian predisposition to talk about spirituality and death whilst regarding sex as a taboo topic was contrasted with the contemporary situation of free and easy talk about sex with spirituality and death being taboo topics.

The Dying Matters Consortium[305] continues to work to raise death's profile[306] and during the last three years death cafés have been run all over the country[307]. Started by Jon Underwood, the aim of such cafes is to create a safe environment in which people:

> drink tea, eat cake and discuss death: not to be morbid, just to raise awareness and to "help people make the most of their (finite) lives". (Tucker: 2014)

Challenging the western attitude to death by talking about it is also found in the work of Stephen Jenkinson[308] who argues that such talk is life-enhancing (Jenkinson, 2015:218-223). Jenkinson's argument in his writing and teaching expounds the role of culture in fulfilling the need of every human being to know who he is, and then be able to learn to live well in order to die well (13-16). This seems to echo Saunders' original vision for the person to 'die peacefully, but also to live until you die' (Rankin, 2007:193). His recent lecture tour in England included a hospice, whose chaplain commented afterwards 'that is what we do! He does not understand hospice care.' Despite these efforts death and dying are still beyond the boundary.

The boundaries of Cicely Saunders's vision

Only one chaplain (Fred) spontaneously demonstrated awareness of Saunders' original vision and of its decline. Amongst the other interviewees there was no indication of the awareness of the original vision or the nature and extent of its decline, although some reported a change of ethos in their hospice.

The very conditions and circumstances which led Cicely Saunders to develop the concept of hospice ultimately led to the challenge to spiritual care being experienced today. In the 50s and 60s the boundaries of the status quo were challenged and people thought 'outside the box' of the dominant discourse of Christianity. The decline of the Christian discourse, described in Chapter One, and the emergence of spirituality, as not necessarily attached to any religion, faith or belief system,

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[305] The National Council for Palliative Care (NCPC) set up the Dying Matters Consortium in 2009 to promote public awareness of dying, death and bereavement. http://www.dyingmatters.org

[306] With a special week in May every year and short films like *Last Laugh,* with Alexei Sayle, and *I didn't want that,* about the importance of making wishes about death and dying known to family and friends.

[307] The first death café in England was created by Jon Underwood in 2011. In 2014 the Church of England produced guidelines entitled 'Grave Talk' with a similar aim of enabling people to talk about death and dying over tea and cake.

[308] Stephen Jenkinson is an activist, teacher, author and farmer. He holds a master's degree in theology from Harvard and a master's degree in social work from the University of Toronto. He is the author of *Die Wise* and the subject of the documentary film *Griefwalker,* directed by Tim Wilson and produced by the National Film Board of Canada, https://www.nfb.ca/film/griefwalker.

undermined the significance of spiritual care such that the position of chaplains came under attack for example in the NHS Battle of Worcester in 2006, which was described in Chapter Two (Swift 2014: 81). This event made the news headlines and affected chaplains outside the NHS. Following Saunders' example a few hospices were established as Christian foundations and a further few were founded by Christian ministers and lay people but the majority of hospices today are secular. Nevertheless it seems that the vast majority of hospices still have a Christian chaplain or Christian Spiritual Care Co-ordinator, whose contract requires the provision of Spiritual Care and prohibits proselytisation[309]. In Chapter Six I described Saunders' original hospice vision as of a community providing security for both patients and staff (du Boulay 2007:73). Economic considerations meant that Saunders had to let go of her community vision but the hospice retained a particular kind of workplace spirituality expressed in teamwork, and a sense of everyone – clerical as well as clinical staff – pulling together. However, the economic situation did not improve and whilst many of the chaplains interviewed felt embedded and were part of the multi-disciplinary team (Alan, Beth, Charles, Queenie) others struggled as new management with little or no understanding, and even suspicion, of what has been called 'the heart of hospice' caused the ethos to change (Fred, Patricia, Eric). Several chaplains (Tracy, Steven, Larry) described living through this change at the time of interview, describing a split between staff who were patient-facing and still community-oriented and administrative staff. A focus on financial survival means that there has to be a reason for every service offered (Help the Hospices 2013a:10) and individuals fear for their jobs, detracting from any sense of community (Tracy, Steven). In this climate the chaplain has a counter-cultural role of demonstrating that a sense of community is crucial to the provision of hospice care. To fulfil such a role the chaplain's own sense of community – not just in the hospice, but as a member of a local worshipping community, in the wider communion of saints and in the community of the Trinity – is important. The data indicates that only half the interviewees belonged to a faith community, perhaps suggesting that its value is not appreciated. Furthermore the interviewees' responses when asked about their own spirituality varied in confidence and in ease of expression, and several expressed gratitude for the opportunity to explore, suggesting that existing supervision and/or spiritual direction arrangements are either not fully utilized or are inadequate.

[309] Chapter Four gives details of The Profile Survey which showed that the overwhelming majority of hospice chaplains are Christian.

Blurred boundaries: Knowledge, professionalism and evidence

The AHPCC Competencies (2006) acknowledge and specify the spiritual care role of staff and volunteers as well as chaplains. This does not detract from the chaplains' discrete body of knowledge not possessed by other professional disciplines. However, whilst the nature of the medical team with consultant, senior and junior doctors is readily accepted the idea that the chaplain is the spiritual care consultant and the other disciplines are part of the team, as described by Alan, is less well received. In addition the nature and value of the chaplain's discrete body of knowledge is not fully appreciated (Tracy). Some people do not wish to think about what they believe, some do not wish to think about death, some do not wish to address what they believe about their own death. My own experience suggests this may be due to discomfort but Beth indicated it is due to ignorance. However, the attitude of patients, families and staff to the chaplain as a professional is not related to the nature of her knowledge but to her person – what she brings in personality, presence and the skill of 'knowing-in-action' (Kinsella, 2010:570) or embodied reflection[310]. Neither is the attitude of management related to knowledge: management's concern is outcome.

Management and professionalization both require evidence, but this was only spoken of spontaneously by five chaplains (Norman, Valerie, William, Oliver, Fred). Opinions were elicited by using the extract[311] but even then Yasmin was the only interviewee who was comfortable with the idea, based on her past experience. Steven commented that he did not like his cynical response that recording the visit, not its content, was important for the commissioning rounds and Larry queried who would benefit from the evidence, warning that there was a danger of 'harassment by questioning'. Valerie expressed great concern about the use of the term 'intervention' and the assessment of interventions based on psychological qualifications in her hospice. She was concerned that the assessment was prescriptive, using behaviour patterns which are not applicable in chaplaincy.

As a word 'intervention' was not commonly used by interviewees and I would argue that it does not sit comfortably with the term pastoral care. Norman said 'we do not see ourselves as people who provide interventions. We respond to a request.' However he felt that management in his hospice did not 'have a terrific appetite for engaging with chaplaincy and assessing it and looking for evidence,' although every so often there would be an attempt to make chaplaincy fit the same task-oriented template as nurses, doctors, physios and social workers. Tracy noted that

[310] See Chapter Seven
[311] See Appendix G.

chaplaincy is difficult for other disciplines to understand because it is hard to quantify – it does not raise money or make interventions although the new system in her hospice does record the facts and figures of phone-calls, patients seen and referrals. However, referring to sitting with a patient listening to his story, Handzo (2011:369) argues that the patient is not looking for answers but expressing spiritual pain and therefore the 'intervention' of compassionate listening is both important and effective[312]. The emphasis is on the value of the experience for the patient – not on the effectiveness of the chaplain – but as yet there is no common outcome taxonomy for chaplains to use and one interviewee (Valerie) questioned whether there ever could be[313]. Whilst outcome measures are easier to understand in relation to the intensity of pain or the range of movement of a limb (Bausewein et al, 2014:26) the chaplain needs to exercise creative thinking, as mentioned by John in relation to recording the watching of the swans[314], in order to develop a new approach to the concept of intervention.

According to UKBHC chaplaincy itself is concerned to be recognized as a profession. The danger is that professionalization may be seen as a way of ensuring jobs – and at what price? Haraway (1991:164) describes the communications sciences as 'the translation of the world into a problem in coding' which could equally be said of the drive to devise spiritual assessment tools which enable recording (coding) of patients' spiritual conditions and needs. This could be argued to be another version of control/domination. Once again the patient has become a problem to be fixed, an object that needs mending rather than a subject who is capable, possibly with help, of finding her own well-being despite the constraints of illness. This again draws attention to the counter-cultural role of the chaplain.

The boundaries of wellness, well-being and spiritual care

The term 'well-being' refers to the whole of a person's existence, whereas 'wellness' is an approach to healthcare concerned with preventing, rather than treating, illness and prolonging life. Neither of these terms were mentioned by interviewees but one of the scenarios described in the working paper 'Working towards a hospice workforce that is fit for the future' (Help the Hospices, 2013b:9-10) is relevant to the chaplain's work. It describes a focus on wellness, funded by individuals who take

[312] See Chapter Seven

[313] One of the US research projects funded by the Templeton Foundation developed a taxonomy of chaplaincy activities (Massey, 2014a, 2014b) which is available, on condition of the provision of feedback, for any chaplain. It is used to analyse the intended effect or good outcome, how the outcome is to be achieved and what intervention the chaplain makes.

[314] See Chapter Five

responsibility for their own care and who increasingly use technology to monitor their health. The scenario also states that there would be an increased use of robots for the delivery of basic care[315] and that, if wellness came to be considered a right, issues of death and dying would be addressed even less frequently than at present. For the hospice chaplain the right to wellness (and its implications of the right to avoid suffering), the use of robots and the decreasing incidence of existential discussions challenge another boundary - the understanding of what it is to be human. If wellness becomes a right does this imply that human beings have the right *not* to experience pain and suffering? Saunders' original vision was not the removal of pain but the bringing of pain 'within the patient's compass' (Saunders, 1958:11). To satisfy management, any reference to God has to be omitted, as shown in Chapter Six. Yet Chapter Seven demonstrated that the presence of the chaplain both symbolized and manifested the presence of God *in* the pain and suffering - regardless of the patient's belief.

Well-being is a person-centred approach which incorporates what the person expects or wants from a healthcare intervention, personal resilience, and support systems of family and community. It is in marked contrast to the doctor's desire of a clinical outcome[316], and necessitates a partnership of patient and doctor rather than the doctor mending the patient (Handzo et al, 2014:43-44). Valued outcomes include: reduced cost, improved quality of care and patient experience, reduced length of stay, reduced use of healthcare. No longer is assessment based on the volume of patient contacts but on the value of those contacts (43), and the value is determined in terms of the well-being of the patient. At the heart of a patient recorded outcome measure (PROM) developed by Snowden et al (2013:3- 16) is the patient who tells his story to the chaplain and in so doing, rather than fixing or overcoming, finds a way of living through the situation (Kelly, 2012: 32), echoing Saunders' bringing of the situation 'within the patient's compass' (Saunders, 1958:11). Where appropriate and non-proselytising the chaplain may use story to remind the patient of God. Mowat et al (2013:39) identify listening and story-telling as core functions - or I might say interventions - of the chaplain. In addition the chaplain is the guardian of the provision of a place in which life stories are told and valued[317].

