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Mark Newitt

Ritual, Pastoral Presence, and Character Virtues in Healthcare Chaplaincy:

A study of chaplains' support to bereaved parents following the *in utero* or neonatal death of their baby.

Abstract

This thesis sets out to understand better how chaplains can support bereaved parents following the death of their baby. Running parallel to this, with increasing demand for evidence-based practice, it aims to evidence the benefit of chaplaincy support and the unique skills of chaplains.

The thesis is based on twelve semi-structured interviews with sixteen parents. These were analysed using a form of grounded theory and compared with the findings of related research. I argue that the root of all other spiritual need is the loss of control parents experienced. Alongside this theme I identify a loss of meaning, a loss of self worth, and a desire to do something in response to their loss.

Although there is not a one size fits all response, the liturgy and ritual provided by chaplains helped counter spiritual distress. I propose that, alongside the ability to perform liturgy and ritual, chaplains are viewed as having authority in both religious and spiritual matters. As liturgy and ritual was appreciated in conjunction with the presence of the chaplain, I explore a virtue-based approach to chaplaincy and recommend the increased use of shadowing and mentoring.

Drawing on Fowler's *Stages of Faith*, I describe how some parents found greater religious faith or increased spiritual awareness as a result of their experience. I speculate that, in order to provide the best possible support to parents, chaplains need to exhibit the characteristics of Fowler's stage 5. Chaplains have a richness of reflection and experience and I appeal to churches to engage more profoundly with them.

I also recommend the continued employment of chaplains within hospitals and argue for the narrative voice to be valued in research. Contra to current NICE guidelines, I contend that parents should be offered the opportunity to see and hold their dead baby.

Ritual, Pastoral Presence, and Character Virtues in Healthcare Chaplaincy:

A study of chaplains' support to bereaved parents following the *in utero* or neonatal death of their baby

Mark Julian Newitt

Doctor of Theology and Ministry Department of Theology and Religion Durham University 2013

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The copyright of this thesis rests with the author. No quotation from it should be published without the prior written consent and information derived from it should be acknowledged.

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Sixteen people are not named, the parents who risked sharing their experience with me. I would like to thank them for trusting me with their stories.

In memory of

Ruth Jennifer Bell

30th June 1980 - 15th May 2011

&

Bethany Rose Richardson

born and died 15th May 2011

Introduction 1

It's amazing that, you know, that level of [chaplaincy] support is offered to us to parents now even at, you know, the stage that I was which was, you know, still really early pregnancy, you know, twenty-one twentytwo weeks it's early. But, that that level... is offered... to us is fantastic, it's really amazing. An' the first thing funding's taken away from won't it.1

1.1 **Background Context**

When the NHS was established in 1948, Ministry of Health circulars stipulated that hospital authorities should give special attention to providing for the spiritual needs of both patients and staff.² To meet this need chaplains, mainly drawn from the Church of England, were appointed to hospitals. Since the time of its inception the NHS has gone through many changes, particularly in the last thirty years, as medical treatment has progressed, patient expectation has changed, and successive governments have attempted to control escalating costs. At the same time, the latter half of the previous century has seen a marked change in the public's attitude to organised religion.³ Despite such extensive altering in its contextual setting, there is very little written about either the theology, praxis, or philosophy of healthcare chaplaincy.⁴ Helen Orchard's 1999 research into the work of chaplaincies states that 'fundamental questions about the work of chaplains remains [sic] little explored, either by academics or practitioners themselves.'5 More recently, Harriet Mowat's 2008 scoping review concluded 'the research literature as it currently stands does not directly or substantially address the issue of efficacy in healthcare chaplaincy.'6 Even in America, where chaplaincy is more established, when exploring the extent to which the spiritual needs of patients are being met, Kevin Flannelly

¹ Sarah CR11. Throughout the thesis parents' names have been pseudonymised and chaplains' ² HMC(48)62, BG(48)65 and RHB(48)76. Cf. James W. Woodward, 'A Study of the Role of the Acute Health Care Chaplain in England' (Ph.D. Thesis, Open University, 1998), 90.

³ Cf. for example, Charles Taylor, A Secular Age (Cambridge MA: Belknap Press, 2007).

⁴ Unless otherwise stated, throughout this thesis chaplaincy/chaplain is taken to refer to healthcare chaplaincy.

⁵ Helen Orchard, Hospital Chaplaincy: Modern, Dependable? (Sheffield: Sheffield Academic Press, 2000), 9.

⁶ Harriet Mowat, The Potential for Efficacy of Healthcare Chaplaincy and Spiritual Care Provision in the NHS (UK) (Aberdeen: Mowat Research, 2008), 31.

et al. conclude 'there appears to be almost no published research that directly answers this question.'⁷

This lack of reflection on practice may in part be due to the fact that, in an increasingly cost-driven and results-focused NHS, chaplaincy has previously led rather a charmed life. Orchard's study, for example, found that in 1999 65% of London chaplaincies had 'no review of their services undertaken by management and 85% were not required to provide any workload statistics to the Trust.'8 A possible reason for this freedom from management oversight can be found in the writing of Chris Swift. In completing his literature search, like others before him, Swift comments on how little has been written on chaplaincy over the past forty years. However, unlike others, Swift's gaze moves beyond recent history to observe that 'despite the almost constant employment of chaplains in hospitals, their history is unwritten.'9 Dedicating over a third of his thesis to exploring the role of the chaplain during critical moments in the history of hospitals in England, Swift argues that the chaplain's authority to act comes from a pre-Enlightenment 'discourse'10 where Christianity was the dominant form of knowledge.¹¹ While today medical/scientific knowledge is predominant, Swift suggests that 'aspects of the chaplain's role... demonstrate more than the remnants of a past discourse and might usefully be seen to draw authority from an epistemic fragment.'12 Just as preachers are sometimes referred to as being 'six feet above contradiction', it may be that the historic religiopastoral power wielded by chaplains provided them with a level of immunity from appraisal.

1.1.1 The increasing need for evidence-based practice

If previously there was little requirement to provide evidence of work undertaken, either from a management review or as part of continuing personal development, the situation is rapidly changing. Today there is increasing politico-economic pressure for evidence-based practice. At the highest level this

⁷ Kevin J. Flannelly, Kathleen Galek, and George F. Handzo, 'To What Extent Are the Spiritual Needs of Hospital Patients Being Met?', *International Journal of Psychiatry in Medicine* 35, no. 3 (2005), 320.

⁸ Orchard, Hospital Chaplaincy, 150.

⁹ Christopher Swift, 'The Function of the Chaplain in the Government of the Sick in English Acute Hospitals' (Ph.D. Thesis, University of Sheffield, 2006), 6.

¹⁰ Swift, following a Foucauldian perspective, understands the term 'discourse' as referring to systems of thoughts composed of ideas, attitudes, courses of action, beliefs and practices that systematically construct the subjects and the worlds of which they speak.

¹¹ Swift, 'The Function of the Chaplain', 77.
¹² Swift, 'The Function of the Chaplain', 50.

can be seen in the creation of the *National Institute for Health and Clinical Excellence* (NICE) which provides 'authoritative advice on the effectiveness of interventions to improve health and reduce health inequalities and on treatments and the best clinical practice.'¹³ NICE guidelines recognise the importance of spiritual care and do not exempt it from appraisal. The guidelines on palliative care, for example, state:

Spiritual care for patients with cancer and their carers should be an integral part of health and social care provided in all care environments and should be open to similar levels of scrutiny and supervision as other aspects of non-physical care.¹⁴

More specific to chaplaincy was the *Caring for the Spirit NHS Project.*¹⁵ Within a climate of growing professionalisation, the project is illustrative of the need, seen by many chaplains, to legitimate their existence and contribution to healthcare. Although never fully implemented, in 2003 it set out a strategy for the development of spiritual healthcare which envisaged that, by 2010, chaplains should be 'delivering evidence-based spiritual healthcare for all users needing such care.'¹⁶ Additionally, in 2004, as part of the review of the NHS pay and reward system, the NHS Knowledge and Skills Framework (KSF) was developed.¹⁷ This provides a way of recognising the skills and knowledge that a person needs to be effective in a particular NHS post. It is also used to make decisions about pay progression and development. If chaplains were unable to evidence meeting their KSF outlines they would be unable to progress up the pay spine.

At the same time as the pressure to demonstrate evidence-based clinical practice, chaplaincy departments have also found themselves the target of cost cutting. In August 2006 healthcare chaplaincy hit the national headlines with news of Worcestershire Acute Hospitals NHS Trust's attempt to dismantle the chaplaincy department by making seventy percent of the chaplains

¹³ NICE, 'A Guide to Nice' (Information Booklet, London, 2005), 10.

¹⁴ NICE, 'Improving Supportive and Palliative Care for Adults with Cancer: The

Manual' (Guidance on Cancer Services, NICE, 2004), 98.

¹⁵ Led by NHS Yorkshire and the Humber and its predecessors in South Yorkshire, between 2002 and its finish in 2007, this was concerned with enabling the chaplaincy and spiritual healthcare workforce to make a greater contribution to healthcare in the NHS in England. ¹⁶ Caring for the Spirit NHS Project, 'Caring for the Spirit: A Strategy for the Chaplaincy and Spiritual Healthcare Workforce' (South Yorkshire Workforce Development Confederation, 2003), 11.

¹⁷ Agenda for Change Project Team, The NHS Knowledge and Skills Framework (NHS KSF) and the Development Review Process (London: Department of Health, 2004).

redundant.¹⁸ Just over a year later, in October 2007, chaplaincy was back in the headlines following research by the public theology think tank *Theos* which stated that chaplaincy care among NHS Trusts had been cut by more than 54,000 hours since 2005.¹⁹

Whether it be management review or as part of continuing personal development, such changes mean that there is increasing need to demonstrate that the work of chaplains is cost-effective and beneficial. However, they should not be the only drivers. Even without such considerations, chaplains should be ethically motivated to provide the best possible care to patients and staff. Stephen Pattison, in his seminal work on pastoral care, cautions that 'if pastors have no perspective on their work they risk complacency, stagnation and possible complicity with that which is less than good or desirable. Ultimately, they risk harming those in their care.'²⁰ With that in mind, at its heart this thesis is an attempt to understand better how chaplains can support bereaved parents²¹ more effectively following the *in utero* or neonatal death of their baby. Running parallel to this, in a time of economic austerity with the NHS facing unprecedented financial pressure and with hospital trusts 'in the front line in the drive to achieve more for less',²² it also aims to evidence the benefit of chaplaincy support and the unique skills of chaplains.

1.2 Overview of the Thesis

Pattison raises the need for perspective in pastoral care. In a related way, I hope that having a perspective on this thesis gives the reader greater understanding. Accordingly, this chapter continues by providing an overview of the journey I take through the thesis. Before that, however, it is important to outline the perspective that I bring to this thesis. I write this as a white, male, ordained Anglican. My work context, Sheffield Teaching Hospitals NHS Foundation Trust (STH), is an acute hospital where in terms of religion, in 2010-2011, 70.8% of

¹⁸ Nursing Times.net, 'NHS chaplains face redundancy,' (January 2007), <u>http://</u>www.nursingtimes.net/nursing-practice/clinical-specialisms/management/nhs-chaplains-face-redundancy/201226.article. [accessed: 7 February 2012]

¹⁹ Theos, 'New research reveals cuts in hospital chaplaincy' (October 2007), <u>http://</u> <u>theosthinktank.co.uk/comment/2007/10/07/new-research-reveals-cuts-in-hospital-chaplaincy</u>. [accessed 20 January 2012]

²⁰ Stephen Pattison, A *Critique of Pastoral Care* (London: SCM Press, 3rd ed. 2000), 1. ²¹ Throughout this thesis, unless otherwise stated, the word parents is taken to refer to bereaved parents.

²² Paul Corrigan and Caroline Mitchell, 'The Hospital Is Dead, Long Live the Hospital: Sustainable English NHS Hospitals in the Modern World' (Report, Reform, 2011), 5.

admissions identified themselves as Christian, 12.9% as atheist or none, 4.5% as Muslim with 10.4% not known or unrecorded.²³ As I allude to in *section* 5.6.3, within chaplaincy there is a debate between those who favour a faith-specific approach, and those who argue for a chaplaincy that reaches beyond traditional religious boundaries to those who have no strong religious affiliation. While I commend open-mindedness and a concern for people of all faiths and none, I believe that what chaplains most distinctively and helpfully have to offer is the 'lived experience of dwelling within a historic religious tradition.'²⁴ I can only speak from my own context and, accordingly, this thesis is addressed to the Christian community. This does not mean that those of other faiths may not find the thesis useful. However, it is for them to decide whether or not to appropriate the findings.

The background context just discussed highlighted a lack of writing on chaplaincy. As I began to explore the possibility of carrying out research into or around chaplaincy, as chapter two sets out, my first undertaking was to be clear how I understood the role and skills of a chaplain. Based on both personal experience and wider reading, my understanding of chaplaincy is set out in *section 2.1*. As patients face demanding situations which can fracture their sense of identity and challenge their world view, a key role of chaplaincy, I believe, is to support people through such times of change and transition. Setting out the skills required, I argue that chaplains need a high degree of expertise. In relation to being attentive listeners I suggest that, because they do not come with a treatment agenda, chaplains may be able to listen in a different way to other medical staff. I also propose that the ability to handle liturgy and liturgical-based ritual²⁵ is a unique skill within the hospital. Both these proficiencies are picked up and drawn upon throughout the thesis.