[315] As demonstrated in the television science fiction drama series 'Humans'. Whilst the exploration of what it means to be human is not new, technological advances have made previous imaginings possible.
[316] Described by Gawande (2014, Lecture 3) and referred to in Chapter Seven.
[317] See Chapter Seven

Theology of chaplaincy: the absence of boundaries

> I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me. (Matthew 25:36)

I have often heard chaplains at AHPCC conferences and area meetings quote this verse but it did not occur in any of the interviews. As described by the interviewees the theology underlying spiritual care appears to be about acceptance, not tolerance, of the other as a human being[318]. All patients are to be offered spiritual care just as the Israelites were instructed that all people were to be treated equally, regardless of rank:

> In the seventh month, on the tenth day of the month, you shall deny yourselves, and shall do no work, *neither the citizen nor the alien* (my italics) who resides among you. (Leviticus 16:29)

Justice is not the prerogative of the members of the dominant culture:

> I charged your judges at that time: "Give the members of your community a fair hearing, and judge rightly between one person and another, whether citizen or resident alien." (Deuteronomy 1:16)

Neither is the good news of the Kingdom the prerogative of the chosen people, for Jesus sent the disciples to all peoples:

> Go therefore and make disciples of all nations, baptizing them in the name of the Father and of the Son and of the Holy Spirit, (Matthew 28:19)

so all are entitled to the ministrations of the chaplain. However, Ian remarked that hospice spiritual care is not an obvious or direct way of bringing the good news to all peoples. He spoke of the marked difference in approach between his colleagues in congregational ministry and himself. Those colleagues could openly 'make disciples of all nations'. In contrast the hospice prohibition on proselytising produced challenges - which he relished. Ian commented that Jesus accepts the centurion where he is (Matthew 8:5-13). He described Jesus's ability to enable people of completely different lifestyle and background – which the Jewish authorities of the day would have described as inadequate - to speak with him, even to argue with him. Ian said this was his justification for working with atheists. Thus the approach of 'being whatever the patient needs me to be' is rooted in Jesus's example and seems to resonate with the recognition of equality found in Jesus's description of the kingdom:

> Then people will come from east and west, from north and south, and will eat in the kingdom of God (Luke 13:29).

[318] Although Ian used both terms: 'In Jesus I see an incredibly accepting, tolerant God.'

A tenet held by all interviewees was that no matter where the patient comes from, even if he does not believe in God, the chaplain will be there for him. Beth spoke of 'the divine in me meets the divine in you' as the theology of 'bottom-up' ministry, that is God in all creation though not necessarily recognized or acknowledged by those with whom she comes into contact. Keith spoke of rejecting versions of God as a puppeteer and as a draconian teacher and accepting God as under all his creation which appears to be a move from top-down to bottom-up theology. This may be a way of expressing incarnational theology[319], which is how many of the chaplain contributors to *Being a Chaplain* described their ministry, even stressing the concept of presence, 'being there amid things' (Threlfall-Holmes and Newitt, 2011:xvi). Taking the concept of bottom-up theology a step further I want to raise one *caveat.* To be the person the patient needs her to be the chaplain acknowledges and celebrates God in every aspect of creation. There is a sense in which this enables her to work with whatever the patient identifies as the source of nourishment - to the chaplain it is God providing the nourishment. The patient however may focus on the source to the exclusion of all else and the chaplain may feel that this idolatry is contributing to the pain[320]. In this circumstance self-awareness is crucial for the chaplain to recognize whether she is treading a fine line to maintain her own integrity without colluding or colliding with the patient's position. Equally the chaplain needs to be alert to her own sources of nourishment, reflecting frequently to ascertain her own motives.

Theology of chaplaincy: personal boundaries

The recognition and maintenance of personal boundaries is an aspect of any caring profession, crucial for best practice for both patient and practitioner. Supervision and spiritual direction both contribute to the well-being of the chaplain in the maintenance of boundaries but the evidence that chaplains practised 'love your neighbour as yourself' (Mark 12:30-31) left something to be desired. Doreen admitted how easy it was to postpone supervision but made the comparison with the miners bathing at the pithead, acknowledging the need to take care of herself. She combined supervision and spiritual direction as did Steven, but of the other Christian interviewees only nine received both supervision and spiritual direction and eleven received some kind of supervision but no spiritual direction.

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[319] Despite the nature of hospice work and the recognition of the transformation of personal tragedy into sustaining energy by a number of interviewees any overt connection with the theology of the crucifixion and resurrection was not found.

[320] I met a female patient who talked about nothing and no-one but her small granddaughter. The child was not allowed into the hospice by her parents so she was both the source of the patient's nourishment and the cause of her pain.

Boundaries of the role: chaplain to the institution

Whilst some interviewees described themselves as chaplains to the institution (Alan, Ian, John, Keith, Queenie, Steven, Valerie, William, Xelda) others spoke of their work with staff as well as patients, indicating that they saw themselves as responsible for the spiritual care of anyone and everyone in the hospice (Tracy, Beth, Eric, Fred). However, whilst such care was evident for clinical staff the situation with administrative and management staff was rarely mentioned.

Neither was there mention of the institution as a whole and the response to the question about ethos suggests that interviewees had not spent much time reflecting on the shared principles, values, meanings which give an organization stability. At one time those shared factors were to be found in the hospice vision established by Saunders, but by the time of this research that vision was replaced by management's mission statement (Greta). Valerie observed that the patient care had not changed but the hospice mission statement had - from patient-centred to a more business like focus on quality of care, suggesting a loss of shared values and meanings. The observation that new management did not appreciate 'the heart of hospice' suggested to Fred that his hospice was losing staff cohesion and shared values. Tracy highlighted the inconsistency between the caring attitude to patients and families and the cavalier attitude to the means of funding that care. In her opinion personnel management was often unnecessarily aggressive.

Pushing the boundaries: The chaplain as the bearer of dangerous memory[321]

Understanding 'dangerous memory' as the means by which the existing social order may be overturned or existing attitudes challenged I am arguing that chaplains may be described as the bearers of dangerous memory on several grounds: as the custodians of what it is to be fully human, as bearers of the memory of the faith community and as bearers of the memory of the vision of Cicely Saunders.

In the context of Liberation Theology and the violation of human rights Grey (1994: 512) argues that an epistemic shift is necessary, to acknowledge and validate the knowledge and experience of those whose human rights have been violated. There is a parallel between listening to the oppressed and weaving their experience into the struggle against the dominant ideology (512) and listening to the patient and weaving his experience into the struggle against the dominant culture of illness and

[321] A description borrowed from Mary Grey's paper (1994) in which she argues the necessary role of dangerous memory in being able to bear the pain of the present and prepare for the future. Such memory is of both suffering and freedom and enables the oppressed to challenge the oppressor. However, she also argues that a shared future also requires the oppressor to re-member, acknowledge his role and work together to ensure that the future is freedom for all, not just for some.

death as problems to be fixed or solved. In both cases the result of not listening is dehumanisation. The subject-object nature of the relationship between patient and doctor and the change in patient identity has already been described, but whilst doctors are being encouraged to treat the patient as a person, chaplains are already doing so. Ian said: 'You encounter whoever you encounter in the way that they need to be encountered'. It is the chaplain who will hear the darkest stories from patients (Ian, Steven, Alan, Beth), stories which might then be described as dangerous memories but which the patient trusts the chaplain to handle appropriately. When the story has been repressed, for whatever reason, it needs to be reclaimed and honoured. In some cases the story will contribute to the diagnosis and management of the illness. That this may be uncomfortable for the doctor has already been noted and it may even be dangerous if it connects with the doctor's own experience. For the patient the important point is that the dangerous memory is no longer hidden and its power to influence the patient is at least minimized if not defeated.

The second type of dangerous memory born by chaplains is that of the faith community, as explored in Chapter Six. They know the biblical tradition, they know the stories and they know what it is not just to believe in God but to 'live out' God (Soelle, 2001; Oliver, 2006:14). It is the chaplain who understands the value and proper use of memories, as expressed in Psalm 136, giving thanks to the Lord 'who alone does great wonders' (verse 4) and reminding Israel of God's action in Egypt. By the recitation of their history the Psalmist reminds the Israelites what it is to be God's chosen people. Encouraged by a chaplain (Charles) the patient tells his own story and is thus reminded of what it is to be fully and freely human . Many of the Israelites' experiences of God's saving action are commemorated in their lives by the whole community:

> These days should be remembered and kept throughout every generation, in every family, province, and city; and these days of Purim should never fall into disuse among the Jews, nor should the commemoration of these days cease among their descendants. (Esther 9:28)

The effect of such acts of remembrance was to re-member the people, to bring them back into the covenant relationship with God. This was not sentimental memory or nostalgia but represented a right handling of history –

> Do not remember the former things, or consider the things of old. I am about to do a new thing; now it springs forth, do you not perceive it? I will make a way in the wilderness and rivers in the desert. (Isaiah 43:18-19)

It is equally important that the hospice patient not indulge in sentiment or nostalgia, nor dwell on past regrets, but recall his personal history in a way that validates and

gives a sense of self-worth. Commemoration is likely to take the form of the celebration of a birthday, wedding anniversary or baptism of a grandchild (Beth, Ian) which serves to re-member the patient into his understanding of faith (whatever that may be), into his family and into the human race.

Thirdly, chaplains enshrine the memory of Cicely Saunders, her life and her work in founding the modern hospice movement, which I shall come back to in the overall conclusions. Fred expressed sadness that new managers did not understand or appeared ignorant of 'the heart of hospice'. Once again the very foundations of hospice care are threatened by financial survival. It may be that the chaplain symbolizes those foundations for some managers who, for whatever reason, find them unacceptable (Eric, Patricia). It is somewhat ironic that management's role is of little direct benefit to patients – is this a contributing underlying cause of the antagonism between patient-facing staff and management commented on by Tracy and Steven?

The hospice

The shifting boundaries of the future of hospice care

The Commission into the Future of Hospice Care showed that the context of end of life care is changing and that hospices, are going to need to re-think their vision and mode of operating (Calanzani, Higginson & Gomes 2013). The Commission's final report (Help the Hospices 2013a) included broadening the range of care to cover dementia. Just as the medieval hospital adapted to care for elderly plague survivors today's hospice needs to adapt to care for dementia sufferers. The report also suggested moving hospice care out into the community, an increased role for volunteers, and joint working with other hospices, the NHS, local authorities, care homes and the communities within which they are set. The Commission published supporting papers on the necessary operating principles (Help the Hospices, 2012c), the role of research (Payne et al, 2013), the expansion and training of the workforce (Help the Hospices, 2013b), the use of volunteers (Help the Hospices, 2012b), end of life care in the community (Calanzani et al, 2013), the role of hospices in dementia care (Hockley and Stacpoole, 2013). However, there were no supplementary papers on spiritual care or complementary therapy.

Described as 'a thought piece' the authors of the dementia care paper observe that hospices need to form partnerships with care homes, where they can educate the staff into understanding that death is not failure and demonstrate how to support staff emotionally and professionally (Hockley & Stacpoole, 2013). However they also observe that hospices need to become more dementia-friendly. In a society which

values people primarily for their intellect (Dartington, 2006:476) this represents an enormous educational challenge to the easy assumption that identity requires intellect and memory (Swinton, 2007b; Holloway, 2014). Furthermore dementia does not fit the interventionist 'fix-it' model of healthcare but requires social care which is not an aspect of the effective and efficient model that dominates organizations (Dartington, 2006:476-477). Social care loses out in the provision for funding because there is no visible end result – nothing has been fixed. Yet the Commission's paper on research in palliative care states:

> In an increasingly competitive economic climate and with the emergence of commercial competitors, hospice managers need to demonstrate the efficacy and efficiency of their service models (Payne, Preston, Turner & Rolls, 2013:12)

Social care also loses out in societal acceptance – the vulnerability of the dementia sufferer frightens many people, perhaps indicating dis-ease with their own vulnerability (Dartington, 2006:477). Dartington suggests that the way forward is via an exploration of vulnerability - to establish the conditions which allow and accept vulnerability (477), which sounds like the training sessions in spirituality run by chaplains for staff. Dartington argues that if we are uncomfortable with the condition of dependency we will walk away, thus failing to treat the vulnerable with respect. Dignity is often lost because of thoughtlessness - which leads an untrained health-care assistant to leave a meal at the end of the bed where the vulnerable person cannot reach or to place the meal in front of a blind person without taking the time to put cutlery in her hand and explain what is on the plate (Dartington, 2013:12). The task has been done because the meal has been delivered but care is not a commodity and 'tick boxes are no substitute for thoughtful care' (Monroe, 2015). The issue here is the value of each and every human being which the chaplain holds and it is this largely unrecognized value which underlies any and all caring professions.

When interviewed about the Commission (Monroe, 2014), on which she was Vice-Chair, Monroe said 'nursing and medicine are the bedrock of palliative care. Most people would put pain-free death as the highest priority.' This demonstrates the general attitude of today's society that pain and mortality are things to be fixed - and nobody wants to be vulnerable to death. Yet the final report of the Commission states that it 'wants a future where hospice care helps people cope with the reality of dying, death and bereavement, and always does so with confident expertise' (Help the Hospices, 2013a:5). Coping with the reality of dying and death is not the same as fixing it; coping is what Saunders described as 'keeping the patient's struggle within his compass' (Saunders, 1958:11). As part of Saunders's hospice vision

learning to embrace death was an aspect of her Christian faith (du Boulay, 2007:123), believing that, in Jesus, God knew life and death as we know them, regardless of whether we believe. Her biographer argues that this belief was clear even in a book written principally for the medical profession:

> Only a God whose love shares all pain from within can still our doubts and questions, not because we understand but because we can trust, there is a sense in which we say 'This is my body' of each dying person and in which the small transformations that we witness continually speak of a Resurrection which will finally redeem and encompass all creation. This is the edge of that unsearchable abyss of deity which we meet in our daily experience, the beyond in our midst. (du Boulay, 2007:123)

Saunders's privileging of trust over understanding echoes de Caussade's argument that words will not explain what is not based on reason (de Caussade, 1989:21). This argument still holds in the secular environment of today – the hospice goal has not changed. Keeping his struggle within his compass, whether or not the patient has a faith, goes beyond our understanding to a trust, which may not be shared but is appropriate to each individual, patient, family member and hospice staff.
The Commission's final report also claims that the envisaged future builds on the history and mission of the hospice movement (Help the Hospices, 2013a:5). However there is no mention of spiritual care. When interviewed Monroe said that it was not possible to cover all contributing disciplines and the commission focused on those considered most important. Given the understanding, mentioned earlier, of nursing and medicine as the bedrock it is not surprising that the roles of the Clinical Nurse Specialist and Palliative Care Doctor (2013b:22) are given attention. Furthermore in identifying the issues facing hospices the report pays significant attention to the use of volunteers. The working paper recognizes that volunteers may be as valuable as financial donors or clinical professionals (Help the Hospices 2012:4) and encourages hospice-owned but volunteer-led volunteer services (5). The final report states:

> The Commission is keen that hospices consider using volunteers differently; extending their roles into the direct delivery of care and offering guidance to users about how to navigate their way through the intricacies of multiple providers of end of life care. (Help the Hospices 2013b:35)

Interestingly the home-visiting and sitting service using volunteers, developed by one of the interviewees (Tracy), seems a good example of using volunteers differently – but it caused one manager to accuse Tracy of empire-building!
The Commission recognizes that hospices can no longer rest on their laurels of 'doing good work', stressing the need to integrate their services with those of the NHS,

local authorities, care homes and other providers 'in order to work together to improve care for all who have life-shortening conditions' (Help the Hospices, 2013b:13). Furthermore the Commission notes that the nature of healthcare is changing from a top down model driven by medicine to a joint model in which individuals and user-organisations are informed enough to define their needs and hospice professionals work in partnership to facilitate and educate (Help the Hospices 2013a:20). For chaplains the difficulty of a needs-led model is that the taboo on death and dying is likely to obscure the need for spiritual care. Therefore training in the identification of spiritual need for all who come into contact with patients and their families is of paramount importance.

Conclusions

The world of healthcare is changing, boundaries are in flux. The Theos Report (Ryan, 2015) notes that some types of chaplaincy serve as a 'ministry of the gaps' and others are the sole providers of pastoral support[322], whilst others like healthcare and prisons are a mixture of both. This suggests that boundaries in healthcare chaplaincy have always been fluid, and none more so than hospice chaplaincy. The Commission for the Future of Hospice Care has met, deliberated and published its findings with recommendations for ways forward, including increasing work in the community which was already being undertaken by some interviewees. NHS England has at last (2015) produced Chaplaincy Guidelines which will affect not only NHS palliative care units but independent hospices as well. Interviewee responses to questions about ethos indicated that most were understandably patient-focused and had not reflected on the institution. Since the training model used by the churches is for congregational ministry there is apparently little need for ministers to learn about and reflect on organisational culture. Nevertheless the data suggests that underlying assumptions based on Saunders' vision, are not shared by new management. Schein (2010:27) comments that it is not uncommon for organisations to hold values that indicate specific desired behaviour but that behaviour is not actually manifest. Interviewees indicated that desired behaviour was present in certain areas (patient-facing) of the hospice organisation but markedly lacking in other areas (treatment of staff by staff and by management).

Illustrating Gula's point (2010:145) that when we are socialized into a culture we are blind to how it influences us, the data suggests that chaplains have been so patient-focused that they have not noticed how it has affected them. Consequently they

[322] Sports chaplaincy is given as an example of gap ministry and the Apostleship of the Sea as an example of being the sole source of pastoral care (Ryan, 2015:33).

have failed to appreciate either the value of a supportive worshipping community outside the hospice, or the benefits of regular spiritual direction, reflection and supervision. Consequently they have not taken adequate care of themselves. Although I have argued for the similarity of chaplain and prophet in Chapter Six I make no claim that chaplains are cognisant of the counter-cultural aspects of the role. If they are to fulfil that role self-care will be absolutely essential, and is a significant part of my conclusions.

Conclusions and recommendations

When I drafted my first research proposal for this project I anticipated being able to establish what constituted 'chaplaincy' by interviewing hospice chaplains on their understanding of 'spirituality' and 'spiritual care'. In Chapter Three I described how the richness of the data led from a search for definitions to a more dynamic exploration of the hospice chaplain's role. To be able to paint a picture of how they perceived themselves and how they understood their work I needed to enable hospice chaplains, whose voice is noticeably absent from the literature, to speak. I also hoped that the process of interviewing and analysing would bring to light specific concerns and thus reveal areas for further research.

From the data a picture emerges of a person who came in to hospice chaplaincy not as a career move but with a sense of divine intervention, with a realistic knowledge and perhaps tiredness of the problems of congregational ministry, with some understanding of his own spirituality but little expressed recognition of how it, or theology, sustained him in his work. His approach to his work, the provision of spiritual care, was not only patient-centred but patient-dominated to the extent of ignoring the context. Even where the spiritual care of staff was included, consideration of the wider hospice setting was minimal. He acknowledged the need for supervision but had little time for reflection on his work, his unique contribution or the hospice ethos. His appreciation of the value of a faith or work community was variable, not helped by his perception of the church's attitude to chaplaincy which varied from lack of concern to antagonism. In addition the concept of hope rarely featured in his work, indicating variance with Saunders' original vision.

However, whilst the demise of discursive or cultural Christianity contributed to the decline of that vision the hospice chaplain is adapting to his secular environment, reframing the expression of his role in concepts such as presence. However, his attitude to the need for evidence is ambivalent suggesting an unarticulated clash with his ministerial integrity. Examination of the role of the chaplain as presence indicated that contemplative practice entailed an acceptance of God's purpose and direction. Justification, in the form of evidence, therefore had no place in the chaplain's practice, whereas for management justification was the ultimate objective. Thus the vulnerability of the chaplain was exposed with an inevitable collision of tectonic plates.

My conclusions and recommendations therefore focus on the lack of adequate self-care and the decline of the original hospice vision.

The chaplain

Self-care: How to be a real chaplain

Since the start of this project in 2011 the pressure on the hospice chaplain to justify her existence has, if anything, increased. She has to fight for her role and for the importance of specialist spiritual care. To ensure that she is being a conduit, as Beth put it, rather than acting from self-motivation or in her own strength, requires adequate self-care. Furthermore that self-care helps avoid breakdown, as mentioned by one interviewee, and burn-out of which Greta spoke. It is the equivalent of the miner's bath mentioned by Doreen facilitating the recognition of what Williams (2010) called 'Compassion Fatigue: or "how to make sure that your patients don't hitch a ride home with you at the end of the day!"' Reflective self-care may also be the place where the chaplain acknowledges the effect on her integrity of working in a secular environment. She may also become aware that the challenge to her role is not just a cost-cutting exercise but a denial of the value of spiritual care, even a denial of what it means to be human. Saving money may be the stated (supposed) justification for removing a service which is not properly understood or appreciated. The opinion of a strong Chief Executive Officer (CEO) will influence other members of the senior management team. For any of them to challenge the CEO would risk their job, so the negative attitude to the chaplain's role and spiritual care becomes a tacit part of the hospice ethos, at least in the administrative areas. Individuals may not agree with that ethos but for fear of job-loss will hide behind the argument that it is how the institution is. In this way they avoid facing the wider significance of the loss of spiritual care from the hospice's claim to offer holistic care.

The chaplain however needs to be aware of these hidden agendas and prepared to address them. Furthermore, if she is to address them in any way it is even more important to review both her understanding of her own spiritual needs and practices and the appropriateness and frequency of her existing supervision and spiritual direction arrangements. The chaplain spends time validating others but she needs to recognize her own need for validation, especially if it is being undermined by an unsympathetic CEO. Being part of a community, as demonstrated in Chapter Six, is one means of validation.