With no evidence base for chaplaincy, in *section 2.2* I turn to look at healthrelated research that holds relevance for chaplains. This commences with a brief review of the ever growing literature that explores links between religion, spirituality and health, noting how many studies are criticised for poor design and inadequate definitions of religion and spirituality. Accordingly, to avoid

 ²³ Patient Administration Data, STH, (2010-11). [no source available in the public domain]
 ²⁴ Stephen Pattison, 'Dumbing Down the Spirit', in Helen Orchard (ed.), Spirituality in Health Care Contexts (London: Jessica Kingsley, 2001), 41.

²⁵ Throughout this thesis when I use the term ritual I use it to relate to liturgically-based ritual.

confusion, in *section* 2.2.2 I provide a detailed picture of how I understand the terms religion and spirituality. Religion is defined as a system of belief and worship that expresses an underlying spirituality, with spirituality understood as relating to issues of meaning and selfhood, particularly with respect to relationships. Having commented on the reductionist nature of much health research, in *section* 2.2.3 I introduce the small but increasing body of research that recognises the importance of narrative within this context. Again, drawing on personal experience and related reading, I suggest that chaplains are well placed to engage in narrative research with the aim of evidencing the often hidden patient story. Recognising how a qualitative research design allows a broader and deeper picture to emerge, in *section* 2.3 I conclude the chapter by describing how I came to the decision to carry out hermeneutical narrative based research with parents.

Having decided on which area to research, in chapter three I undertake a literature review of research relating to bereaved parents. This begins with comments on the Stillbirth and Neonatal Death Society (Sands) guidelines which are seen as the benchmark for good practice following pregnancy loss.²⁶ Chaplaincy is only briefly mentioned, but the value of liturgy and ritual is acknowledged. From research carried out by the DIPEx Charity²⁷ I note how parents valued chaplains because they did not attempt to 'fix everything.' This is an intriguing finding that I draw upon at several points during the thesis. Next, in section 3.1.3 I discuss the NICE guidelines Antenatal and Postnatal Mental Health. In particular, I critique the statement that parents should not be encouraged to see and hold their dead baby. Following this, in section 3.1.5 I outline how research with parents has led to the development of new theories of grief and bereavement, including that of continuing bonds. After highlighting, again, the importance of the subjective voice, in section 3.2 I provide an overview of the principle UK based source looking at the work of chaplains with bereaved parents, Ewan Kelly's Marking Small Lives. Key to Kelly's findings is the notion of how the co-creation of liturgy and ritual helps meet the spiritual need of parents. By co-creation Kelly means the practice of parents working with chaplains to personalise and shape rites and rituals. In

²⁶ Within the thesis pregnancy loss is taken to refer to stillbirth, miscarriage, termination for fetal abnormality and neonatal death.

²⁷ DIPEx stands for Database of Individual Patients' Experience of illness. The research was carried out by the Health Experiences Research Group at University of Oxford.

addition, I call attention to the poor expectations that parents had of chaplains. This work is drawn heavily on through the remainder of the thesis as the only direct comparison to my research. Finally, in *section* 3.3 I present the aims of my study. These are: to see if Kelly's findings could be replicated; to discern if particular parts of chaplaincy support were more important than others; and to understand better the beliefs and expectations that parents hold about chaplains.

Before turning to my findings, in chapter four I detail the methodology used and describe the study design. Starting in section 4.1 I sketch out how I have used the pastoral cycle and my decision, within the empirical research, to utilise hermeneutic phenomenology as a way to evidence lived experience. In section 4.2 I open by explaining my reasoning for selecting semi-structured interviews to gather data. Because studies looking at bereavement in relation to spiritual or religious belief and practice are often criticised for not using validated measurement tools, I also relate my decision to use the self-report Royal Free Questionnaire for Spiritual and Religious Beliefs (RFQ)²⁸ to provide greater contextual understanding. This is followed by a description of the inductive approach to analysis that I took; using a form of grounded theory called constant comparison. In relation to recruitment and selection, as part of section 4.2.1 I set out my reasons for including within the study parents that I had supported personally as a chaplain - a noticeable difference between myself and Kelly. I then close the chapter with brief comments on possible limitations of the study design.

Having traced my journey to carrying out research and set out my methodology, in chapter five I turn to my findings. This is initiated in *section* 5.1 with a précis of the demographic differences between Kelly's and my participants. Amongst the variances, as factors that may affect our findings, I pick out the level of social deprivation, and how long parents had been bereaved. This is followed by a breakdown of the answers given in the RFQ. Parents articulated a wide variety of belief and practice with some holding apparently contradictory convictions. Rather than being a result of problems with the questionnaire, I argue that this reflects wider societal trends towards

²⁸ Michael King, Peter Speck, and Angela Thomas, 'The Royal Free Interview for Spiritual and Religious Beliefs: Development and Validation of a Self-Report Version', *Psychological Medicine* 31, no. 6 (2001).

people forming individual and subjective spiritualities. Where they provide helpful insight or wider context, I link to both demographic details and data from the RFQ throughout my findings.

While recognising that each parent's experience was unique, in *section* 5.2 I set out the four commonly held themes of spiritual need that I identified. These are a loss of control, a loss of meaning, a loss of self worth, and a desire to do something in response to their loss. The first three of these are themes discerned by Kelly, whilst the latter is a theme I have singled out. Parents in my study differed from those in Kelly's with regard to the sense of isolation that they felt. Exploring possible reasons for this, I suggest length of time bereaved and parents' personality type. After this, in *section* 5.3 I move to describe how the liturgy and ritual provided by chaplains helped meet each of the themes of spiritual need identified. At a general level I note how the simple act of choosing to have a ceremony gave control back to parents, and allowed them to 'do something.' Alongside this, I also highlight the importance parents placed on mementos of the ceremonies.

As I analysed my interviews it became clear that there was not a one size fits all response. Instead, chaplains had varied their support to fit with each parent's need. Summarised as a desire for 'options' or 'authoritative action', I explore the differing desires of parents in section 5.4. Having argued that co-creation may not be appropriate for all parents, I outline the need for chaplains to make rapid decisions as to what type of support parents wished for. Mercifully, contrary to the poor expectations which are set out in section 5.5, parents actual experience of chaplaincy was largely positive. Their apprehension, however, raised the intriguing question of why they wanted chaplaincy support in the first instance. Drawing on the writing of Douglas Davies and John Austin, in section 5.6 I suggest this is due to two connected reasons. The first is the ability to perform liturgy and ritual. The second is that chaplains are viewed as having both religious authority concerning the eternal destiny of a baby and also in spiritual matters pertaining to selfhood and identity. Following this, in section 5.7 I consider how insights from anthropology concerning ritual help illuminate aspects of the chaplains role and identity. This leads to section 5.8 and an examination of intuition, which I suggest may be significant in helping chaplains make almost instantaneous decisions.

A major theme that developed out of my analysis was the way that liturgy and ritual was appreciated, not in isolation, but in conjunction with the presence of the chaplain who performed it. This was implicit in much of the preceding chapter, but in chapter six I develop it in detail. I begin in section 6.1 by setting out the ways that parents valued the presence of a chaplain. Particularly important was attentive listening that made them feel treated as individuals. Interestingly, although they were not with them the whole time, parents often conceived of chaplains as a constant or consistent presence. Parents also spoke about how the presence of a chaplain brought them comfort and strength. Arising from this, in just a short time, parents could develop strong bonds with a chaplain. I discuss reasons for this in section 6.2 by making connections with insights from attachment and community theory. Recognising that these relationships form in the context of emotionally demanding situations, in section 6.2.3 I call attention to the need for chaplains to exercise self-care and, in order to avoid burnout or compassion fatigue, to disengage from those they have been supporting

Turning from a concentration on the presence of a chaplain, in section 6.3 I introduce what was, for me, an unexpected finding. As a result of their experience and the support provided by a chaplain, some parents found greater religious faith or increased spiritual awareness. In describing the varying forms that this took I note how, once again, it is difficult to separate out factors relating to the liturgy and ritual provided, and those relating to the presence of the chaplain. Recalling that there is a persistent theme within the Judeo-Christian tradition that suffering can be the prelude to a deeper spirituality, in section 6.3.2 I explore parents' comments in relation to James Fowler's theory of stages of faith. Noting criticisms of Fowler's theory, I outline how I take a flexible and non-linear viewpoint commenting that, whatever view of faith stages is taken, it is not hard to see how the death of their baby can cause parents to question previously held world views. Further drawing on Fowler, I call attention to the way that there are strong resonances between the way parents recounted chaplains relating to them and descriptions of faith in Stage 5.

Resulting from the understanding that the presence of a chaplain being with parents is as important to them as the liturgy and ritual performed, in chapter seven I make a connection with virtue ethics. This consideration of a virtuebased approach to chaplaincy is, I believe, unique in the literature. In addition to setting out key terms, I begin this exploration in section 7.1 by observing how, in virtue ethics, character is seen as central to judging the rightness of an action. Following this, in section 7.2 I move to describe why a virtue-based approach has much to offer chaplaincy. In the complex environment of supporting parents, I suggest that, rather than following principles, the chaplain's character can guide them to know the right way to respond. Alongside proposing that the habituation of appropriate virtues is a way to understand the use of intuition, I also explore the use of emotion in virtue ethics. As a way of understanding how character acts as the driver for decisionmaking, in section 7.3 I discuss the notion of a regulative idea. I note how this can include, but should go beyond, codes of conduct, and the way that it ought to relate to widely held understandings of human flourishing. Within this section I also describe how there is a hierarchy of regulative ideals, with certain virtues exercising a regulative role over others. In section 7.4 I turn to explore what might be a distinctively Christian regulative ideal for chaplains supporting parents. Drawing on my interviews, I suggest the aim of engendering an encounter with hope. Developing this, I describe how such 'hope' must be able to embrace the pain and brokenness felt by parents, and explore it further in relation to notions of presence and quest.

Having set out various concepts that relate to a virtue-based approach, in *section* 7.5 I move to look at some of the virtues that, I believe, should form the character of a chaplain. Instead of providing an exhaustive list, along with practical wisdom, widely regarded as the rudder that guides all virtues, I outline three further virtues that I believe play a central role in determining how and when other virtues may be applied. These regulating virtues are attentiveness, openness, and probity. In *section* 7.6 I turn to discuss what a virtue-based approach might mean for the training and development of chaplains. Virtue ethics views an action as right if it is what a virtuous person would do. Accordingly, virtue and wisdom are learned by observing the virtuous. Commenting on the apparent lack of practical elements within chaplaincy courses, and how little is known about how chaplains carry out

interventions, I argue for the increased use of shadowing and mentoring at all levels.

Chaplains are connected with and participators in a number of different bodies. In chapter eight I present my conclusions and recommendations in relation to the community to which they are most pertinent. These could perhaps be encapsulated as a plea to each community to take chaplaincy seriously. Firstly, however, in section 8.1 I summarise my findings relating to the spiritual need parents exhibited and how they valued chaplaincy support. In relation to the health service in section 8.2, among other conclusions, I argue for the continued employment of chaplains and for the narrative voice to be valued alongside quantitative research. I also state, in opposition to the NICE guidelines, that I believe parents should be offered the opportunity to see and hold their dead baby. Christian chaplains often sit on the margins of the churches that they are authorised by, yet have a richness of reflection and experience they could offer to them. Accordingly, in section 8.3 I appeal to churches to engage more profoundly with chaplains. Finally, in section 8.4 I make a number of recommendations to the chaplaincy community. Alongside suggesting learning about nonverbal communication, most of these are aimed at gaining greater insight into the virtues and attributes necessary for chaplaincy, and how chaplains both conceive of and carry out their interventions.

2 <u>The Role and Skills of a Chaplain and How</u> <u>Chaplaincy Might Best be Evidenced</u>

As I described in *section* 1.1 there is very little written about the work of chaplains, and even less on the efficacy of chaplaincy practice. In his 1946 handbook *Visiting the Hospital* Bernard Wall relates the following tale:

A Chaplain once went onto a ward and was waiting for the Sister, when he happened to overhear a new patient ask his neighbour, "Who is this fellow?"

"He's the Hospital Chaplain," replied the neighbour.

"Oh," said the first speaker, "and what's he come for?"29

On a similar theme Orchard begins her investigation into hospital chaplaincy by juxtaposing two quotations, one from 1968 and one from 1999, both asking fundamental questions about the purpose and function of chaplaincy within the NHS.³⁰ Over a decade later, particularly within England and Wales, there continues to be no consensus answer to the question, as Swift puts it, of 'what the chaplain has come for – and what his or her presence beside the patient is intended to achieve.'³¹ Accordingly, as I put my research proposal together, my first task was to provide my own answer to that question. Based on reflections on my own practice and wider reading, section 2.1 sets out my understanding of the role and skills of a chaplain. Having completed this, in section 2.2 I turn to explore how the efficacy of chaplains might best be evidenced. This section begins by noting the reductionist nature of much research investigating links between religion, spirituality and health. After setting out my understanding of the terms 'religion' and 'spirituality', I turn to the developing discipline of narrative research and suggest that chaplains are well placed to provide the human story absent from much of modern medicine. Finally, pulling together themes from the preceding two sections, section 2.3 concludes the chapter by describing the thought process that led to my decision to carry out research with parents.