The tension that accompanies always 'being there', sapping validation, is expressed in the poem 'How to be a Real Chaplain' (Elfick, H. & Head, D. 2004: 52), shown in the text box. The poem, whose author, David Head, was a hospice chaplain for fourteen years, expresses the plight in which a chaplain may find himself, and points to the need for self-awareness, reflexivity and frequent supervision. Without these

there is a real risk of turning 'Empathy' and 'Being Available' into idols and experiencing burn-out.

How to be a Real Chaplain

I'm only tired but it must look like scorn,
to judge from comments or apologies
floating up stairs or along corridors
towards my travelling back.

Look, I've had a hard week, OK? Or I'm busy.
Or manners aren't that important to me
just now. Give me a break. But no.

Each doorway is a gauntlet of bouquets to run,
each corner hides the beggars of emotional baksheesh
with psychic palms outstretched. I have had it to here.
Do I burn out or burn, slum or slip my leash?

This paper, thinner than a pool of pee, receives
the printed shapes that say 'piss off'.
These I can hide, stood upright in a file.

Like a good anarchist, my confessor is called
'A4'. Like Luther's, it's started to say 'enough'.
Sort your life out – get some sleep or some friends –
change your diet. Silently it tells me

not to use the same rag to wipe the floor
and to try to sweep the feelings from my face;
ourselves are so much easier to abuse;

and that once the fluff is in my eyebrows
and the smears of last week's polish on my lips,
I act as if they were my mask, not paint flaking
from those idols, Empathy and Being Available.

Another of Head's poems (Elfick, H. & Head, D. 2004: 54) is far more succinct, and the words are laid out, seemingly at random and with what might be regarded as unnecessary space, to support the experience being expressed. It is perhaps not surprising that by the time the book of poetry was published in 2004 Head had in fact returned to parish ministry.

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Self-care: Training and reflective practice

The outgoing AHPCC President entitled her 2015 Conference speech 'Daring to be real.' She observed that when she started in hospice chaplaincy in 1994 'nobody seemed to imagine I needed any training or particular preparation for the role.' Illustrating the enormous gap between theory and practice, between the spoken descriptions of palliative care and what actually happens, she argued that the former are often romanticised and the latter are often excruciatingly painful[323]. Such romanticising colludes with fantasy and is dehumanising. Davies (2015) links it with being unreal, masking the reality of pain rather than cloaking with palliative treatment[324]. It is an attempt to ignore, even deny, the suffering and maintain a world in which all is well, leading to a different understanding of what it is to be human.

[323] On her first day in the hospice: she was warmly greeted by a senior nurse: 'I'm so glad you're here. The husband of one of our patients, who died earlier this morning, has locked himself in the viewing room, with a bottle of whisky from the drinks cabinet… Can you do something?' (Davies, 2015)

[324] The word palliative derives from the Latin *pallium* meaning cloak or cover.

The importance of reflection was acknowledged by interviewees and often associated with growing older and life experience but neither self-awareness nor reflection were reported as having been included in the congregational/ parish model of training which the majority had undertaken. Furthermore the data leads me to conclude that the training did not include the value to ministry/chaplaincy of the Christian mystical tradition, the pastoral advantages and disadvantages of the clerical collar or organisational issues. Interviewees also indicated that training in end of life issues was minimal. Training courses in healthcare chaplaincy are available[325], but the extent to which organisational issues are addressed varies and the coverage of the non-proselytising role of nurturing humanity rather than promoting religion is not clear[326].

At the same time it is clear that some kind of training is helpful, if only to demonstrate to fervent evangelicals the challenge of the non-proselytising hospice ministry. In fact hospice ministry requires the very opposite of overt evangelical enthusiasm: the chaplain lays her faith on one side in order to be present to and with the patient. Just as Christ laid aside his divinity to be present to and with human beings so must the chaplain:

> Let the same mind be in you that was in Christ Jesus, who, though he was in the form of God, did not regard equality with God as something to be exploited, but emptied himself, taking the form of a slave, being born in human likeness. And being found in human form, he humbled himself and became obedient to the point of death – even death on a cross. (Philippians 2:5-8)

In order to be in unity with humanity – *enosis* – the chaplain experiences *kenosis* or emptying. However, whilst presence, as being rather than doing, was spoken of *kenosis* was not mentioned. Some interviewees spoke of letting go or leaving self at the door but again the term *kenosis* was not used. This may be because the chaplain has not identified his experience as *kenosis* and even if he had how would this be expressed in terms of the skills and knowledge required for chaplaincy? Even the AHPCC Standards and Competencies are skills and knowledge oriented and do not include the practice of spiritual disciplines which contribute to the making of a chaplain. If spiritual disciplines such as prayer, which management can be expected to understand, are not included what chance is there of including the little known

[325] St Christopher's offers a short residential introductory course as well as one-day courses for those in congregational ministry. Part-time and distance learning courses are available but funding would be an issue for most chaplains.

[326] St Mary's foundation degree includes 'Working in the NHS'- but the majority of hospice chaplains work in independent hospices – and I am advised that the Masters in Healthcare Chaplaincy offered by Cardiff and Leeds Beckett also include organisational issues.

concept of *kenosis*? Research is needed to establish the nature of the language to use with management[327], including an acceptable explanation of the actual practice of *kenosis.*

Self-care: Language

The chaplain needs to be secure in the various languages entailed in her work: the theological and liturgical language of her faith, the everyday language used by those to whom she ministers, medical language and terminology and language which management will understand and accept. Her multi-lingual skills also include recognizing and negotiating the connections between the everyday language and theological or liturgical language, and translating the soft everyday language into management language. However, it is important to recognize the danger of dehumanization in management language. The aim is to preserve the care of the spirit, to ensure that the patient feels that he matters not just physically but as a whole person. Equally there is a need for management to recognize that they too matter as individual people, and for the hospice as a whole to realize that it matters not just as a financially viable business but as a caring organisation, which brings me to the chaplain's role to the institution.

The hospice

Chaplain to the institution

As chaplain to the institution the principles of spiritual care should be applied not only to patients and staff but to the organization as a whole. Using the definition shown in the text box the chaplain would recognize and respond to the needs of the hospice overall. This necessitates asking the meaning of the organization – what does it exist for? Does it believe in itself? How does it present itself to the public? What are relationships between staff like? What are relationships with other bodies, such as stakeholders, like?

> **Spiritual care** is that care which recognizes and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires. (NHS Education for Scotland, 2009:6)

[327] The October 2015 meeting of Chaplains in Healthcare UK, Research Network (CHURN) expressed a willingness to research a unified standard of reporting.

In a general context it is easy to accept that individuals need role models to guide development but forget that organizations also need role models (Gavin & Mason 2004:381). In the hospice context the focus on the patient may well obscure or obliterate concern for both staff and institution and further research is needed in this area. The resulting imbalance of the valuing of human beings - patients are more important than members of staff or volunteers – produces an unacknowledged and unhealthy dominant culture which many staff tacitly accept. The chaplain needs to be alert to the danger of being absorbed into that culture and maintain and demonstrate her belief in the equality of all people. Her stance will therefore be counter-cultural and she will need to deploy all her prophetic skills, as described in Chapter Six, to challenge this situation.

The chaplain and the hospice

Management's need for evidence and the chaplain's ambivalence

The paucity of evidence for the value of chaplaincy and spiritual care means that the service is vulnerable to cutbacks. Management in both the NHS and in independent hospices is facing financial constraints and the restriction, possibly the removal, of the chaplaincy service is a soft cut[328]. The new NHS England *Chaplaincy Guidelines* are only guidelines – whilst all prisoners have a legal right to access the services of a chaplain there is no such right for patients, even though spiritual care was part of the NHS from the start (Welford, 2010).

At this point in time research which demonstrates the value of chaplaincy to management is conspicuous by its absence. Approaches to research on spiritual care were outlined in chapter nine. Unfortunately the Integrated Patient Outcome Survey (IPOS) is an assessment of palliative care with only one measure of spiritual care: the patient's experience of peace, with no reference to a chaplain. In contrast the Patient Reported Outcome Measure (PROM) seeks to establish the effectiveness of the chaplain, albeit through a patient-reported measure. The American-developed taxonomy is a tool by which the chaplain analyses what might otherwise be considered an anecdote in terms of assessment, desirable outcome, chaplain's action[329].

[328] The National Audit report on the NHS shows that the deficit for 2013/2014 was £743 million – and rising. If the NHS cuts spiritual care, hospices are likely to follow suit.

[329] The assessment is the equivalent of the medical term 'diagnosis'. The desirable outcome is the objective. The chaplain's action is the equivalent of the medical term 'intervention'.

The PROM is executed by the patient or family member but the taxonomy is executed by the chaplain, so is the taxonomy acceptable as evidence?[330] The focus of the chaplain's work is undoubtedly the patient (or member of the patient's family or a member of staff), someone other than herself. To focus on and practice 'it is more blessed to give than to receive' (Acts 20:35) suggests a naiveté which fails to appreciate that giving without receiving may lead to burn-out. The lack of self-care suggests a misplaced self-denial which not only makes chaplains vulnerable to burn-out, already discussed, but also throws light on the ambivalence towards producing evidence for what they do. Evidence is justification for the chaplain's work – the focus is on the chaplain, which is the opposite of her patient-centred work. Anything which serves to justify, whether it be evidence, or how to handle management or the language to use with management is chaplain-facing rather than patient-facing. To focus on herself is alien to her perception of serving others and the acquisition of evidence seems to contradict the caring role[331]. Through contemplative-type practice she has laid herself on one side to provide space for the other. To focus on herself seemingly challenges her integrity, which would benefit from supervised reflective practice.

Epistemological differences

Not only is reflective practice essential for the chaplain but her work is characterized by embodied reflection[332] and intuitive knowledge. Whilst this kind of knowledge is found in many professions, including medicine and management, most other professions have technical knowledge as well. In the present economic climate the latter tends to dominate because it can demonstrate outcomes, thereby justifying that profession's existence. Furthermore hospice managers seem to be ignorant of or to have lost sight of the intuitive knowledge in their own profession. The tacit, non-rational, intuitive knowledge which constitutes the major part of the chaplain's work is therefore treated with suspicion. Yet in Saunders's original vision of hospice care such knowledge was crucial for all staff – it was precisely that knowledge which enabled the staff to say 'you matter because you are you' and which caused Saunders to be credited with bringing humanity back into medicine (Rankin, 2007: 193). In the intervening years humanity has lost ground to financial concerns.

[330] The CHURN meeting recognized the problem of establishing validity and reliability.
[331] This may also explain the general ambivalence to research amongst chaplains – it is not just the lack of time or the lack of research skills but an underlying discomfort with the focus, which may be an area for further research.
[332] See Chapter 5

I hasten to add that for patient and family the dominant characteristic of the hospice is still care but outside the patient-facing areas the concept of 'you matter because you are you' is not deemed relevant or economical. Whether this ideological inconsistency is due to poor self-awareness amongst management or is a deliberate tactic is beyond the remit of this study but may be an area for future research.

You matter because you are you: the decline of the original vision

By the mid-1980s Saunders' mantra was known around the world:

> You matter because you are you, and you matter to the last moment of your life. We will do all we can not only to help you die peacefully, but also to live until you die (Rankin, 2007:193).

Saunders' original vision was for the hospice as a community, but the extent to which today's hospices are communities varies. The AHPCC executive is keen to establish whether the hospice still is a safe place in which the patient can tell her story to a person who is comfortable with his own story and spirituality. To that end a scoping project has been commissioned to research whether hospices do still have a chaplain or Spiritual Care Co-ordinator and the extent to which that post is under threat[333]. If the chaplain is perceived to be the bearer of the original vision he may be seen as a threat to any change which management deem necessary to secure financial viability. One possible change suggested in the final report of the Commission into the Future of Hospice Care (Help the Hospices, 2013a) is to integrate with NHS, local authorities, care homes and other providers. A management suspicious of or unaware of the original hospice vision may see integration with a local NHS hospital trust as straightforward. Managers may even regard a hospice as a small-scale hospital. However, as was shown in Chapter One, hospitals are places that mend and save lives whereas hospices do not save lives but are places of hospitality where people learn to live until they die. Is it the failure to appreciate this fundamental difference that leads management to constantly question the value of spiritual care?

The anecdotal nature of spiritual care and the stories that abound in everyday language raise the question of whether such language is perceived by management to belittle the cause and indicate a lack of value[334]. Furthermore it is not known

[333] Research is to cover status, hours, pay, size of hospice, scope of role, out-of-hours cover, multi-faith provision, ethos. The method of research is under review.

[334] The chaplains' use of non-conformist language has been compared with the non-liturgical, non-Latin, everyday French language of Marguerite Porete in the thirteenth century (Thomas, 2015:69). Using this language Porete wrote *The Mirror of Simple Souls* which was judged heretical by the inquisitorial process and she was burnt at the stake (Babinsky, 2003:35).

whether management is aware of or suspects the somewhat ambivalent attitude of the church to chaplaincy and follows the church's example. Further research with management is needed to answer these questions.

This study shows that, even using everyday language, some chaplains still struggle to grasp and express their own spirituality, which suggests that their defence of their work will not be the most robust. The previously mentioned ambivalent attitude of the church means that there is as yet little institutional support for or even appreciation of chaplaincy[335]. Chaplains will have to fight their own corner and acknowledge that anecdotes presented as case studies may be helpful as illustrations, especially in training contexts, but they do not satisfy management's requirements for evidence and added value. If they are to survive chaplains have not only to live and work with the unknownness of the spiritual but also find a way of handling the on-going tension between the soft language of the spiritual and the hard language of management. Further research is needed to explore how chaplains may best explain their work to management.

Summary

In 1980 Cicely Saunders was said to have brought humanity back into medicine and yet in the 2014 Reith Lectures Atul Gawande made a plea for the very same thing. In my view a failure to provide spiritual care is to subvert the understanding of what it is to be human. The chaplain, as bearer of the memory of what it is to be human, and repository of the memory of the story of Cicely Saunders and the modern hospice movement, is in a unique position to demonstrate being human and to encourage others to recognize and not to fear their own humanity. The chaplain is also in a unique position to explain the role of palliative care in the face of arguments for euthanasia and assisted suicide. However, spiritual care is no longer a given, as it was for Saunders, and the role of the chaplain is under threat because of economic pressures. In addition, as Saunders' original vision is eroded and new people take on the spiritual care role will they even be aware of the story of Cicely Saunders?

I therefore recommend that AHPCC ensures that the story is transmitted[336], reviews the training situation and establishes a working party for the development of an on-going spiritual appraisal tool which would be acceptable to management. The working party should also consider reframing the term 'intervention', to include

[335] I understand that Victoria Slater's recent book *Chaplaincy Ministry and the Mission of the Church* challenges the church to recognize and support the significant contribution of chaplaincy.

[336] Perhaps on the website and/or through a leaflet for all new members.

presence, discernment, and compassionate listening as interventions. AHPCC also needs to encourage chaplains to review their supervision and spiritual direction arrangements in order to be better equipped to face the issues around the need for evidence. To minimize the risk of job loss and to ensure patients, their families and staff continue to receive spiritual care, a chaplain needs to have a clear understanding of role and self. This may entail constructing a role identity for management whilst maintaining integrity by being grounded in the present moment, committed to God's purpose (de Caussade 1989), in short being able to say 'I am who I am in God' (adapting Exodus 3:14). Therefore the picture of the hospice chaplain given at the beginning of these Conclusions and based on the interview data will not suffice for the hospice chaplain of the future. Whilst the job will continue to be patient-centred, or other-centred, and the chaplain's way of being will continue to be God-centred the pressure for justification will increase so that the chaplain will need to be competent at putting the case for spiritual care and demonstrating why she is the person to provide that care. The description will therefore be:
A person who comes in to hospice chaplaincy not as a career move but with a sense of divine intervention, who may or may not have experience of congregational ministry. She has an understanding of her own spirituality and can recognize and articulate how it, and theology, sustain her in her work. Her approach to her work, the provision of spiritual care, is person-centred and offered to patients, their families and all staff. She has an awareness of the ethos and spirituality of the whole institution and an awareness of the social, psychological and spiritual role of the hospice in the community. She is passionate about supervision, comfortable articulating her inner events, and builds reflection time and contemplative-type practice into her daily work. Her biblical knowledge is good and she values her visits to her spiritual director recognizing that her own spirituality needs nourishment to sustain her unique contribution to the hospice. She is appreciative of the support that she receives from her faith community, and encourages the friendship of the hospice community. She is not affected by the lack of support from her commissioning church. Her knowledge of the story of Cicely Saunders' original vision is good but she appreciates that visions evolve. Her ministerial integrity is not threatened by the requirements of evidence-based practice and she is comfortable reframing exchanges and interactions as interventions. Her vulnerability does not stem from being out of step with management objectives but is grounded in her sense of who she is in God.

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Appendices: List

Appendix A Email invitation to hospice chaplains to take part in the profile survey

Email to AHPCC chaplains

Dear Geoff,

You may recall that I am undertaking some PhD research, under the auspices of St Mary's University College Twickenham, into how hospice chaplains understand 'spiritual care' and 'chaplaincy'.
I plan to interview around twenty chaplains and I hope that this sample will be representative of the membership of the AHPCC. However, until now the Association has not collected data on members. The Executive have given their blessing to a short factual questionnaire which will provide such data.
The results of the questionnaire will come to me and I will treat all information in confidence. Nobody else will have access to the information until it is presented by me to the Executive and to the membership, hopefully at Conference next year.
However, I will use the information as a guide to selecting interviewees for the research. Interviews are scheduled to start in the Spring.

The questionnaire is a Bristol Online survey, a facility provided by St Mary's, and can be found at
http://www.survey.smuc.ac.uk/hospchaps2012

I hope you will feel able to complete this questionnaire and I would be grateful for a speedy response.

Thank you for your cooperation.

Jacki Thomas

Appendix B Revised Consent Form

St Mary's University College Twickenham London

NAME OF PARTICIPANT _____

Title of project: The understanding of the concepts of spiritual care and chaplaincy amongst Chaplains in hospices and palliative care units in England.

Researcher and contact details: Jacki Thomas 01344 882654
Jacki.thomas@btinternet.com

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand my role in this research, and all my questions have been answered to my satisfaction.
2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.
3. I have been informed that the confidentiality of the information I provide will be safeguarded.
4. I am free to ask any questions at any time before and during the study.
5. I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University College processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me.

Name of participant (print)……..

Signed…….. date……..

Name of witness (print)……

Signed…….. date……..

……

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.
Title of Project: The understanding of the concepts of spiritual care and chaplaincy amongst Chaplains in hospices and palliative care units in England.

I WISH TO WITHDRAW FROM THIS STUDY

Name (print)……

Signed…….. date……..

St Mary's University College
Waldegrave Road, Strawberry Hill, Twickenham TW1 4SX
Switchboard 020 8240 4000 www.smuc.ac.uk

St Mary's
University College
Twickenham
London

PARTICIPANT INFORMATION SHEET

Section A: The Research Project

1. Title of project
The understanding of the concepts of spiritual care and chaplaincy amongst chaplains in hospices and palliative care units across the United Kingdom.

2. Purpose & value of study
The majority of hospices in the UK are independent and small and spiritual care can be low in budgetary priority, resulting in a need to produce evidence not just for the efficacy of spiritual care but for its very existence. NHS palliative care units may be part of a large organisation but they are subject to similar evidentiary and financial pressures
The introduction of the Government's End of Life Care Strategy may have influenced management attitudes such that spiritual care is now accepted as something that should be offered but there is still ambiguity and confusion about what constitutes spiritual care and who provides it.
Whilst there is much conceptual research on spiritual care, and much of that undertaken by the nursing profession, there appears to be a lack of empirical research in this area.
The aim is to establish, present and publish what hospice and palliative care unit chaplains understand by the terms 'spiritual care' and 'chaplaincy', and thus establish that Chaplains have a unique contribution to make to the provision of spiritual care in hospices and palliative care units.

3. Invitation to participate
An online Profile Survey was sent out with the assistance of the Association of Hospice & Palliative Care Chaplains to members of that organisation. At the end of the survey respondents were asked to indicate whether they would be happy to be interviewed for this research.
An invitation is being extended to a selection of those who indicated a willingness to participate.

4. The research is being organized by Jacki Thomas, under the Supervision of Peter Tyler.

5. Results
It is hoped to present the results to the Association of Hospice & Palliative Care Chaplains and any other interested groups. It is also hoped to publish the results.

6. Funding for the first year of the project has been obtained from Help the Hospices, the M.F.Wright Trust and the Adams Fund, and for the second year from the M.F.Wright Trust.

7. For further information please contact Jacki Thomas either by phone 01344 882654 or email: Jacki.Thomas@btinternet.com

Section B: Your Participation in the Research project

1. You have been invited to take part in the project as a Hospice Chaplain.
2. You may accept or refuse the invitation.
3. You may withdraw from the project at any time.
4. If you agree to take part you will be interviewed at a time and location convenient to you. It is anticipated that the interview will take between one and two hours.
5. It is not anticipated that there are any risks involved in this interview but the subject matter may lead you to reflect on personal beliefs and attitudes.
6. Agreement to participate in the research should not compromise your legal rights if something goes wrong.
7. There are no special precautions needed in connection with this project but you should ask for a re-arrangement if you are not well on the day.
8. The interview will be recorded and a transcript made in order to facilitate analysis.
All the information will be stored, password protected and backed up daily, on a computer in a secure alarmed building.
9. It is hoped that you might find the interview helpful, if not beneficial, in clarifying your thoughts and reflecting on your professional practice.
10. The interview will take between one and two hours.
11. Your information will be kept confidential, your name will not be used – all participants will be coded in order to protect anonymity.

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP TOGETHER WITH A COPY OF YOUR CONSENT FORM.