²⁹ Bernard Wall, Visiting the Hospital: A Practical Handbook for Hospital Chaplains and Clergy Who Visit Hospitals (London: Mowbray, 1946), 9.

³⁰ Orchard, Hospital Chaplaincy, 9.

³¹ Swift, 'The Function of the Chaplain', 213.

2.1 The Role and Skills of a Chaplain

I entered full-time healthcare chaplaincy in September 2006 when I took up a job at STH. Foundational in my understanding of the nature of chaplaincy has been my involvement in providing pastoral and spiritual care to a patient called Adrian on the leukaemia unit.³² My reflections on that provision have been published in several places and much of the material in this section is drawn from those publications.³³

2.1.1 Accompanying people through times of transition

As a result of his research into chaplaincy, Michael Wilson described the hospital as 'a place of conflict and truth.'³⁴ People are often suddenly brought face to face with the ultimate questions about life and meaning. Frequently, what they have always felt or thought no longer seems to make sense, their vision of the future is shattered, and the narrative by which they understand their life breaks down. Edmund Pellegrino and David Thomasma describe how, when a person suffers, they experience:

- **1.** Finitude: an intimation of their own mortality.
- 2. Vulnerability: an exposure of self to the power of others.
- **3.** Dissolution: a fracturing of their own personhood.
- **4.** Disruption: a destruction of normal family and community life.³⁵

Reading his blog, it is clear that the experience of hospitalisation and isolation invoked all of these experiences in Adrian.³⁶ They are experiences common to many patients and my involvement with Adrian was typical of much chaplaincy work. Such work is perhaps best classified under the title 'pastoral care.' Here, it is important to differentiate between 'pastoral care' and 'pastoral counselling.' Although, as Alan Boyd and Gordon Lynch note, there can be a considerable degree of overlap in the skills used in each domain, there is a key difference in the way that boundaries are structured.³⁷ In pastoral counselling,

³² Because I make reference to his blog it would be difficult to pseudonomize Adrian's details as would be normal. Before he died Adrian gave me permission to use his name and personal correspondence.

³³ Mark Newitt, 'Hospital Chaplaincy Services Are Not Only for Religious Patients', BMJ 338 (2010); 'The Role and Skills of a Hospital Chaplain: Reflections Based on a Case Study', *Practical Theology* 3, no. 2 (2010); 'The Role and Skills of a Chaplain', in Miranda Threlfall-Holmes and Mark Newitt (eds.), *Being a Chaplain* (London: SPCK, 2011).

³⁴ Michael Wilson, 'The Hospital - a Place of Truth' (Report, Birmingham, 1971), 57.

³⁵ Edmund D. Pellegrino and David C. Thomasma, *Helping and Healing* (Washington DC: Georgetown University Press, 1997).

³⁶ Adrian Sudbury, Baldy's Blog, <u>http://baldyblog.freshblogs.co.uk/</u> cf. particularly archived entries for March 2007 to July 2008.

³⁷ Alan Boyd and Gordon Lynch, 'Establishing the Therapeutic Frame', in Gordon Lynch (ed.), *Clinical Counselling in Pastoral Settings* (London: Routledge 1999), 70.

the relationship is based around an explicitly agreed, firm set of boundaries. However, as with Adrian and myself, in pastoral care boundaries are typically left unspoken and are more flexible. This does not mean that pastoral care is inferior to pastoral counselling. Far from being a 'Mickey Mouse' form of counselling, David Lyall argues that pastoral care should be seen as a discipline in its own right.³⁸ Lyall sets out his definition of pastoral care in some detail, and it is worth reproducing the opening paragraph:

Pastoral care involves the establishment of a relationship or relationships whose purpose may encompass support in a time of trouble and personal and/or spiritual growth through deeper understanding of oneself, others, and/or God. Pastoral care will have at its heart the affirmation of meaning and worth of persons and will endeavour to strengthen their ability to respond creatively to whatever life brings.³⁹

This definition matches well the progression of my care with Adrian. Early visits and general conversation helped build up a relationship of trust. Following this, echoing the definition, I was able to work at a deeper level helping Adrian make sense of what was going on in relation to himself and his understanding of the world, and to find sources of strength and hope. Looking back at my involvement with Adrian I would say that, overall, the aim was to support him through times of transition by rediscovering, as Rachael Stanworth puts it, 'a sense of personal wholeness and interconnectedness where "the personal" carries a more expansive and inclusive meaning than mere "individualism".'⁴⁰ Initially, this meant helping him through the changes associated with his treatment and then, latterly, the move from life to death.

While some literature highlights a lack of clarity among chaplains as to their role,⁴¹ the task of accompanying people through times of transition is highlighted by both practitioners and commentators writing about chaplaincy. Writing in 1971, Wilson describes the chaplain as an adventurer who 'explores the dangerous territory of man's making and breaking.'⁴² More recently, drawing on his linguistic background and noting the various gaps that a

³⁸ David Lyall, Integrity of Pastoral Care (London: SPCK, 2001), 20.

³⁹ Lyall, Integrity of Pastoral Care, 12.

⁴⁰ Rachel Stanworth, Recognising Spiritual Needs in People Who Are Dying (Oxford: Oxford University Press, 2004), 224.

⁴¹ Caring for the Spirit NHS Project, 'Caring for the Spirit'; Derek J Fraser, 'Clarity and Cost Effectiveness in Chaplaincy', Scottish Journal of Healthcare Chaplaincy 7, no. 1 (2004); Orchard, Hospital Chaplaincy.

⁴² Wilson, 'The Hospital', 57.

chaplain can be called to stand in, Iain Macritchie suggests a model of the chaplain as translator occupying the 'uncomfortable space between', with the task of the chaplain as being alongside 'those in translation.'⁴³ Again, emphasising themes of transition, Mark Cobb writes of the chaplain's context as one 'which is primarily related to change; of restoring people's health, or enabling people to adapt to impaired physical function, or supporting people as their irreparable bodies fail and die.'⁴⁴

2.1.2 Attentive listeners

What tools, though, does a chaplain bring to help people through such transitions? During Adrian's time in isolation I mainly used what can best be classified as counselling skills. Showing empathy and unconditional positive regard enables the quick development of trust. As Ladislaus Boros comments, 'if someone in the goodness of his heart, without passing judgement, approaches us reverently, we feel "clothed" and protected by his goodwill.'⁴⁵ Hospital patients can often spend a great deal of time talking to themselves. Ruminating in this way, it is very easy for the mind to run away with itself and imagine all the worst-case scenarios. Skills associated with active listening enable a patient to tell their story and engage in conversation with another. Mary Wolfe puts it well when she writes:

through conversation we turn around our ideas and experiences with each other... and we thereby also review those ideas and experiences... conversation provides us with one way in which either to revisit our experiences or to entertain possibilities of future experiences.⁴⁶

Noticeably, a chaplain is one of the few people to whom a patient is able to tell 'the story' of what is happening. This is not to say that medical staff and other allied health professionals are incapable of listening. It is, though, to recognise that, by coming with a therapeutic agenda, they have an input into the narrative in a way that a chaplain, responding to need as presented, does not. As Harriet Mowat and John Swinton suggest, 'chaplaincy is arguably one of the few roles within the hospital that could truly be needs-led.'⁴⁷

 ⁴³ Iain Macritchie, 'The Chaplain as Translator', Journal of Religion and Health 40 (2001), 206.
 ⁴⁴ Mark Cobb, 'Change and Challenge: The Dynamic of Chaplaincy', Scottish Journal of Healthcare Chaplaincy 10, no. 1 (2007), 4.

⁴⁵ Ladislaus Boros, Being a Christian Today (London: Geoffrey Chapman 1979), 65.

⁴⁶ Mary Wolfe, 'Conversation', in Linda Deer Richardson and Mary Wolfe (eds.), Principles and Practice of Informal Education: Learning through Life (Oxford: RoutledgeFalmer, 2001), 126.
⁴⁷ Harriet Mowat and John Swinton, What Do Chaplains Do? The Role of the Chaplain in Meeting the Spiritual Needs of Patients (Aberdeen: Mowat Research, 2005), 34.

Closely linked to active listening is the gift of attending. Simone Weil writes:

Those who are unhappy have no need for anything in this world but people capable of giving them their attention. The capacity to give one's attention to a sufferer is a very rare and difficult thing; it is almost a miracle; it *is* a miracle. Nearly all those who think they have this capacity do not possess it. Warmth of heart, impulsiveness, pity are not enough.⁴⁸

The way that we look upon someone else is one of those almost imperceptible signals that can be the making or breaking of an encounter. M. Scott Peck offers the analogy of looking at each other through 'soft eyes' as shorthand for regarding people with respect, rather than with distrust, fear, resentment or prejudice. To look at someone with soft eyes, he suggests, is to 'see the suffering and courage and brokenness and deeper dignity beneath.'⁴⁹ John Ruskin famously said, 'to be taught to see is to gain word and thought at once, and both true.'⁵⁰ Chaplains are, in many ways, akin to artists in their practice. Like the artist, the chaplain is called to give attention to familiar situations, to see beyond them or see them differently, and to engage more deeply with the humanity and spirituality within them.

2.1.3 Trained in pastoral theology

If chaplains only needed to be good listeners, with the gift of attending, it might be asked why not just employ people with appropriate listening skills? As a counsellor, Carl Rogers believed that, when certain necessary and sufficient conditions were expressed within a therapeutic relationship, significant learning or constructive change takes place.⁵¹ In contrast, while recognising that 'some clients seem to need only the opportunity to tell their stories',⁵² Gerard Egan's viewpoint was that these core conditions are not enough on their own and that clients need help in setting decisions, goals and plans.⁵³ While I reiterate that chaplains are not counsellors, there can be, as stated in *section* 2.1.1, an appreciable overlap between pastoral care and pastoral counselling. As

⁴⁸ Simone Weil, *Waiting for God*, trans. Emma Craufurd (New York: Harper Perennial Modern Classics, 2009), 64.

⁴⁹ M. Scott Peck, The Different Drum: Community Making and Peace (London: Arrow Books, 1987), 69.

⁵⁰ John Ruskin, 'Cambridge School of Art: Inaugural Address (1858)', in Dianah Birch (ed.), John Ruskin Selected Writings (Oxford: Oxford University Press, 2004), 95.

⁵¹ Carl R. Rogers, On Becoming a Person: A Therapist's View of Psychotherapy (London: Constable, 1967), 281-85.

⁵² Gerard Egan, The Skilled Helper: A Problem-Management and Opportunity-Development Approach to Helping (Belmont CA: Thomson Brooks/Cole, 8th ed. 2007), 231.

⁵³ Egan, The Skilled Helper, 1-28.

patients wrestle with an awareness of their mortality, or seek to reconnect with their sense of self, or attempt to develop new perspectives on their situation, they may well want to explore and debate issues rather than just be listened to. Accordingly, as Stanworth rightly comments, 'it is hard to see how I can accompany anyone facing deep questions of meaning and identity without some prior contemplation of my own personhood.'54 To help patients explore their spiritual story, chaplains need, therefore, to develop the capacity for deepseated theological reflection on lived experience that comes from a training in pastoral theology. It is important to recognise that, while hospital chaplaincy teams can be both ecumenical and multi-faith, the requirement to combine pastoral and theological expertise is widespread. The person specification for my position, for example, required the theological qualifications that came with being ordained or accredited by a nationally recognised church, and three years experience in a ministry of pastoral care. Similarly, alongside training in the Holy Qur'an and Islamic Law, the specification for our Muslim chaplain required three years employment in a community role or pastoral care position.

In combining such training and experience I do not see my task as being to tell people what to think, but rather to help them explore and think for themselves. Sherly Williams illustrates this point using a passage from *Winnie-the-Pooh* where Christopher Robin was able to help Pooh to new insight because he was in a different position from Pooh and therefore could see something not available to Pooh. From his vantage point Christopher Robin was able to share 'what he saw - not as judgement, but as information that could be shared for the other to reflect upon; not as "I know it differently from you and perhaps that could be useful to you".'55

This is a particularly vital role for patients who do not belong to and/or believe in a particular faith tradition. The latter half of the previous century has seen a marked change in the public's attitude to organised religion. At best this may be referred to as a move to 'believing without belonging.'⁵⁶ A more sceptical account is given by Steve Bruce that might be summarised as not

⁵⁴ Stanworth, Recognising Spiritual Needs, 229.

⁵⁵ Sherly Williams, 'The Therapist as Outsider: The Truth of the Stranger', British Journal of Psychotherapy 16, no. 1 (1999), 6.