Jan 21st 2013

Appendix D Revised Participant Information Sheet

St Mary's University College Twickenham London

March 27th 2013

Dear XXXX ,

Thank you for offering to take part in my research which is being undertaken as a PhD project. There are therefore ethical guidelines for its conduct which require me to give you information on the background and purpose of the project:

1. The purpose of the research is to establish, present and publish what hospice and palliative care unit chaplains understand by the terms 'spiritual care' and 'chaplaincy'. I hope to present the results to the Association of Hospice & Palliative Care Chaplains, and any other interested groups, and to publish the results.

2. My supervisor is Dr Peter Tyler, Reader in Pastoral Theology & Spirituality (tylerp@smuc.ac.uk) and my contact details are Jacki.thomas@btinternet.com or 01344 882654 or 07753197923.

3. The interview has been arranged for 3.30pm on Monday xxxxxxx at YYYYY Hospice, Town postcode, but should you be unwell on the day please telephone me. You are free to withdraw from the project at any time.

4. Whilst I do not anticipate that there are any risks involved in this interview the subject matter may lead you to reflect on personal beliefs and attitudes.

I will ask your permission to record the interview in order that I may make a complete or partial transcript to help my analysis. The transcript will be seen only by me and it will be stored, password protected and backed up daily, on a computer in a secure alarmed building. Your information will be kept confidential and your name will not be used, although material and quotations using a pseudonym may be used in the final thesis. I will be the only person able to identify the pseudonym.

I hope that you will find the interview interesting and helpful, if not beneficial in clarifying your thoughts and reflecting on your professional practice.

You will be given a copy of this information together with a copy of your consent form.

St Mary's University College
Waldegrave Road, Strawberry Hill, Twickenham TW1 4SX
Switchboard 020 8240 4000 www.smuc.ac.uk

St Mary's
University College
Twickenham
London

St Mary's University College

ETHICS SUB-COMMITTEE

APPLICATION FOR ETHICAL APPROVAL

This form **must** be completed by the researcher for all undergraduate, postgraduate and staff research proposals involving contact with, observation of, or collection and storage of confidential information or data about human participants.

Undergraduate and postgraduate students should have the form signed by their supervisor.

For staff research proposals the form should be forwarded to the School representative of the Ethics Sub-Committee for signature.

If ,for research projects (staff, undergraduate or postgraduate), the proposal is being submitted for approval to a properly constituted ethics committee external to the University College (e.g. LREC), please submit a copy of the letter approving this application to the Secretary of the Ethics Sub-Committee. External ethical approval may not cover research/ work carried out in the University College and the Secretary will advise if further action is required.

Before completing this form, please refer to the University College's ethical standards for research and any relevant professional guidelines. As the researcher/ supervisor, you are responsible for exercising appropriate professional judgement in this review.

Please refer to the '*Guidelines for completing the Application for Ethical Approval*' when completing this form. All Ethics Application forms must be submitted and signed by your supervisor. If appropriate, your supervisor will refer your application to the School Ethics Sub-Committee representative for Level 2 or Level 3 consideration. For Level 2 consideration, the form will be approved and sign by the School Ethics Sub-Committee representative. For Level 3 consideration, this form should be signed and submitted in hard copy to the Secretary to the University College Ethics Sub-Committee, at least 10 working days prior to the meeting at which it is being considered. All forms and guidance notes are available on the intranet:
http://portal.smuc.ac.uk/ethics-committee.html

Please note: the signed, completed Ethics form must be included as an appendix to the final research project.

If you have any queries when completing this document, please consult your School's Ethics Sub-Committee representative.

Ethics Sub-Committee
Updated November 2010

1. Name of Proposer(s)	Jacqueline Thomas
2.SMUC email address	1160626live.smuc.ac.uk
3. Name of Supervisor *(if applicable)*	Peter Tyler

4.Title of project
The understanding of the concepts of spiritual care and chaplaincy amongst chaplains in hospices and palliative care units across the United Kingdom.

5.School	Theology, Philosophy, History
6. Programme (if undergraduate research or taught Masters)	
7.Type of activity/research (Staff/undergraduate student research/postgraduate student)	Postgraduate

8. Confidentiality	
Will all information remain confidential in line with the Data Protection Act (Amendment 1998)?	YES/~~NO~~
9. Consent	
Will written informed consent be obtained from all participants/ ~~participants' representatives~~?	YES/~~NO~~
10. Pre-approved protocol Has the protocol been approved by the Ethics Sub-Committee under a generic application?	~~YES~~/NO/ Not applicable
11. Approval from another Ethics Committee	
Will the research be approved by a Local Research Ethics Committee (NHS) or other Ethics Committee?	~~YES~~/NO/ Not applicable
Are you working with children under 18 years of age or vulnerable adults?	~~YES~~/ NO
12. Identifiable risks	
a) Is there significant potential for physical or psychological discomfort, harm or stress to participants?	~~YES~~/NO
b) Are participants over 65 years of age or have limited ability to give voluntary consent, including cognitively impaired persons, prisoners, persons with a chronic physical or mental condition, or those who live in or are connected to an institutional environment?	~~YES~~/NO
c) Is any invasive technique involved, or the collection of body fluids or tissue?	~~YES~~/NO
d) Is an extensive degree of exercise or physical exertion involved?	~~YES~~/NO
e) Is there manipulation of cognitive or affective human responses which could cause stress or anxiety?	~~YES~~/NO

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f) Are drugs, including liquid and food additives or other substances to be administered?	~~YES~~/NO
g) Will deception of participants be used of a nature which might cause distress or which might reasonably affect their willingness to participate in the research?	~~YES~~/NO
h) Will highly personal, intimate or other private or confidential information be sought?	YES/~~NO~~
i) Will payment be made to participants other than to cover expenses or time involved?	~~YES~~/NO
j) Is the relationship between the researcher/ tutor and the participant such that participants might feel pressurised to take part?	~~YES~~/ NO

Please note it is still incumbent on you to observe the College's rules on ethics in the conduct of your research, and in particular to ensure that your research complies with the Data Protection Act by which you are legally bound.

When any doubt arises in relation to the above, always discuss this with your School representative of the Ethics Sub-Committee.

Ethics Sub-Committee
Updated November 2010

13. Proposed start and completion date
Please indicate when the study is due to commence, timetable for data collection and expected date of completion

September 2011 literature search + preparation for
February 2013 – October 2013 data collection
ongoing – October 2014 data analysis
completion expected 2016/2017

14.Sponsors/Collaborators
Please give names and details of sponsors or collaborators on the project

15. Other Research Ethics Committee Approval
Please indicate whether other approval is required or has been obtained (e.g. NHS, LEA etc) and whether approval has previously been given for any element of this research by the University College Ethics Sub-Committee

None applied for

16. Purpose of the study
Please give the aims of the research and provide a **brief** rationale for the study including any existing knowledge and benefits of the proposed research.

The aim of the research is to establish, present and publish what hospice and palliative care chaplains understand by the terms 'spiritual care' and 'chaplaincy'.
The Government's End of Life Care Strategy requires that spiritual care be offered but there is still ambiguity and confusion about what it is and who provides it.
Whilst there is much conceptual research on spiritual care, mostly by the nursing profession, there appears to be a lack of empirical research. Chaplains, and their hospices, would benefit from this research because it will provide evidence for their confidence in the spiritual care service provided.

Ethics Sub-Committee
Updated November 2010

17. Study Design/Methodology
Please provide details of the design of the study (qualitative/quantitative etc) and the proposed methods of data collection (exactly what you will do and how; nature of tests, questionnaires, type of interview, ethnographic observation etc) including what will be done to participants, the extent of their commitment and the length of time they will be required to attend for testing. Please also include details of where the testing will take place.

Copies of questionnaires to be used and/or interview schedules should be attached to this application.

Qualitative research using thematic analysis

Semi-structured interviews, approximately twenty, with chaplains of various faiths/belief systems, various ages and length of time in hospice chaplaincy, and both sexes.

Participants will be interviewed in a place and at a time convenient to them.

It is anticipated that the interview will take between one and two hours.

Interviews will be recorded so that transcripts may be made and analysed.

18. Participants
Please describe how many participants will be required to complete the study, their age, sex, how they will be chosen/recruited and inclusion/exclusion criteria.

Interviews

Male and female totalling approximately twenty. Selected for age; length of time in hospice chaplaincy; faith/belief system — predominantly Christian but also Jewish, Moslem, Buddhist, humanist — full time/part time, ordained/lay

19. Consent
Please provide copies of the consent form, information sheet, debriefing sheets (if relevant) for participants and any other documentation in relation to consent, e.g. letters to parents, Heads of Schools etc. attached

19a) Are there any incentives/pressures which may make it difficult for participants to refuse to take part (i.e. will coercion be used in the recruitment of participants)?

None known

19b) Will any of the participants be from any of the following groups? No
Children under 18
Participants with learning disabilities
Participants suffering from dementia
Other vulnerable groups

If children under 18 years of age are participating has the researcher/investigator a current CRB disclosure?

19c) How will consent be obtained?

Participants asked to sign form.

Ethics Sub-Committee
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St Mary's
University College
Twickenham
London

PARTICIPANT INFORMATION SHEET

Section A: The Research Project

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The majority of hospices in the UK are independent and small and spiritual care can be low in budgetary priority, resulting in a need to produce evidence not just for the efficacy of spiritual care but for its very existence. NHS palliative care units may be part of a large organisation but they are subject to similar evidentiary and financial pressures
The introduction of the Government's End of Life Care Strategy may have influenced management attitudes such that spiritual care is now accepted as something that should be offered but there is still ambiguity and confusion about what constitutes spiritual care and who provides it.
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An invitation is being extended to a selection of those who indicated a willingness to participate.

4. The research is being organized by Jacki Thomas, under the Supervision of Peter Tyler.

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It is hoped to present the results to the Association of Hospice & Palliative Care Chaplains and any other interested groups. It is also hoped to publish the results.

6. Funding for the first year of the project has been obtained from Help the Hospices, the M.F.Wright Trust and the Adams Fund, and for the second year from the M.F.Wright Trust.

7. For further information please contact Jacki Thomas either by phone 01344 882654 or email: Jacki.Thomas@btinternet.com

Section B: Your Participation in the Research project

1. You have been invited to take part in the project as a Hospice Chaplain.
2. You may accept or refuse the invitation.
3. You may withdraw from the project at any time.
4. If you agree to take part you will be interviewed at a time and location convenient to you. It is anticipated that the interview will take between one and two hours.
5. It is not anticipated that there are any risks involved in this interview but the subject matter may lead you to reflect on personal beliefs and attitudes.
6. Agreement to participate in the research should not compromise your legal rights if something goes wrong.
7. There are no special precautions needed in connection with this project but you should ask for a re-arrangement if you are not well on the day.
8. The interview will be recorded and a transcript made in order to facilitate analysis.
All the information will be stored, password protected and backed up daily, on a computer in a secure alarmed building.
9. It is hoped that you might find the interview helpful, if not beneficial, in clarifying your thoughts and reflecting on your professional practice.
10. The interview will take between one and two hours.
11. Your information will be kept confidential, your name will not be used – all participants will be coded in order to protect anonymity.