⁵⁶ Grace Davie, Religion in Britain since 1945: Believing without Belonging (Oxford: Blackwell, 1994).

believing and not belonging.⁵⁷ Whichever view is taken, there has been a sharp decline in church attendance over the past sixty years.⁵⁸ However, as Paul Heelas and Linda Woodhead describe in The Spiritual Revolution, this does not mean that people are no longer interested in 'enriching one's experiences; in finding ways of handling negative emotions; in becoming sensitive enough to find out where and how the quality of one's life - alone or in relation - may be improved.'59 Such research findings are particularly important in light of a report published by the National Secular Society in April 2009. This argues that chaplaincy services are an 'irrelevance' for most people and recommends that public funding for chaplains be phased out and that 'clerics' from a patient's 'own place of worship' be called out when required.⁶⁰ The report can be challenged on several levels. Firstly, it trades on a particular understanding of secularisation which sees religion in terminal decline. However, drawing on Charles Taylor's work A Secular Age, and his own experience as a chaplain, Swift argues that 'it is a mistake to equate the decline of religious authority with the demise of religious longings and spiritual desire.^{'61} Secondly, the report takes no account of the research literature on the role of spirituality in healthcare. It is, in fact, widely recognised that patients draw upon their spirituality in relation to various issues, for example, psychological well-being, illness adaptation, coping and quality of life.62

While it may be the case that those with a link to a faith community can call upon a known 'cleric', the problem, as noted by Michael King *et al.* when looking at measuring people's spiritual beliefs, is that 'people with no religious affiliation find it difficult to express their spiritual beliefs and experiences.'⁶³

⁵⁷ Steve Bruce, God Is Dead: Secularization in the West (Oxford: Blackwell, 2002).

⁵⁸ Cf. Robin Gill, The 'Empty' Church Revisited (Aldershot: Ashgate, 2003); Bob Jackson, Hope for the Church: Contemporary Strategies for Growth (London: Church House Publishing, 2002).
⁵⁹ Paul Heelas and Linda Woodhead, The Spiritual Revolution: Why Religion Is Giving Way to Spirituality (Oxford: Blackwell Publishing, 2005), 4.

⁶⁰ National Secular Society, 'An Investigation into the Cost of the National Health Service's Chaplaincy Provision' (Report, London, 2009), <u>http://www.secularism.org.uk/uploads/3549db17aa47a28474059911.pdf</u>, [accessed 5 October 2009]

⁶¹ Christopher Swift, Hospital Chaplaincy in the Twenty-First Century: The Crisis of Spiritual Care on the NHS (Farnham: Ashgate, 2009), 169.

⁶² Russell D'Souza, 'The Importance of Spirituality in Medicine and Its Application to Clinical Practice', *Medical Journal of Australia* 186, no. 10 (2007); Harold G. Koenig, 'Religion, Spirituality, and Medicine: Research Findings and Implications for Clinical Practice', *Southern Medical Journal* 97, no. 12 (2004); Paul S. Mueller, David J. Plevak, and Teresa A. Rummans, 'Religious Involvement, Spirituality, and Medicine: Implications for Clinical Practice', *Mayo Clin Proc* 76, no. 12 (2001); Scott A. Murray *et al.*, 'Exploring the Spiritual Needs of People Dying of Lung Cancer or Heart Failure: A Prospective Qualitative Interview Study of Patients and Their Carers', *Palliative Medicine* 18, no. 1 (2004).

⁶³ Michael King *et al.*, 'Measuring Spiritual Belief: Development and Standardization of a Beliefs and Values Scale', *Psychological Medicine* 36, no. 3 (2006), 424.

Accordingly, decline in orthodox religious expression far from removing the need for chaplains may actually generate a need for chaplains who, as skilful interpreters, 'listen openly, and respond creatively, to personal spiritualities.'⁶⁴

2.1.4 Skilled in handling liturgy and ritual

In early 2010 the Doonesbury comic strip, written by Garry Trudeau, introduced a new character, a female army chaplain. In one strip, having been called to the hospital, the chaplain is grateful to discover that the soldier will recover. However, having given the good news, the medic continues by saying that the soldier was worried he would not be eligible for rites as he is from a multi-faith family. The chaplain answers that something could have been sorted out. Amazed, the medic asks 'You do mash-ups?', to which the chaplain responds, 'It's not pretty, but yeah.'65 Although the context might be different, such a scene would, one suspects, resonate with many chaplains. Writing about taking children's funerals, Bill Burleigh, for example, states the need for 'huge flexibility' and combining 'balloons, poems and fairy dust' with a 'gently worded prayer of commendation.⁶⁶ Using liturgy and ritual to help patients mark important moments and events requires more skill than simply reading text from a page. While I have various liturgical resources on my shelves, none contain a form of prayer for making peace with 'a God I've never even been sure if I believe in' as I have been asked to facilitate.67

If, as I suggest, much of the work of chaplains is about helping people through times of transition, then it is not surprising that liturgy and ritual is important. Writing from an anthropological perspective, as part of his understand of ritual Timothy Jenkins describes it as 'often to do with transition.'⁶⁸ Its use in helping people through difficult times is attested in other writing. David Hodge, for example, notes how rituals 'serve to ease anxiety and dread, alleviate isolation, promote a sense of security, and establish a sense of being loved and appreciated.'⁶⁹ The importance of such skills to a chaplain can be seen by the

⁶⁴ Swift, Hospital Chaplaincy, 135.

⁶⁵ Gary Trudeau, *Doonesbury*, [Cartoon] (May 2010), <u>http://www.gocomics.com/doonesbury/</u>2010/05/18. [accessed 20 September 2010]

⁶⁶ Bill Burleigh, 'Sheffield Children's Hospital NHS Foundation Trust', in Threlfall-Holmes and Newitt (eds.), *Being a Chaplain*, 49.

⁶⁷ Adrian Sudbury, email to the author, 14 May 2008.

⁶⁸ Timothy Jenkins, An Experiment in Providence: How Faith Engages with the World (London: SPCK, 2006), 38.

⁶⁹ David R. Hodge, 'Spiritual Assessment: A Review of Major Qualitative Methods and a New Framework for Assessing Spirituality', *Social Work* 46, no. 3 (2001), 209.

fact that in his handbook for hospital chaplains, Cobb dedicates a whole chapter to liturgy and ritual.⁷⁰ Accordingly, there is a need to be creative in designing liturgy and ritual so that it is appropriate to different situations. It is a capability that Swift alludes to in an almost throwaway line, commenting that others in the healthcare setting do not have 'this ability to handle ancient words (and invent a few new ones on occasions!).'⁷¹ The artistry required in handing liturgy and ritual provides a further reason for the employment of chaplains, rather than simply someone who is a good listener.

Although I am not investigating the nature of ritual it is worth giving a brief statement of my theoretical understanding. Roy Rappaport, in his majestic *Ritual and Religion in the Making of Humanity*, argues that ritual is a form of communication. He contends that, 'ritual is not simply an alternative way to express any manner of thing, but that certain meanings and effects can best, or even *only*, be expressed or achieved in ritual.'⁷² He continues by stating that, while the boundary is not sharp or clear, ritual's efficacy may be understood as physical, through the deployment of matter and energy, or meaningful, grounded in principles of communication.⁷³ Importantly, Rappaport cautions that:

To distinguish between the domains in which the physical and meaningful prevail is not to declare that the boundary between them is sharp or clear. It is unlikely that any sea has ever been parted by prayer or turned back by command, and we may be equally confident that no prince has ever been transformed into a king, no man and woman into husband and wife, by matter and energy alone. But prayer as well as drugs may have an effect upon the physical well-being of those praying and even upon the health of those for whose sakes prayers are offered.⁷⁴

The description of ritual as communication is supported by writing from a more sacramental perspective. John Macquarrie suggests that we live in a sacramental universe where the material world 'can become a door or channel of communication, through which he [God] comes to us and we may go to him.'⁷⁵ Macquarrie also distinguishes between the sacrament's outward part,

⁷⁰ Mark Cobb, 'Liturgy and Ritual', Chap. 9, *The Hospital Chaplains' Handbook: A Guide for Good Practice*, (Norwich: Canterbury Press, 2005).

⁷¹ Swift, 'The Function of the Chaplain', 89.

⁷² Roy A. Rappaport, *Ritual and Religion in the Making of Humanity* (Cambridge: Cambridge University Press, 1999), 30.

⁷³ Rappaport, Ritual and Religion in the Making of Humanity, 113.

⁷⁴ Rappaport, Ritual and Religion in the Making of Humanity, 113.

⁷⁵ John Macquarrie, A Guide to the Sacraments (London: SCM Press, 1997), 6.

relating to matter and form, and its inward part which 'effects its reality in the life of the believer.'⁷⁶

While the exact nature of ritual is contested, there is much consensus regarding its role in pastoral situations. Davies asserts that, rather than being a code to be cracked for its meaning, ritual is something performed as an end in itself and 'its meaning lies in the very act of performance.'77 Linked to that, Elaine Ramshaw argues that one of the functions of ritual, in a pastoral context, is to reaffirm meaning and purpose at times of transition or tragedy.⁷⁸ This understanding, that ritual helps us communicate meaning, particularly in situations where we struggle to find the appropriate words, is echoed by Herbert Anderson and Edward Foley. In their excellent book exploring narrative and ritual, they suggest that, 'to be a human being is to ritualise the human narrative and... ritual is actually the way we access and enter the human story.⁷⁹ Like Davies, they too see performance as integral, where 'ritual is embodied expression.'80 These various strands of thought on ritual may be drawn together in Kelly's statement that ritual is, 'a mechanism by which people's wrestling and searching and struggling can be verbalised and validated by another or others, and acted out by some if not all.'81

2.1.5 Critical, creative, and reflexive thinkers

The understanding I have set out of 'what a chaplain comes for' illustrates a challenging and demanding vocation that requires a high degree of expertise and proficiency. This is starkly at odds with a reflection on the role of the chaplain provided by Orchard following her research into the work of chaplains in London:

One site had a particularly well thought through "empty handed" approach, which characterised the practice of the Anglican and Free Church chaplains and their view about the contribution of others. Care was described as being "not about dispensing spiritual nuggets". If this is the case, then one need have no nuggets to dispense – anyone can go in empty handed. Conversely, if the role is closely aligned with

⁷⁶ Macquarrie, A Guide to the Sacraments, 47.

⁷⁷ Douglas J. Davies, Anthropology and Theology (Oxford: Berg, 2002), 113.

⁷⁸ Elaine Ramshaw, Ritual and Pastoral Care (Philadelphia: Fortress Press, 1987), 25-26.

⁷⁹ Herbert Anderson and Edward Foley, Mighty Stories, Dangerous Rituals: Weaving Together the Human and the Divine (San Francisco: Jossey-Bass, 1998), 26-27.

⁸⁰ Anderson and Foley, Mighty Stories, Dangerous Rituals, 27.

⁸¹ Ewan Kelly, Marking Short Lives: Constructing and Sharing Rituals Following Pregnancy Loss (Oxford: Peter Lang, 2007), 110.

religion, then there are requirements on the part of the caregiver. If not nuggets to dispense, then specialist knowledge: facts about ritual, creed, practice and the like. And while a person can be an expert in matters of religion, the "empty handed" approach requires no expertise; indeed it is not possible to be *the* expert on matters spiritual, as no one has the full facts, answers, or truth.⁸²

It is certainly true, as recognised by both past and current chaplains, that we should not arrive at the bedside with pre-prescribed solutions to pre-perceived problems.⁸³ In this way, the chaplain must indeed come empty handed. However, Swift is correct to challenge Orchard's assertion that anyone can go in empty handed; in any pastoral situation our hands are full of unspoken signals - dress, titles, expectations - that cannot be put down and influence the encounter.⁸⁴ Chaplains are, as Swinton and Mowat state of researchers, not only co-creators of the mode and content of an encounter, but also the story that is told within it. For this reason, chaplains need to be critically self-aware, developing the reflexivity to identify and reflect critically upon the ways in which they may have shaped an encounter.⁸⁵

Alongside reflexivity, chaplains need to be critical and creative thinkers. Norman Autton argues that chaplains must be rooted and grounded theologically if they are to respond successfully to the baffling situations they encounter.⁸⁶ This view is endorsed by Macritchie, who states that the hospital is no place for a chaplain who does not have a theology of suffering and healing. However, he also recognises the need for creativity, pleading for 'a sense of theology as toy, a sense of being allowed to play with theology and enjoy it, even have fun with it!'⁸⁷ The imagination of chaplains in responding to human need is acknowledged by Cobb. He is critical, though, of how often ingenuity is justified on pastoral rather than theological grounds and reminds chaplains of the importance of remaining 'alert to the theological task of self-conscious critical thinking, inquiry and interpretation.'⁸⁸ Here, reinforcing the need to combine pastoral gifts with theological knowledge, there is a tension

⁸² Orchard, Hospital Chaplaincy, 139.

⁸³ Norman Autton, Pastoral Care in Hospitals (London: SPCK, 1968), 293; Swift, 'The Function of the Chaplain', 194-96; Wilson, 'The Hospital', 293.

⁸⁴ Swift, 'The Function of the Chaplain', 213.

⁸⁵ John Swinton and Harriet Mowat, Practical Theology and Qualitative Research (London: SCM Press, 2006), 58-61.

⁸⁶ Autton, Pastoral Care, 126.

⁸⁷ Macritchie, 'The Chaplain as Translator', 208.

⁸⁸ Cobb, 'Change and Challenge', 9.

'between the necessity of study and training on the one hand and of originality and creativity on the other.'⁸⁹

Patients in hospital can suffer a combination of finitude, vulnerability, dissolution and disruption, as much of what they believed about the world and their own sense of personal identity are challenged. In the provision of pastoral and spiritual care, chaplains support them through difficult times or times of transition. By attending to the stories of patients' lives, chaplains help them seek meaning and hope, connect with what really matters in their life, and mark important moments and events. In carrying out their work, chaplains require a deep well of resources that they might draw upon. From a biblical perspective they need to be like 'the master of a household who brings out of his treasure what is new and what is old.^{'90} A more unorthodox metaphor might be the 'Room of Requirement' in Hogwarts School; a magical room 'always equipped for the seeker's needs' which, therefore, might be viewed as containing everything and nothing.⁹¹ Far from relying on magic, or requiring 'no expertise', chaplains, however, require a high degree of specific expertise and proficiencies. In listening and building relationships of trust, chaplains use counselling skills such as empathy and unconditional positive regard. Importantly, though, chaplains need more skills than simply being good listeners. The offering of a spiritual perspective requires a grounding in pastoral theology. Alongside this, chaplains also need to be able to use liturgy and ritual with creativity and imagination. With this as my understanding of the role and skills required, I turn to the questions of the links between religion, spirituality and health and how the benefit of chaplaincy support may best be evidenced.

2.2 Research Investigating Religion, Spirituality and Health

While there is very little written directly on or about chaplaincy, there is an ever growing mountain of research relating to the relationship between religion, spirituality and health. Searching databases for articles relating to these subjects produces an avalanche of material that has relevance, to one degree or another, to the work of a chaplain. Noting much of its narrow focus, I

⁸⁹ Heije Faber, Pastoral Care in the Modern Hospital, trans. Hugo de Waal (London: SCM Press, 1971), 87.
⁹⁰ Mt. 13.52

⁹¹ J. K. Rowling, Harry Potter and the Order of the Phoenix (London: Bloomsbury, 2003), 343.

begin with a swift overview of reviews and meta-analyses of research that examine links between religion, spirituality and heath. In light of criticism that many of these studies have confused or overlapping definitions of religion and spirituality, I continue by outlining of my understudying of the terms. Following this, in *section 2.2.3* I draw attention to the wider picture given by narrative research and suggest, due to the intangible and irreducible nature of much of their work, this is a natural home for chaplaincy research.

2.2.1 An overview of overviews

Not surprisingly, reflecting the enlightenment positivistic tendency to view only observable 'scientifically' verifiable evidence as acceptable, the vast majority of research investigating religion, spirituality and health is based on quantitative analysis. Ideologically it must be remembered that, rather than looking at wholeness - 'the physical, mental, emotional and spiritual integration of individuals both within themselves and in relation to their environment'92 the purpose of most of it is to investigate principles of healthcare; i.e. whether certain religious practices lead to health benefits in particular situations. While some individual trials return a negative effect, overall, critical reviews and metaanalyses suggest evidence of positive associations between religious involvement and multiple health indicators.⁹³ Notably, these overviews invariably sound a cautionary tone over the limitations of much of the existing research. In particular they note that most lack multidimensional, psychometrically tested measures of religion. As talk of religious involvement indicates, much of this research investigates religiosity, rather than particular interventions. The significant exceptions to this are studies into the therapeutic effects of intercessory prayer. While chaplains may wish to bring both theological and methodological criticisms to such studies, recognising that trials of prayer cannot be interpreted as proof/disproof of God's response to

⁹² The Methodist Church, 'A Methodist Statement on The Church and the Ministry of Healing' (Methodist Conference: 1977), section 8, <u>www.methodist.org.uk/downloads/pi_healingministry_77.pdf</u>. [accessed 1 June 2012]
⁹³ Orit Freedman *et al.*, 'Spirituality, Religion, and Health: A Critical Appraisal of the Larson

⁹³ Orit Freedman *et al.*, 'Spirituality, Religion, and Health: A Critical Appraisal of the Larson Reports', Annals (Royal College of Physicians and Surgeons of Canada) 35, no. 2 (2002). (In 1998 David B Larson et al completed publication of a series of four reports entitled The Faith Factor and a consensus report Scientific Research on Spirituality and Health.); Mueller, Plevak, and Rummans, 'Religious Involvement, Spirituality, and Medicine'; David R. Williams and Michelle J. Sternthal, 'Spirituality, Religion and Health: Evidence and Research Directions', Medical Journal of Australia 186, no. 10 Suppl (2007).

those praying, Leanne Roberts *et al.* conclude that 'mostly, this review suggests no real effect of prayer on health outcomes for the patients being prayed for.'⁹⁴

2.2.2 Defining spirituality

It is important here to make a comment concerning definitions of spirituality. There are, perhaps, as many different definitions as there are books on the subject. As a result, echoing the criticisms just noted, research into the role of spirituality and health has been hampered by poorly designed studies and confused or overlapping definitions between religion and spirituality.⁹⁵ Reasons for this are explored by Harold Koenig, probably the highest profile writer in this area. In a recent article he traces how definitions and understandings of spirituality have changed and developed over time.⁹⁶ In what he terms the 'traditional-historical' understanding, spirituality was originally used only in relation to a subset of deeply religious people. We might think here, for example, of ascetics and monks. In this model, religion and the secular are seen as distinct and different 'sources' of human values, meaning and purpose. Today, the meaning of spirituality has expanded, not only to subsume religion and include positive indicators of mental health as part of its definition, but also to embrace secular sources. In this definition everyone, including atheists and agnostics, is viewed as having a spirituality. Such definitions, he suggests, while helpful in the clinical setting, are useless in terms of research. This is because, to incorporate secular people, many modern definitions of spirituality include indicators of positive psychological states. This, he argues, is tautological because 'by including indicators of mental health in the definition of spirituality, this assures a positive correlation between spirituality and mental health.'97

I am not attempting to measure particular health benefits, mental or physical, that might come from being religious or spiritual. Nevertheless, it is important that I am clear over my understanding of these terms. A few years ago I was involved in the creation of a series of posters that the chaplaincy department at

⁹⁴ Leanne Roberts et al., 'Intercessory Prayer for the Alleviation of Ill Health', Cochrane Database of Systematic Reviews (Issue 2, 2009), 24.

⁹⁵ Michael B. King and Harold G. Koenig, 'Conceptualising Spirituality for Medical Research and Health Service Provision', BMC Health Services Research 9, no. 1 (2009), Background section, http://www.biomedcentral.com/1472-6963/9/116. [accessed 7 May 2012].

⁹⁶ Harold G. Koenig, 'Concerns About Measuring "Spirituality" in Research', *The Journal of Nervous and Mental Disease* 196, no. 5 (2008).

⁹⁷ Koenig, 'Concerns About Measuring "Spirituality" in Research', 350.

STH uses around the hospital to raise awareness of our service. There are five posters containing one of the following statements:

- **Seek** meaning and hope
- **Explore** your spiritual resources
- **Connect** with what matters in your life
- Mark changes and important moments
- **Deepen** your spiritual journey

As they suggest, I understand 'the spiritual' as relating to that which gives meaning, purpose and hope to people's lives, and to do with identity, values and beliefs. It is my experience that, when exploring these concepts, patients will often speak about their relationships with others. As Swinton, drawing on the philosopher John Macmurray states:

We become who and what we are (develop our personhood and identity) not as we reflect on our own, but as we relate to and engage with others. It is as we encounter others in meaningful personal relationships, as we engage in actions with and towards one another, that we discover the limits of the self: our identity and personhood.⁹⁸

It is, therefore, not surprising that, in difficult times where people face a fracturing of their own personhood, their connection to others, be that friends, family, or the divine, becomes increasingly significant. I make explicit the significance of relationship for a particular reason as it helps guard against reductionist accounts of spirituality that simply narrow it down to psychological states. Spiritual care is, thus, an attempt to address dimensions of illness, disability, suffering and bereavement that go beyond the immediate and physical. Within this I see religion as being 'a particular system of faith and worship expressive of an underlying spirituality.⁵⁹ As Peter Speck outlines, those who are 'spiritual' will not necessarily express this in a religious way.¹⁰⁰ This view of spirituality might be summarised as being to do with things that relate to issues of ultimate concern.

⁹⁸ John. Swinton, 'Identity and Resistance: Why Spiritual Care Needs 'Enemies'', *Journal of clinical nursing* 15, no. 7 (2006), 919.
⁹⁹ Peter Speck, 'The Meaning of Spirituality in Illness', in Mark Cobb and Vanessa Robshaw

⁹⁹ Peter Speck, 'The Meaning of Spirituality in Illness', in Mark Cobb and Vanessa Robshaw (eds.), *The Spiritual Challenge of Health Care* (Edinburgh: Churchill Livingstone, 1998), 22. ¹⁰⁰ Speck, 'The Meaning of Spirituality in Illness', 23.

2.2.3 How should chaplains carry out research?

Alongside quantitative research there is an increasing recognition of the role of narrative for health research. The belief behind narrative research is well expressed by Brian Hurwizt, Trisha Greenhalgh and Vieda Skultans and is worth repeating in full:

that human subjectivity should no longer be seen as the devalued opposite of scientific objectivity, linked in some assumed zero-sum relationship whereby more of the one must necessarily mean less of the other. Rather, objective assessment (for example, medical diagnosis) and objective intervention (for example, medical treatment or palliation) provide but one important dimension of knowing. However complete the objective dimension, if we exclude subjectivity and its narrative expression through dialogue, we remove diversity of viewpoint and impoverish the knowledge we can gain about human suffering and the impact of our efforts to care.¹⁰¹

Put more simply, it is the belief that the human story, alongside the medical figures, provides a more comprehensive description of what is happening. A good example of this is provided by Eugene Wu *et al.* in *Narrative Research in Health and Illness.* The chapter begins with an extract from an article written by Wu and Joseph Sung in *The Lancet.*¹⁰² This article described Wu's diagnosis with SARS, subsequent illness pathway and treatment, from a precise medical perspective. It is, as the chapter authors note, 'strikingly dispassionate and written in an impersonal, telegraphic style, lacking emotion as required by modern scientific journals.'¹⁰³ Wu was, subsequently, invited to provide a more personal account of his own illness. This was then analysed alongside the medical record by the chapter authors. In conclusion they describe how Wu's diary entries provide 'the human story so necessary in making sense of SARS that was so strikingly lacking in *The Lancet.*'¹⁰⁴ Such a view point is supported by Mowat who writes:

Evidence is arguably not only what we can see and touch but also that which we feel. Evidence is therefore what people say about feelings as

¹⁰¹ Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans, 'Introduction', in Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans (eds.), *Narrative Research in Health and Illness* (Oxford: Blackwell, 2004), 3-4.

¹⁰² Eugene B. Wu and Joseph J. Y. Sung, 'Haemorrhagic-Fever-Like Changes and Normal Chest Radiograph in a Doctor with Sars', *The Lancet* 361, no. 9368 (2003).

¹⁰³ Eugene Wu *et al.*, 'Soldiers Become Casualties: Doctors' Accounts of the Sars Epidemic', in Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans (eds.), *Narrative Research in Health and Illness* (Oxford: Blackwell, 2004), 39.

¹⁰⁴ Wu et al., 'Soldiers Become Casualties', 42.

much as what changes take place in the body as a consequence of a new therapeutic drug. $^{105}\,$

Much of the work of a chaplain is with intangibles such as feelings. Writing about his time in isolation following a bone marrow transplant, Adrian commented:

My last week and a half in isolation was an awful period for me. I'd not eaten in that time, my stomach was constantly sore, I felt so alone and cold... Yet interestingly it was a hospital chaplain who was one of the greatest helps to me through these difficult times. He would pop in at least once a week and chat with me about anything and everything. We would have a laugh together and I can't tell you how wonderful it was to converse with someone who wasn't medically or emotionally connected to me or make inquiries as to how many times I had "opened my bowels" that day.¹⁰⁶

It is unlikely that Adrian's white blood cell count, or any other measurable markers, were changed as a result of my visit. Yet, it is clear that the visit was greatly beneficial to him. As argued in *section* 2.1, by attending to the stories of their lives, listening and building relationships of trust, chaplains help patients seek meaning and hope, connect with what really matters in their life, and mark important moments and events. In doing so we use creativity, intuition, imagination and compassion. These things are irreducible in numerical terms and not easily measured. Unfortunately, such values do not sit well in today's society where what counts is what can be measured. This obsession with numbers and measuring is attacked by David Boyle in his polemical book *The Tyranny of Numbers*, lamenting that as a result:

Things that can't be measured - love, creativity, awe, religion, altruism - get forgotten by professionals and sometimes get ridiculed too. We are now in a world that is designed to be measured, that praises and promotes people with hard measuring skills, and downgrades those with human imaginative ones.¹⁰⁷

Putting the above two paragraphs alongside each other makes it clear that chaplains are well equipped to provide the human story that is missing from much of modern medicine. Expanding this point, Swinton cautions against

¹⁰⁵ Mowat, The Potential for Efficacy, 21.