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP TOGETHER WITH A COPY OF YOUR CONSENT FORM.

original

St Mary's
University College
Twickenham
London

NAME OF PARTICIPANT: _____

Title of the project: The understanding of the concepts of spiritual care and chaplaincy amongst chaplains in hospices and palliative care units across the United Kingdom.

Main investigator and contact details: Jacki Thomas 01344 882634

Members of the research team:

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.
2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.
3. I have been informed that the confidentiality of the information I provide will be safeguarded.
4. I am free to ask any questions at any time before and during the study.
5. I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University College processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me.

Name of participant (print).....Signed.....Date.....

Name of witness (print).....Signed.....Date.....

If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: The understanding of the concepts of spiritual care and chaplaincy amongst chaplains in hospices and palliative care units across the United Kingdom

I WISH TO WITHDRAW FROM THIS STUDY

Name: _____

Signed: _____ Date: _____

St Mary's University College
Waldegrave Road, Strawberry Hill, Twickenham TW14SX
Switchboard 020 8240 4000 Fax 020 8240 4255
www.smuc.ac.uk

20. Risks and benefits of research/ activity

20a) Are there any potential risks or adverse effects (e.g. injury, pain, discomfort, distress, changes to lifestyle) associated with this study? If so please provide details including information on how they will be minimised.

Participants may find themselves reflecting on past painful experiences. Interviewer to ascertain at beginning of interview the nature of interviewee's support systems.

20b) Does the study involve any invasive procedures? If so, please list the researchers' or collaborators' experience in the use of these procedures.

No invasive procedures

20c) Will individual/group interviews/questionnaires include anything that may be sensitive or upsetting?

Individual interviews may introduce sensitive areas

20d) Please describe how you would deal with any adverse reactions participants might experience.

Interviews - ensure that participant has spiritual director and/or supervisor to reflect with.
Questionnaire will be optional

20e) Are there any potential benefits of participating in the research to the participants (e.g. gaining a knowledge of their fitness, finding out personality type, improving performance etc)?

Participants may be led to reflect on their knowledge and practice, and thus improve their overall skills and key competencies.

Ethics Sub-Committee
Updated November 2010

21. Confidentiality, privacy and data protection

21a) What steps will be taken to ensure participant's confidentiality?

Names will be coded
Names will not be used in reporting findings.

21b) Will the data be stored securely? Yes

Stored on a computer with password protection, backed up daily. Building is alarmed.

21c) Who will have access to the data?

Proposer

21d) Will the results of analysis include information which may identify people or places?

Where only one person of a particular faith/belief system is interviewed identification may be possible

22. Feedback to participants

Please give details of how, if appropriate, feedback will be given to participants.

Findings will be presented (to AHPAC) and published.

The proposer recognises their responsibility in carrying out the project in accordance with the University College's ethical guidelines and procedures and will ensure that any person(s) assisting in the research/ teaching is also bound by these. The Ethics Sub-Committee must be notified of and approve any deviation from the information provided on this form.

Signature of Proposer(s)	Date:
Jacqueline M Thomas	June 11th 2012
Signature of Supervisor (for student research projects)	Date:
	20/6/12

Ethics Sub-Committee
Updated November 2010

23. Approved at Level 1/ ~~Referred to School representative for Level 2 consideration~~* *delete as applicable No pressing issues Name of School representative of the Ethics Sub-Committee for staff (Pending reassignment of schools - on behalf of representative) Signature of School Representative:	15/7/12 Date:

24. Approved at Level 2/ Level 3 assessment is required* *delete as applicable Signature of School Representative:	Date:

Ethics Sub-Committee
Updated November 2010

Appendix F Script for interview page 1

Script – for guidance *Supplementary questions are in italics*

Thank you for agreeing to take part in this interview.

First of all I want to stress that you don't **have** to say anything but anything you do say will be treated in strictest confidence and where material is included in the write-up names will be changed. I also want to stress that I would like to hear your experience and opinion – I won't be expressing my thoughts during the interview, although we could discuss items of particular interest later.

To help my memory and with your permission I'd like to record the interview (slight pause for objection) and therefore I'd like to begin by testing the microphone – I'll say the date and then please tell me your name and the name of your hospice….I'll just play that back to make sure all is well.

I'd like to begin with a reminder of the information that you gave in the survey - you are aged between 50 and 60, you are male, Christian and a Methodist ordained minister. You are trained in counselling, spiritual direction, pastoral care and pastoral supervision. you have been in hospice chaplaincy for 5 years, full-time. Is that still correct?

I'd like to explore your understanding of your work and I think it would help if you first describe how you come to be in hospice chaplaincy…

how long was your Parish/congregational experience? (may not be relevant)
Why move?

What, if any, are the differences between these ministries?
What kind of support did & do you receive for each kind of ministry?

What, if any, connections do you have with a local church?

How would you describe the church's attitude to hospice ministry? *Your churches and the church generally*

Summarize back to interviewee

I'd like now for you to tell me about your hospice:
How would you describe it?
What is the ethos?
where do you fit? who do you report to?
How do others see you? (nursing staff, medical staff and others whom you meet on the ward, the clerical or office staff, CEO, Trustees)
Who are your main contacts?
do you visit every patient or is there a referral system?
who refers?
Who, if anyone, act as gate-keepers?

How do you introduce yourself to a new patient, the patient's family, new members of staff?
How do you explain what you are there for?
What is your impression of the expectations of most people?
(Issues of religion versus spirituality)
What about respite care patients? What do they think you are there for?

If ordained: What do you wear? (dog collar)

Summarize back to interviewee

What would you say are the main issues that patients raise and what is your response?

What concepts, if any, do you find helpful? *Eg hope, connectedness, meaning/purpose, journey*

Summarize back to interviewee

What, if any, spiritual assessment process does your hospice use?
Why use this?
Who does it?
(Issues of religion versus spirituality)

How do you feel about the different levels of spiritual care as described in the AHPCC Standards and Competencies? (Summary of Competencies available if needed).
To what extent does your hospice reflect this model?
Are nursing staff, for example, aware of and practising their part?

How multicultural is the catchment area of the hospice?
To what extent are you meeting people of other cultures/faiths? How are the spiritual needs of these people met?
(Issues of religion versus spirituality)

Any mention of generic chaplaincy?

How would you describe the frustrations of your work?
What, if anything, do you think the hospice can do to ease the frustration?
What if anything could the hospice do to improve your efficiency?

To what extent do budgetary constraints affect your work?
Do you anticipate that budgetary constraints will increase and if so how do you think this will affect your work?

What do you think of the Self-assessment section in the AHPCC Standards?

To what extent does your Job Description match what you do?
Summarize back to interviewee

I'd like to change gear now and ask you some more personal questions about your own spirituality –
How would you describe your own spirituality?
How would you describe your own spiritual journey?
What or who are your major influences?
How would you describe your significant experiences? (desert/ coming alive/ epiphany/ blossoming/ flourishing)

What sustains you?
What enables you to stay with the pain of others?

To what extent does your own spirituality play a role in the work you do as Hospice chaplain?
To what extent do your own experiences motivate/influence your work?

How is your spirituality adequate for your hospice work?
How easy is it to speak of your own spirituality?
How easy is it to explain spirituality to other people/patients/staff?

How do you look after yourself?
How do you rate your work/life balance?
Summarize back to interviewee

How would you describe the relationship between your calling/ordination vows and your non-proselytising chaplaincy role?

How have you changed over the years you have been in hospice?

Summarize back to interviewee

There has been quite a lot of discussion as to how the terms spirituality and spiritual care are to be understood – how do you define spirituality and spiritual care?

How do you define chaplaincy?

To what extent does your hospice accept these definitions?
Who accepts/ does not accept?
What are their reasons? Source of conflict?

Summarize back to interviewee

I have here some definitions which I'd like you to comment on – first of all Spirituality. To what extent do you agree with this/ find it helpful?
(What are your feelings on the phrase 'may or may not include God'?)

Here is a definition of spiritual care – to what extent do you agree with this/ find it helpful?

What do you feel about these comments – *show Swinton and mine (Pastors extract – removed)*

Reflecting on your time in hospice: What are the main changes you have seen in the last few years? *(may not be applicable to new chaplains)*
What would you like to see happening in the world of hospice chaplaincy in the next few years?

what would you say is your unique contribution to hospice?
What does a chaplain/ spiritual care provider offer that no-one else does?

What are your thoughts on this statement? *Show Threlfall-Holmes quote*

From the survey I have discovered that there are no hospice chaplains under the age of forty – why do you think this is?

Is there anything else you would like to say?

How has our conversation compared with your expectations?

Please do email me if you would like to talk further but for now:
Thank you very much for you co-operation and your honesty. Some of our conversation has been quite deep so please take care as you return to the hospice/go to your next engagement.

Appendix G The extracts

These extracts were individually laminated. Each was used where appropriate. There was no heading and the source was not included on the laminated version shown to the interviewees.

Spirituality gives transcendent meaning and aspiration to a person's life, and may or may not include God. Spirituality concerns all that makes for an individual's existence as a person and our capacity as human beings for self-transcendence, relationship, love, desire, creativity, altruism, self-sacrifice, faith and belief. (AHPCC Guidelines 2012)

Spiritual care is that care which recognizes and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires. (NHS Scotland 2009)

Comment on pastors (dispensed with after first two interviews)
Our actual work takes shape under the pressure of the marketplace, not the truth of theology or the wisdom of spirituality. (Peterson 1992:5)

Unique contribution
'What chaplains bring to the institution that it cannot get from social workers, mentors and so on is both an expertise in faith matters and an awareness of the spiritual dimension in life – to put it in secular terms – that arises from a deep grounding in one's own faith.' (Threlfall-Holmes & Newitt 2011:136)

The need for evidence
'Chaplaincy needs to be evidence based and evidence led….
My only caution is that we are careful that our right and proper attempts to meet the criteria laid down by the healthcare system do not blind us to the obvious: often it is that which cannot be seen or measured that proves to be vital. In our movement towards technical excellence we must be careful not to lose our soul.' (Swinton, 2013)

Whilst not disputing the need for evidence-based practice we should be careful that such practice does not destroy, ignore or simply lose what may be essential to life - that which cannot be seen or measured. (my paraphrase of Swinton)

Personal spirituality (shown to only two interviewees)
'I was a priest in a time that is not especially convivial toward the clergy. I had, nevertheless, achieved what I believed to be a sustainable spirituality and an ability to elaborate upon it with minimal cant and hypocrisy.'
(MacIntyre, Linden (2011) *The Bishop's Man* London: Vintage books)

Appendix H Pen portrait of Eric page 1

He greeted me with a smile and a hug but I knew he was not happy and he did not say why straight away. As we got into the questions he asked me to turn off the recorder so that he could fill me in on what was happening as that would help me understand why he answered some questions the way he did. He was totally absorbed in his own circumstances but nevertheless pleased to be interviewed, expressing the hope that my research would help him and others who encountered a similar situation.