¹⁰⁶ Adrian Sudbury, 'The Waiting Room (Part 15)', Baldy's Blog, (May 2011), <u>http://</u>

baldyblog.freshblogs.co.uk/2007/09/the-waiting-room-part-15.html. [accessed 27 May 2012] ¹⁰⁷ David Boyle, *The Tyranny of Numbers: Why Counting Can't Make Us Happy* (London: Harper Collins Publishers, 2000), 215.

chaplains 'attempting to latch on to a research agenda which is frequently set within a narrowly scientific model.'¹⁰⁸ Instead, he argues for the development of narrative and interpretative research based on listening to and reflecting on stories that will expose 'the hidden existential dimensions of health and illness' and enable chaplains 'to add a vital and often missing dimension to the contemporary understanding and practice of healthcare.'109 Support for such a viewpoint comes from the work of Stanworth who argues for the place of spiritual interpretations alongside psychological and psychosocial understandings of human experience. This is done through the argument that we 'live and die in story' and that spiritual interpretations provide a horizon of understanding 'beyond the reach of the humanities, psychology, even of philosophy.'¹¹⁰ Stanworth's argument for the place of metaphor and symbol in understanding ourselves is strong and persuasive, particularly her noting that 'scientists exploit metaphor as much as theologians because it also allows them, at least partially, to depict reality without needing to be irreducibly definitive.'111

As noted previously, much research into spirituality and health tends towards reductionist accounts seeking to discover the effects of specific interventions in specific circumstances. By contrast, a narrative approach will almost certainly take a wider viewpoint. The value of this wider viewpoint is supported by those writing in relation to spiritual assessment. Just as there are seemingly endless definitions of spirituality there are increasing numbers of tools for undertaking a spiritual assessment. Often arranged as neat acronyms, most of these are based on asking a particular set of questions.¹¹² Such 'scores on the doors' approaches are a long way from the work of Stanworth whose starting point is the philosophical and hermeneutical world of writers such as Paul Tillich and Carl Jung. While such assessment tools provide a useful reminder of questions to ask or areas to explore, they result in a static picture. The problem

¹⁰⁹ Swinton, 'Rediscovering Mystery and Wonder', 230.

¹⁰⁸ John Swinton, 'Rediscovering Mystery and Wonder: Toward a Narrative-Based Perspective on Chaplaincy', Journal of Health Care Chaplaincy 13, no. 1 (2002), 230.

¹¹⁰ Stanworth, Recognising Spiritual Needs, 23.

¹¹¹ Stanworth, *Recognising Spiritual Needs*, 21. ¹¹² E.g., HOPE, SPIRIT, FICA and Mor-VAST: Gowri Anandarajah and Ellen Hight, 'Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment', American Family Physician 63, no. 89 (2001); Todd A. Maugans, 'The Spiritual History', Arch Fam Med 5, no. 1 (1996); Christina Puchalski and Anna L. Romer, 'Taking a Spiritual History Allows Clinicians to Understand Patients More Fully', Journal of Palliative Medicine 3, no. 1 (2000); Karren A. Skalla and J. Patrick McCoy, 'Spiritual Assessment of Patients with Cancer: The Moral Authority, Vocational, Aesthetic, Social, and Transcendent Model', Oncology Nursing Forum 33, no. 4 (2006).

with this is that spiritual functioning is dynamic. As various writers point out, an assessment carried out on admission may bear no resemblance to a patient's needs a couple of days later.¹¹³ Instead, as Bruce Rumbold states, 'spiritual assessment must be a process, not merely an event, as it needs to take account of emergent insights and accommodate the patient's exploration of particular issues if he or she so chooses.'¹¹⁴ This is a reminder that, when researching spiritual care, space must be left to take account of this dynamic effect. For example, having explored issues of guilt, a patient may be upset when a chaplain leaves, but having talked about such feelings may experience relief or resolution later in the day. Noticeably, in relation to such understandings, as part of an audit of the Northern Ireland Hospice chaplaincy service, George Kernohan *et al.* chose to use semi-structured interviews that reviewed the overall satisfaction of patients with the chaplaincy service rather than particular interventions.¹¹⁵

2.3 Deciding what to Research

In section 2.1 I proposed that a key role of the chaplain is helping people through periods of transition and that one of chaplains' unique skills is the ability to handle liturgy and ritual. This suggested that one obvious place to carry out empirical research was to investigate some aspect of the use of liturgy and ritual by chaplains. As a chaplain I perform a wide repertoire of liturgical and ritual interventions. These range from the naming and blessing of a dead baby to prayers and/or anointing prior to surgery; from hearing confession and giving absolution to the blessing of a marriage or relationship; from administering Holy Communion to prayers of commendation for those close to death or who have just died.

From this range I decided to investigate the benefit of chaplaincy support to parents following pregnancy loss. There were several practical motives for this. First, since starting as a chaplain a particular focus of my work had been within

¹¹³ Tom Gordon and David Mitchell, 'A Competency Model for the Assessment and Delivery of Spiritual Care', *Palliative Medicine*, no. 18 (2004); Jeanette Power, 'Spiritual Assessment: Developing an Assessment Tool', *Nursing Older People* 18, no. 2 (2006); Bruce D. Rumbold, 'A Review of Spiritual Assessment in Health Care Practice', *Medical Journal of Australia* 186, no. 10 Suppl (2007).

¹¹⁴ Rumbold, 'A Review of Spiritual Assessment ', 61.

¹¹⁵ W. George Kernohan *et al.*, 'An Evidence Base for a Palliative Care Chaplaincy Service in Northern Ireland', *Palliative Medicine* 21, no. 6 (2007).

the neonatal and maternity units. It was, therefore, both an area of interest and I had good contacts with clinical staff. Second, here at STH, chaplaincy support is written into the guidelines and protocols for the care of bereaved parents. These guidelines result in a high level of chaplaincy involvement which, given the likely difficulty of recruiting participants for a bereavement study,¹¹⁶ would provide a large pool of potential participants. Third, there were good precedents for carrying out research with parents to support my ethics application.

This left me with the critical decision of how to carry out my research. For a number of important reasons I chose to adopt a hermeneutical narrative-based approach that allowed me to evidence parents' overall perceptions of chaplaincy support following their bereavement. As is made clear in the literature, individual isolated assessments do not do justice to either the complex nature of health, or the importance of the patient's perspectives on the whole of their healthcare journey. Furthermore, I was also keen not to collude with the view that only the measurable is valuable. Consequently, having come to this decision, in order to better focus my empirical research, I began to explore the related literature. It is to the findings of this more focused literature search that I now turn.

¹¹⁶ Cf. for example, Wolfgang Stroebe and Margaret S. Stroebe, *Bereavement and Health: The Psychological and Physical Consequences of Partner Loss* (Cambridge: Cambridge University Press, 1987).

3 <u>Related Research with Bereaved Parents</u>

If, as described in section 1.1 there is little written about chaplaincy at large, there is even less written on what parents look for in terms of support from a chaplain. In her literature review of parents' perceptions of end-of-life care (ELC) on paediatric intensive care units, Jennifer Longden found only one UK based source and this paper by Rosie Midson and Bernie Carter does not address chaplaincy support.¹¹⁷ There is a small body of literature from America that does relate to the work of chaplains more directly. However, as Longden comments, 'there is a limited ability to generalize findings from studies in the USA to UK practice mostly because of the variations in the law and the organization of health care that modifies ELC practices.'118 Further, as Mowat notes, differences in faith traditions and the way chaplaincy has developed, means that findings regarding chaplaincy are not directly transferable to the UK context.¹¹⁹ Accordingly, the only work directly addressing this topic with a UK perspective comes from Kelly and, in particular, his book Marking Short Lives. However, while not written with a direct interest in chaplaincy, there is a range of research which has relevance for my study. This literature will be discussed first, and then in section 3.2 Kelly's work in greater detail.

3.1 National Guidelines and other Related Research

3.1.1 The Sands guidelines

Perhaps the most influential of all writing concerning the care of parents are the Sands *Guidelines for Professionals* which are now in their third edition. Alongside the views and experience of parents, the current guidelines also draw upon research evidence and discussion with healthcare professionals. Widely recognised as an essential benchmark for good practice, they provide comprehensive information as to care and treatment for all forms of childbearing loss. Albeit briefly, specific mention is made of both spiritual care and chaplaincy.

¹¹⁷ Rosie Midson and Bernie Carter, 'Addressing End of Life Care Issues in a Tertiary Treatment Centre: Lessons Learned from Surveying Parents' Experiences', *Journal of Child Health Care* 14, no. 1 (2010).

¹¹⁸ Jennifer V. Longden, 'Parental Perceptions of End-of-Life Care on Paediatric Intensive Care Units: A Literature Review', *Nursing in Critical Care* 16, no. 3 (2011), 137.

¹¹⁹ Mowat, The Potential for Efficacy, 18.

As discussed previously, I understand spirituality as relating to issues of ultimate concern. While not defining spirituality, it would seem that the guidelines take a similar viewpoint. Noting the type of questions that often arise as parents struggle to make sense of what may feel a senseless situation, they affirm that 'spiritual and religious beliefs and questions may become particularly important, even to people who do not normally consider themselves religious.'120 There are several references to the value of liturgy and ritual throughout the guidelines. For example, writing about the possibility of a blessing for a baby before termination, they describe how 'it may help women to know that many parents who have had a termination for fetal abnormality have welcomed such suggestions and have valued the opportunities this gave them.'¹²¹ More generally the guidelines comment on the potential spiritual, social and emotional significance that ritual can carry for people. Significantly, they note that religious ritual 'can be comforting even to people whose daily life takes little account of religion.'122 While Kelly is not referenced nor the term co-creation used, in the section on arranging a private funeral the guidelines do suggest a numbers of ways that parents might have input to the service.123

Despite highlighting the importance of ritual, chaplaincy and chaplains are referred to infrequently throughout the guidelines. There is, however, one very positive statement on the potential support that chaplains can provide:

Parents, their family members and staff members sometimes find it particularly helpful to talk to a chaplain because he or she is not directly involved in clinical decisions and can bring a different perspective to the encounter. They may also feel that a chaplain has more time to sit with them and let them talk.¹²⁴

This statement draws upon research carried out by Hazel McHaffie with parents whose babies died following decisions about whether or not treatment should be withdrawn. A number of further points from that research are of note. McHaffie relates how parents were surprised that chaplains did not 'try to "cram

¹²⁰ Judith Schott, Alix Henley, and Nancy Kohner, Pregnancy Loss and the Death of a Baby: Guidelines for Professionals (London: Sands UK/Bosun Press, 3rd ed. 2007), 16.

¹²¹ Schott, Henley, and Kohner, Pregnancy Loss, 117.

¹²² Schott, Henley, and Kohner, Pregnancy Loss, 17.

¹²³ Schott, Henley, and Kohner, Pregnancy Loss, 191.

¹²⁴ Schott, Henley, and Kohner, Pregnancy Loss, 18.

God or religion" into them.'¹²⁵ Chaplains who had helped support parents were subsequently often asked to take the funeral because they had seen the baby and knew, to some extent, the parents.¹²⁶ When planning funerals, parents were 'appreciative of efforts to get to know them and their wishes in order to arrange a sensitive service in tune with their beliefs.'¹²⁷

3.1.2 DIPEx Health Experiences Research

Similar comments about the value of chaplaincy support can be found in research undertaken by the Health Experiences Research Group at Oxford University in partnership with the DIPEx Charity. In 2006 they interviewed forty people in relation to terminating a pregnancy due to fetal abnormality. Whilst it was not the focus of the questions, various interviewees raised the importance of the support provided by chaplains. The researchers report comments about how 'easily and naturally chaplains acted with the baby' and that 'many women found that hospital chaplains were able to comfort them because they were used to "taking on other's sadness" without trying to "fix everything".'128 From the perspective of my understanding that within the hospital the handing of liturgy and ritual is a unique skill of the chaplain, it is interesting to note that the rituals provided by chaplains were greatly valued. The researchers remark that 'most people felt the service had helped relieve their sadness.'129 This finding accords with other research that notes how 'individuals rely on rituals and belief systems to help them cope with grief and loss.'130 It may be thought that subjective viewpoints make it impossible to discover which components of a ritual people find helpful. However, research findings have been fairly consistent. Often cited aspects include:

- Having a sense of the specialness or sacredness, using symbolic objects such as photos, prayer, poetry and music to help facilitate the ritual.
- The time-limited and structured nature of the ritual providing a safe context for expressing grief.

2010), <u>http://www.healthtalkonline.org/Pregnancy_children/</u> <u>Ending_a_pregnancy_for_fetal_abnormality/Topic/2009/</u>. [accessed 27 May 2012] ¹³⁰ Alice Running, Lauren W. Tolle, and Deb Girard, 'Ritual: The Final Expression of Care', *International Journal of Nursing Practice* 14, no. 4 (2008), 305.

¹²⁵ Hazel E. McHaffie, Crucial Decisions at the Beginning of Life: Parents' Experiences of Treatment Withdrawal from Infants (Oxford: Radcliffe Medical Press, 2001), 131.

¹²⁶ McHaffie, Crucial Decisions, 220.

¹²⁷ McHaffie, Crucial Decisions, 223.

¹²⁸ Healthtalkonline, 'Ending the pregnancy: Treatment, care and communication' (May 2012), <u>http://www.healthtalkonline.org/Pregnancy_children/</u>

Ending_a_pregnancy_for_fetal_abnormality/Topic/2006/. [accessed 27 May 2012] ¹²⁹ Healthtalkonline, 'Losing the baby: Saying goodbye to the baby - services & funerals' (May 2010), <u>http://www.healthtalkonline.org/Pregnancy_children/</u>

• The inclusion of others allowing individuals to see that they are not alone in their grieving.¹³¹

3.1.3 The NICE Guidelines

Alongside the Sands guidelines, reference must also be made to another set of national guidelines. These are the NICE clinical guidelines Antenatal and Postnatal Mental Health. Varying in detail, these consist of four documents that contain a number of different, but related, statements and recommendations relating to mothers seeing and holding their dead baby. The full guidelines on clinical management and service guidance state that:

A matched case-control study found that women who had been encouraged to have continued contact with their dead baby, for example, holding the baby, had increased rates of depression, anxiety and PTSD symptoms than women who had either not seen the baby at all or who had not held the baby (Hughes et al., 2002). This study also found that having a funeral or keeping mementoes was not associated with increased rates in morbidity, although since many of these women also held their baby, this is not straightforward to interpret. However, the findings of this suggest that women should not be encouraged to hold their dead baby if they do not wish to.¹³²

These findings then lead to the following recommendation that, 'mothers whose infants are stillborn or die soon after birth should not be routinely encouraged to see and hold the dead infant.'133 Even more bluntly, the quick reference guide starkly informs staff, 'do not routinely encourage mothers of infants who are stillborn or die soon after birth to see and hold the dead infant.'134

While not amended or included in any of the documents downloadable from the NICE website,¹³⁵ the website itself, following campaigning led by Sands, contains the following clarification statement:

This recommendation is not intended to suggest that women should not be given the choice of seeing and holding their baby but rather

134 NICE, 'Antenatal and Postnatal Mental Health: Clinical Management and Service Guidance' (Quick Reference Guide, London, 2007), 9. ¹³⁵ NICE, 'Antenatal and postnatal mental health (CG45)' (March 2012), <u>http://</u>

¹³¹ Running, Tolle, and Girard, 'Ritual', 305.

¹³² NCCMH, Antenatal and Postnatal Mental Health: The Nice Guidelines on Clinical Management and Service Guidance (Leicester and London: The British Psychological Society and The Royal College of Psychiatrists, 2007), 196.

¹³³ NCCMH, Antenatal and Postnatal Mental Health, 199.

www.nice.org.uk/CG45. [accessed 8 April 2012]

that they should not be routinely encouraged to take up this choice if they do not wish to.

In line with patient-centred care it is expected that treatment and care should take into account the woman's individual needs and preferences. Sensitive support will be required in offering this choice or other choices such as seeing or holding the baby with other family members present. Current evidence suggests that seeing and holding the baby is not beneficial for everyone and if women do not wish to see or hold their baby they should not be encouraged to do so.¹³⁶

Lastly, and this has been updated following the Sands campaign, is a statement within the 'information for people who use NHS services' document:

Although most babies are born healthy, sadly some babies die. If your baby is stillborn or dies soon after birth, it is your choice whether or not you wish to see or hold your baby, and your health professional should support you in making this decision. There is some evidence to suggest that seeing and holding the baby may not be helpful for everyone. You should not be routinely encouraged to see and hold your baby if you do not wish to.¹³⁷

3.1.4 Concerns over the NICE guidelines

Sands was particularly concerned, quite rightly, about the removal of choice from parents. However, I would also wish to raise issues with the interpretation given to the research findings. The research quoted by the guidelines stated that, among other things, the level of contact a parent had with a stillborn infant correlated with increased adverse outcomes. From this, Patricia Hughes *et al.* 'speculate... that seeing and holding the dead infant further traumatises a woman who is already intensely distressed and physically exhausted.'¹³⁸ In speculating in such a way Hughes *et al.* make a logical fallacy by inferring causation from correlation. Today, pregnancy tests can tell within fourteen days of conception that a woman is pregnant. From an early gestation, through discussing names and making physical preparations such as decorating rooms, many parents will have invested emotionally, spiritually and materially in their baby, forming strong bonds of attachment. Consequently, loss, at any gestation, is experienced as a devastating shock. Given this, it is entirely possible that parents who wish to see and hold their baby chose to do so because they have

¹³⁶ NICE 'CG45 Antenatal and Postnatal Mental Health: Summary of Changes' (June 2010), <u>http://www.nice.org.uk/guidance/index.jsp?action=article&o=49516</u> [accessed 8 April 2012]. ¹³⁷ NICE, 'Mental Health Problems During Pregnancy and after Giving Birth' (Understanding NICE Guidance Information for People who use NHS Services, 2007), 9.

¹³⁸ Patricia Hughes *et al.*, 'Assessment of Guidelines for Good Practice in Psychosocial Care of Mothers after Stillbirth: A Cohort Study', *The Lancet* 360, no. 9327 (2002), 117.

formed a stronger bond with their baby than those who decide not to see their baby. From this perspective, seeing and holding a baby is a sign of greater trauma rather than a cause. In support of this it is worth noting anthropological evidence that, in places with high infant morality, children may not be given names or recognised as 'a person' until it is more certain they will survive.139 Moreover, it is important to point out that the research compares outcomes between those who did see their baby and those who chose not to see their baby. If the bluntness of the quick reference guidelines is followed it is likely that parents would be discouraged from seeing their baby. Nancy Kohner and Alix Henley describe how parents who did not mark their baby's life and death in some way 'find they can neither grieve as they want to grieve, nor allow their grief to rest.'140 Hughes et al. state that there is limited quantitative evidence as to the effect this may have. However, they do note that one limited study suggested 'that there was higher anxiety 3 years from stillbirth when the mother reported she was not allowed as much time with the dead child as she wished.'141

3.1.5 Continuing bonds - models of grief and bereavement

The Sands guidelines were developed in response to the concern and anger expressed by parents at the way stillbirth and miscarriage were dealt with in hospitals.¹⁴² The last thirty years have seen a seismic shift in the way healthcare professionals respond to childbearing loss. Like the guidelines, much of this has stemmed from women writing about their experiences and the subsequent research aimed at evidencing the lived experience of parents suffering the death of a baby. Drawing on both physiological and anthropological perspectives, this research has led to changes in both bereavement and grief theory. Traditional understandings of grief suggest that the longer someone lived the greater the loss felt when they died. Models of bereavement based on such understandings see the severing of bonds with the deceased as a means of resolving grief. A good example of this, as outlined in the first edition of his book, can be seen in the fourth of William Worden's grief tasks. Here the final task in the grieving

 ¹³⁹ Rosanne Cecil, 'Introduction: An Insignificant Event? Literary and Anthropological Perspectives on Pregnancy Loss', in Rosanne Cecil (ed.), *The Anthropology of Pregnancy Loss: Comparative Studies in Miscarriage, Stillbirth and Neonatal Death* (Oxford: Berg, 1996), 6-7.
 ¹⁴⁰ Nancy Kohner and Alix Henley, *When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death* (London: Routledge, rev. ed. 2001), 77.

¹⁴¹ Hughes et al., 'Assessment of Guidelines', 117.

¹⁴² Christine Moulder, Understanding Pregnancy Loss: Perspectives and Issues in Care (London: Palgrave Macmillan, 1998), 16.

process 'is to effect an emotional withdrawal from the deceased person so that emotional energy can be reinvested in another relationship.'¹⁴³

In contrast to this understanding, researchers working with parents have argued that, despite the shortness of life, parental grief 'may be more intense and longer lasting than grief resulting from other bereavements.'¹⁴⁴ As one parent put it, 'When your parent dies, you have lost your past. When your child dies, you have lost your future.'¹⁴⁵ Women who have suffered the death of a child talk about never fully recovering but continuing to live with the hurt. As part of this they describe how painful memories and sensations continue to arise on key dates such as anniversaries of the due date or the actual delivery day. This phenomenon has been given the term 'shadow grief.'¹⁴⁶ Its characteristics are simply but profoundly described in the introduction to the tale of Tom Thumb:

Ere thrice the Moone her brightnes change, A shapelesse child by wonder strange, Shall come abortiue from thy wombe, No bigger than they Husbands Thumbe: And as desire hath him begot, He shall haue life, but substance not; No blood, nor bones in him shall grow, Not seene, but when he pleaseth so: His shapelesse shadow shall be such, You'l heare him speak, but not him touch: And till the world to ending come, There shall be tales told of Tom Thumbe.¹⁴⁷

Research with parents has also led to the emergence of new models of bereavement. In contrast to severing bonds, these introduce the concept of continuing bonds where the end of grief comes with 'integrating the child into the parent's life in a different way than when the child was alive.'¹⁴⁸ Studies have shown that parents need to talk about the meaning and influence their

Review of Controlled Studies', International journal of palliative nursing 8, no. 9 (2002), 452. ¹⁴⁵ Elliot Luby, quoted in James R. Woods and J. L. Esposito Woods, (eds.), Loss During Pregnancy or in the Newborn Period: Principles of Care with Clinical Cases and Analyses (Pitman NJ: Jannetti Publications, 1997), 6.

 ¹⁴³ J. William Worden, Grief Counselling and Grief Therapy (London: Tavistock, 1983), 15.
 ¹⁴⁴ Neneh Rowa-Dewar, 'Do Interventions Make a Difference to Bereaved Parents? A Systematic

¹⁴⁶ Larry G. Peppers and Ronald J. Knapp, 'Shadow Grief', chap. 6, Motherhood and Mourning: Perinatal Death, (New York: Preager Special Studies, 1980).

 ¹⁴⁷ Iona Opie and Peter Opie, *The Classic Fairy Tales* (Oxford: Oxford University Press, 1974), 42.
 ¹⁴⁸ Dennis Klass, 'The Deceased Child in the Psychic and Social Worlds of Bereaved Parents During the Resolution of Grief', in Dennis Klass, Phyllis R. Silverman, and Steven L. Nickman (eds.), Continuing Bonds: New Understandings of Grief (London: Taylor & Francis, 1996), 214.

child continues to exert upon their life and that they 'derive consolation and solace from holding on to possessions and carrying out rituals associated with their child.'149 It must be noted that such understandings are not universally accepted by all grief theorists. In particular, questions are asked as to whether continuing bonds are associated with healthy ongoing life and, if so, whether they are adaptive for some and maladaptive for others.¹⁵⁰ Despite raising such issues, it is noticeable that, in his fourth edition, Worden has changed the direction of his fourth task. Rather than withdrawing energy, the task is now, 'to find an enduring connection with the deceased in the midst of embarking on a new life.^{'151} In relation to theories of grief, Davies makes a crucial point that most understandings of grief and bereavement implicitly use a medical framework. Construed in this way, grief is seen as analogous to illness. A bereaved person has been struck down with something but, given time, the expectation is they will recover and return to how they were before.¹⁵² Such a framework can be seen behind the research of Hughes et al. and the NICE guidelines. The problems with this medical framework, as Davies describes, is that it ignores,

deep facts of existence, whether existential experiences lying at the heart of life, or religious experiences at the centre of faith. Some experiences influence human life so much that people are never the same again. They simply become different people through what has happened to them. To speak of recovery is to talk about a kind of backward change, an undoing of what has been done, an unliving of part of life.¹⁵³

We see an example of this in the words of Richard Olsen, the founder of the National Stillbirth Society in America, when he writes 'I don't want to be well adjusted. I don't want to be accepting. I don't want to be healed. When healing is to be freed of feeling.'¹⁵⁴

¹⁴⁹ Ruth Davies, 'New Understandings of Parental Grief: Literature Review', *Journal of advanced nursing* 46, no. 5 (2004), 511.

¹⁵⁰ J. William Worden, Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner (Hove: Routledge, 4th ed. 2010), 3.

¹⁵¹ Worden, Grief Counselling and Grief Therapy, 4th ed., 50.

¹⁵² Douglas J. Davies, Death, Ritual and Belief: The Rhetoric of Funerary Rites (London: Continuum, 2nd ed. 2002), 51.

¹⁵³ Davies, Death, Ritual and Belief, 54.