We met in the tiny, tiny chapel which is 'used for counselling by counsellors who move everything and don't put anything back.'

He had noticed the original advertisement but wasn't actively looking for a job, but then friends nudged him to apply so he arranged a pre-application visit and felt very comfortable. The Hospice sent him an application form – he was the only one shortlisted but the interview date was not convenient so he assumed from a 'godly' perspective that it wasn't to be. The hospice changed the date. At the interview he was asked 'why do you want this job?'. He replied 'I'm not looking for a job, I'm in ministry. If I'm appointed it will be a continuation of my ministry.'
After thirty years of church-based ministry it was a challenge:

> 'meeting people at a significant time in their life's journey…the variety of people is much greater…here you are forced to meet those fringe people and those outside of church much more…your approach is not as religious based, it's actually much more on the front line.'

Although not a Christian establishment the hospice was founded by local Christian ministers but he is concerned that it is becoming increasingly difficult to identify those Christian origins. The vision was rewritten recently, focusing on care, compassion and love but with emphasis on being for all faiths.
When he started at the hospice he made a conscious effort not to appear 'religious' – he's not overly 'religious' anyway, although he is happy with ritual and religion.

> 'I talk much more about working out of my relationship with God rather than my religious beliefs. So I am what I am and the God I believe in is within me, therefore wherever I go he is part of me, he is who I represent and therefore on that basis whatever I seek to do, I seek to do it well, to the best of my ability and with integrity.'

He introduces himself as the chaplain but does not 'cut and run' if a patient says 'not interested' or 'I'm not ready for you yet'. He finds something they are interested in, befriends them showing genuine interest:

> 'allowing them to tell me their story, who they are, what their interests are, what their family life has been like, to discover their senses of achievement and significance in life.'

People facing terminal disease begin to wonder 'what's it been worth? Have I done anything of any value in my life?' He comments that they may not use those words but the thought process is there.
He observes that many people don't understand that they have a spiritual side. 'Spirituality is associated with being religious and I think that's right because that's where it belongs.' Nevertheless he tries to help the non-religious person and the spiritually unaware recognize:

> ' what *is* spiritual, those things that touch you deeply, those things that make you what you are, those things that touch your emotions and make your personality, likes & dislikes & all of those things.'

He seeks to affirm and empower - he is not there to force:

> 'I'm not there as a counsellor to dig, I'm simply there as a presence, to evoke some kind of response and to help them be comfortable with where they are at this particular time.'

He also tries to help them explore what lies ahead finding that many people, including those with no faith, have some understanding of beyond. Being reunited with those who've gone before is very *real* for many people, even though they do not know how or where.

With those who question this possibility he speaks of his own faith, being comfortable with uncertainty and mystery:

'what I believe actually works for me but it is still a mystery, I am comfortable having an attitude of faith trusting in something I don't fully understand'.

He's not there to judge what they believe but to support them and the lack of assertiveness required by the role sometimes makes him feel 'very liberal, wishy-washy, airy-fairy.'

He observed that a number of patients have been happy to listen him and come to the same conclusion, perhaps feeling that 'if the chaplain says it's a mystery it's ok for me to say so.'

He does not use a formal spiritual assessment tool but assesses as he goes along. He devised such a tool but it is a tick-box item and he wants to revise it. However he needs to help the nursing staff understand their role in spiritual care – at present no time is allowed for teaching. He gives new staff the RCN booklet and tries to have one-on-one conversations.

His main frustration is not having enough time with patients because of fitting in with the ward routine and visitors.

Asked about his own spirituality he said 'variable'. He is a free-church minister, which he describes as fairly free, and a member of the XXXXXXXX Community which has a rule of office and a rule of life = availability and vulnerabiity. The community is his anchor, returning to morning and evening prayer whenever he is struggling spiritually. He has not been able to go on retreat recently and 'I could do with days out just to be quiet, spiritually quiet, and channelled.'

His main source of spiritual sustenance is Celtic Christianity, also charismatic renewal in late 70s and 80s, but also he is a talker and will share with and receive sustenance from colleagues, ministers, friends.

Reflecting on what enables him to stay with the pain of others his initial reaction was that he didn't know, but then 'Something inside holds me, gives me the ability to…I would say that as I'm getting older I'm becoming more emotional….or I'm feeling the emotions more…'

Asked what he did with the emotions:

'I don't do anything at the moment, it wells and then it settles down. I've yet to explore and handle… I asked whether he would take this to his spiritual director – he said 'probably'.

Asked to what extent his spirituality plays a role in his work he said:

> 'I'm beginning to feel what God feels – that sounds really super-spiritual but there is a sense in which we talk about our heart beating with God's heart. Maybe God feels this and I'm feeling what he's feeling and therefore what is now coming out is a natural out-working whereas before I would just feel it but professionally not show it, now it's becoming more difficult not to show.'

I asked: 'Like Jesus weeping over Jerusalem?'

he replied: I would have difficulty putting myself there – I am not worthy

I observed: But God's put you there – not you

He: But maybe that's what it is

I started to ask if he knew The Salvador Dali painting of Christ on the cross looking down on the world and he finished the description for me – he knew the painting well. He will explore his spirituality and his work further because of this recent recognition.
He understands spirituality as 'What makes us the people we are' and spiritual care as 'enabling people to recognize who they are and where they are in the life journey.' Asked whether that was the chaplain's role he replied:
'Yes I think so though I've never put it in words like that before.'

Extracts
The extracts on spirituality and spiritual care elicited the response 'says what I said'. The extracts on evidence based practice 'I like this because it's what I feel – it's recognizing there needs to be some evidence but without losing something'
'I would want to have all of these plastered across my office wall.' He asked me to send them to him and I did.
The unique role of the chaplain is:
' I say these words cautiously – to be a bit of a maverick, not a loose canon that goes around causing damage within the structures but outside the structures. Within the structure – there is an accountability but given the freedom to cross boundaries, to permeate all areas, or access all areas, and to take with you what should really be the concept of hospice so that everybody feels connected, somehow you are the oil travelling through the whole machinery so you are connecting people in finance, fund raising, secretaries, volunteers – several shops, hub (warehouse), to meet with, to mix with as well as come alongside patients and families'.
I've always described myself as:

> 'one who crosses boundaries and I have been allowed to do that. However I'm feeling that doors are closing at that higher level. Ability to act as connecting oil but now more difficult. Still manage to do it most days – and nobody else does that.'

He feels supported by members of Baptist church he attends.
But feels that Chaplaincy is still marginalized to a greater or lesser extent. There are still some who think that those who can't cope in church-based ministry end up in chaplaincy. He observes that most chaplains find such fulfilment that they do not want to go back into church-based ministry, but there are those who feel increasingly marginalized and so are forced back into church-based ministry.

Appendix I Profile Survey poster presentation of findings

St Mary's University Twickenham London

First Profile of UK Hospice Chaplains

Jacki Thomas
Theology, Philosophy and History

Background

Until the latter part of the twentieth century there was very little literature on the role and practice of healthcare chaplaincy. The economic climate and the secular society have stimulated increased interest in the appropriateness of spiritual and religious care in healthcare. However, only 14% of the literature has been produced by chaplains and little of that is by hospice chaplains (1). To establish how hospice chaplains understand 'spirituality', 'spiritual care' and 'chaplaincy' would make a significant contribution to existing knowledge and a qualitative research project of semi-structured interviews was planned. However, in the absence of published data to use for the selection of interviewees it was first necessary to conduct a survey of hospice and palliative care chaplains. There are 223 hospice and palliative care units in the UK(2) but whether there is a chaplain on the staff is not known. However, the Association of Hospice & Palliative Care Chaplains (AHPCC) sanctioned the survey amongst its registered members.

Aim: to obtain a profile of the membership of AHPCC. *Permission sought & given at AGM May 2012*

Purpose: to use the profile to select interviewees for the research into how said chaplains understand the concepts of 'spirituality', 'spiritual care' and 'chaplaincy'.

Method: an online survey, using Bristol Online Survey, was carried out amongst members of AHPCC.

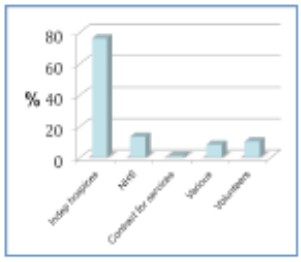
Data collected: gender, age, faith group, denomination, full/part-time, employment status, job title, prepared to be interviewed.

Pilot survey carried out followed by full survey:
147 Personalized emails were sent September 2012, and 15 to new members in May 2013. Survey closed July 2013.

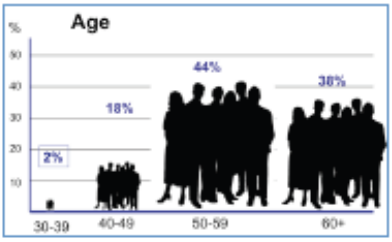
The Findings

Gender

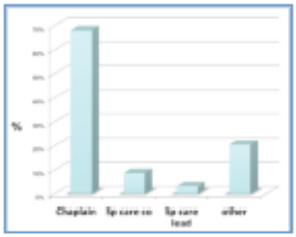
Nature of hospice employment



Age

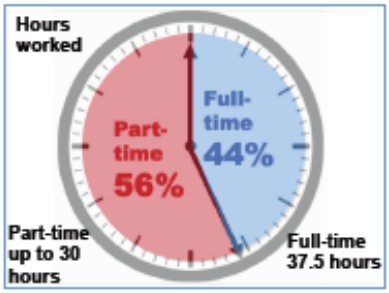


Job title

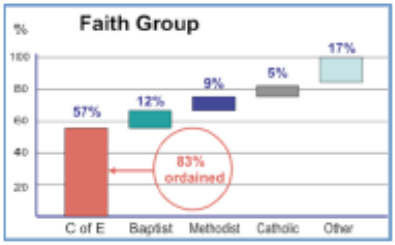


"I'd like to think that it's something to do with experience, including life experience and having reflected on that rather than the fact that we're just a load of old fogeys" (interviewee)

Hours worked



Faith Group



Summary of Findings

67% response rate to survey (108 of 162 members)

Hospice chaplain is

- Slightly more likely to be male than female
- aged 50+
- 97% Christian and predominantly ordained Church of England
- Slightly more likely to be part-time than full-time, with females more likely to be part time
- Most likely to be employed by an independent hospice
- Most likely to have a job title of 'Chaplain'

84% of respondents were happy to be contacted with a view to being interviewed.

References
1. Holloway,M., Adamson,S., McSherry,W. & Swinton,J. (2011) *Spiritual Care at the End of Life, a systematic review of the literature* London: Department of Health
2. May,C.& Hodson,M.(eds) (2012) Hospice & Palliative Care Directory 2012-2013 London: Help the Hospices

Appendix J Rembrandt: The Prodigal Son

Appendix K Batoni: The Return of the Prodigal Son

Appendix L Munch: The Scream