¹⁵⁴ Richard K. Olsen, 'Coping is a Cop Out', Loss 3, no. 6 (2002), <u>http://www.kotapress.com/</u> <u>loss/Loss_V3_lssue6%28Jun02%29/la_Olsen_R1_Coping.htm</u>. [accessed 28 April 2012]

3.1.6 Religion, spirituality and grief

Not surprisingly, given the volume of research looking at spirituality and health, there are also studies that have investigated the relationship between religious and/or spiritual belief and adjustment to bereavement. Systematic reviews of the research show that most studies suggest a positive relationship between religion and adjustment to bereavement.¹⁵⁵ While that may be the case, as a result of their review, Gerhild Becker *et al.* conclude that no statistically significant findings could be reported.¹⁵⁶ It is important to note here that the majority of studies in these reviews do not focus on parental loss. As described, studies of parents have led to the development of new models of grief which view 'normal' adjustment to bereavement very differently. Pertinently, Jennifer Wortmann and Crystal Park conclude their integrative review by stating:

Our take-home message is that the question, "Is religion/spirituality related to adjustment to bereavement?" is too simple. In fact, we echo Pargament's (2002) admonition for researchers to instead ask the richer question: "How helpful or harmful are particular forms of religious expression for particular people dealing with particular situations in particular social contexts according to particular criteria of helpfulness or harmfulness?"¹⁵⁷

The 'particulars' in this citation are a reminder of the importance of the subjective viewpoint argued for in *section* 2.2.3. As mentioned at the end of *section* 2.1.3, there is good evidence for the fact that patients draw upon religion and/or spirituality both in making decisions around their treatment and as a coping mechanism. Investigations into efficacy are therefore, in some ways, asking the wrong question and missing the point. Rumbold sums this up well when he writes:

The interpretations of spirituality made within health frameworks do not do justice to the way spirituality is understood in society in general. It seems clear that most in our society would see health care as encompassed by spirituality, not spirituality encompassed by health care. That is, health care issues will be placed within the broader concerns of spirituality. For example, while from a health care

¹⁵⁵ Gerhild Becker *et al.*, 'Do Religious or Spiritual Beliefs Influence Bereavement? A Systematic Review', *Palliative Medicine* 21, no. 3 (2007); Jennifer H. Wortmann and Crystal L. Park, 'Religion and Spirituality in Adjustment Following Bereavement: An Integrative Review', *Death*

Studies 32, no. 8 (2008).

¹⁵⁶ Becker et al., 'Do Religious or Spiritual Beliefs Influence Bereavement?'. p215

¹⁵⁷ Wortmann and Park, 'Religion and Spirituality in Adjustment Following Bereavement', 727-28.

perspective it may be vital to do everything possible to preserve a patient's life, from that patient's perspective the struggle to preserve life may be quenching his or her spirit.¹⁵⁸

Consequently, regardless of any health benefits, the simple fact that patients view the meeting of their spiritual needs as important means that consideration should be given to discovering and better understanding such needs. This leads us neatly to the work of Kelly.

3.2 Ewan Kelly's Marking Short Lives

Supported by his experience of being a chaplain to two busy maternity units, Kelly's findings are based on sixteen interviews carried out with parents. While noting that 'every parent's experience of their baby's death was unique.'¹⁵⁹ Kelly states that the spiritual needs they articulated can be grouped into four main themes. I would suggest that there are strong links between each of them.

3.2.1 Four themes of spiritual need

The first outlined is social isolation. Death is a topic that is little spoken about in society. It is not uncommon to hear bereaved people speak of acquaintances crossing the street to avoid talking to them. Even when people wish to show care and concern they often struggle to find the right words to say and so may stay silent to avoid causing offence. It is, therefore, not surprising that many parents 'felt unsupported and alone in their grief.'¹⁶⁰ Given research quoted above that suggests parental grief is both longer lasting and more intense than other grief, it is understandable that parents 'often felt other family members, friends and acquaintances did not understand what they had experienced and were currently living through.'¹⁶¹

Secondly, Kelly identifies a loss of meaning and purpose. As noted earlier, from early gestations many parents will invest heavily in their baby forming strong bonds of attachment. Where once parents were looking forward expectantly, suddenly 'their dreams about future parenting had been shattered and their plans and sense of purpose for the future had been lost.'¹⁶²

¹⁵⁸ Rumbold, 'A Review of Spiritual Assessment ', 61.

¹⁵⁹ Kelly, Marking Short Lives, 123.

¹⁶⁰ Kelly, Marking Short Lives, 123.

¹⁶¹ Kelly, Marking Short Lives, 123.

¹⁶² Kelly, Marking Short Lives, 126.

Next, Kelly distinguishes a loss of control. Despite a desire to alter what they were experiencing, parents described a sense of powerlessness in relation to events that had happened.¹⁶³ This impotence to affect proceedings was exacerbated by various factors. Culturally, there was an absence of prevalent norms regarding how to deal with the death of a baby. This left parents without 'comparative markers to aid their decision making.'¹⁶⁴ At an existential level, from the middle of the second trimester parents did not expect the death of their baby. Consequently, their understanding of living in a world 'in which modern medicine was omnipotent' was radically shaken.¹⁶⁵

The fourth of Kelly's themes is a loss of self worth. In relation to a woman, medical textbooks describe expectant motherhood as 'a discrete biopsychosocial process that transforms and broadens her role to that of mother.'¹⁶⁶ Accordingly, as Davies notes:

The woman *becomes* a mother through this experience, so that if she is bereaved of her child it is the mother and not only a woman who is bereaved. In this sense motherhood is an existential fact of life and not simply a sociological description.¹⁶⁷

The force of this existential loss is seen in Davies comment that, in comparison to the term widow for a bereaved wife, 'there is no word for a mother who has lost her child.'¹⁶⁸ Given this, it is perhaps to be expected that Kelly found that the inability to have successfully given birth left mothers in particular expressing 'a sense of failure as a parent.'¹⁶⁹

3.2.1 How the co-creation of liturgy and ritual help meet spiritual need

The largest chapter of Kelly's book, approximately a third longer than any other, is given over to exploring how 'participating in rituals to mark their baby's life and death and in the construction of those rituals significantly enabled key parental spiritual needs to be met.'¹⁷⁰ The findings in this chapter are rendered more diffusely than the spiritual needs identified in the previous chapter. Rather unhelpfully, they are not directly correlated to the four main

¹⁶³ Kelly, Marking Short Lives, 127.

¹⁶⁴ Kelly, Marking Short Lives, 127.

¹⁶⁵ Kelly, Marking Short Lives, 128.

¹⁶⁶ Woods and Woods, (eds.), Loss During Pregnancy or in the Newborn Period, 7.

¹⁶⁷ Davies, Death, Ritual and Belief, 54.

¹⁶⁸ Davies, Death, Ritual and Belief, 54.

¹⁶⁹ Kelly, Marking Short Lives, 129.

¹⁷⁰ Kelly, Marking Short Lives, 144.

themes previously identified. Nevertheless, it is possible to map one to the other, as I will do in what follows.

Against the sense that others do not fully comprehend what they are going through, Kelly describes how the simple fact that they are marking their baby's life and death enables parents to communicate something of the significance of their loss.¹⁷¹ Such ritual also provides parents with a forum to share their story with friends and family, and for that experience to be both heard and more fully understood.¹⁷² Kelly likewise found that parents used ritual, particularly funerals, 'as a safe and non-threatening common reference point in conversation with others to aid discourse about their baby.'¹⁷³ Accordingly, ritual may have an on-going role in reducing feelings of isolation.

In relation to a loss of meaning and purpose, Kelly suggests that the co-creation of ritual is particularly important. By suggesting resources and sharing something of the experience of other parents, chaplains helped normalise parents' grief allowing them to identify 'with the range of feelings and spiritual issues that others had felt and struggled with.'¹⁷⁴ In the midst of a distressing time Kelly notes that sharing in rituals offered parents 'the possibility of the formation of positive and life-enhancing memories to associate with their baby.'¹⁷⁵ For some parents Kelly relates that naming and blessings acted as a 'symbolic gesture of intended parenting.'¹⁷⁶ Aspirations of future parenting may have been broken, but through such ritual parents could provide their baby with something of the family, religious and cultural care they had envisioned. From an existential perspective, Kelly reports that co-creation also facilitated an element of reframing by offering parents 'some time and space to begin the ongoing struggle of attempting to make sense of, or find meaning in, their experience in relation to their beliefs and worldview.'¹⁷⁷

As well as helping to affirm the significance and reality of their baby, Kelly found that parents 'greatly appreciated the fact that they could make informed

¹⁷¹ Kelly, Marking Short Lives, 178.

¹⁷² Kelly, Marking Short Lives, 177.

¹⁷³ Kelly, Marking Short Lives, 179.

¹⁷⁴ Kelly, Marking Short Lives, 165.

¹⁷⁵ Kelly, Marking Short Lives, 150.

¹⁷⁶ Kelly, Marking Short Lives, 186.

¹⁷⁷ Kelly, Marking Short Lives, 162.

choices about the rituals performed for their baby.'¹⁷⁸ Taking ownership of the ritual helped to assuage parents feelings of powerlessness. Even if they decided not to have input into a ceremony, simply choosing to have some sort of ceremony in the first place put decision-making power back into the hands of parents.

At a time when parents felt helpless and lacking, 'co-authoring and participating in ritual for their babies crucially fulfilled a deep need within parents to do something for their baby.'¹⁷⁹ For some parents, as Kelly illustrates, sharing in ritual felt as if it was their only opportunity to be a parent to their baby.¹⁸⁰ In response to feelings of guilt, failure and low self-esteem, ritual offered an 'affirmation of parents' spiritual resources.'¹⁸¹ As well as facilitating parents to provide 'best possible parenting', ritual marking also helped reaffirm the beliefs and values, which provided parents with meaning and purpose.¹⁸²

3.2.2 Poor expectations of chaplaincy support

Not directly fitting into the above framework, Kelly records a number of other findings. Where appropriate these will be picked up as part of the analysis of my interviews. I will though, discuss one further theme from Kelly's research and that is the low expectations that parents had of chaplains. Kelly describes how:

Parents talked at great length during the interviews of the very marked contrast between their expectations of chaplains and the ritual they may perform and the actuality of the support given, the ritual shared and the approach of the chaplain who worked with them.¹⁸³

Such expectations were that chaplains would be 'inappropriately formal, detached and paternalistic.' Rather than listening and responding they were foreseen as being 'inflexible and directive.' Perhaps most damningly, rather than offering time and commitment to their particular needs, parents expected chaplains to take advantage of the situation in order to 'preach and proselytize.'¹⁸⁴ Fortunately, echoing the findings of McHaffie, parents went on to

¹⁷⁸ Kelly, Marking Short Lives, 145.

¹⁷⁹ Kelly, Marking Short Lives, 145.

¹⁸⁰ Kelly, Marking Short Lives, 147.

¹⁸¹ Kelly, Marking Short Lives, 184.

¹⁸² Kelly, Marking Short Lives, 186.

¹⁸³ Kelly, Marking Short Lives, 137.

¹⁸⁴ Kelly, Marking Short Lives, 137-38.

describe how the actuality of the support was in marked contrast to their expectations. Once chaplains began to work with parents, Kelly notes that, alongside the actual rituals, 'the chaplain's way of being and relating became increasingly important.'¹⁸⁵ In his descriptions of how 'it was the chaplain's integrity and compassion, discernment and empathy that parents remember not just what he or she said or did,'¹⁸⁶ there is a strong echo of the DIPEx research finding concerning the way chaplains acted with parents and brought comfort through not trying to fix everything.

3.3 Deciding what Interview Questions to Ask

Although I have carried out naming and blessings without parents in attendance, most have taken place with them present. If the tenor of NICE guidelines is followed, and parents' continued contact with their dead baby is viewed as being harmful, then it might be argued that naming and blessings should be discouraged. In section 3.1.4 I questioned the suggestion that seeing and holding a baby causes additional trauma. Instead, I postulated that, as a result of bonds already formed between parent and baby, wanting to see and hold their baby may be a sign of greater trauma rather than its cause. In relation to bonds Kelly describes how the process of ritualisation formed, cemented or deepened continuing bonds between parents and their baby.¹⁸⁷ Even if it is accepted that seeing and holding a baby does not cause additional trauma, it might be suggested that liturgy and ritual, through strengthening bonds, contributes to future problems and should, therefore, be discouraged. Against such an argument it is worth noting that Hughes et al. found that having a funeral and keeping mementoes 'made no obvious difference to outcome.'¹⁸⁸ Furthermore, alongside stating that no parent in his research regretted seeing their baby, Kelly found that, paradoxically, the process of ritualising their baby's life and death also assisted a process of detachment:

As well as enabling parents to bond with their baby and begin to acknowledge the impact of the baby's life and death on their lives and relationship, the process of ritualization also allowed them to begin to detach from him or her, i.e. to let go physically of their baby as well as

¹⁸⁵ Kelly, Marking Short Lives, 196.

¹⁸⁶ Kelly, Marking Short Lives, 200.

¹⁸⁷ Kelly, Marking Short Lives, 149-53.

¹⁸⁸ Hughes et al., 'Assessment of Guidelines', 117.

starting to let go psychologically of the relationship they had hoped for with him or her. $^{\rm 189}$

In stark opposition to the NICE guidelines, both Kelly and the Sands guidelines provide good evidence that parents value seeing and holding their baby and find it helpful in working through their grief. Such conflicting conclusions provide a good rationale for my research. In addition, the value ascribed to ritual and liturgy supports my decision to explore chaplains work in this area as a way of evidencing their benefit.

As an intervention that has various interacting components, and where there is flexibility and tailoring of the intervention, the support offered by a chaplain to parents may be understood as a complex intervention. The Medical Research Council (MRC) has published guidance for developing and evaluating complex interventions.¹⁹⁰ While I would wish to argue against the inherently reductionist worldview that assumes it is possible to measure all outcomes, the guidelines do offer helpful advice. Particularly useful are some of the key questions, functions and activities set out for different stages. As chaplaincy interventions, in the form of rites and rituals, already exist, this study sits more in the evaluation phase. Here, the task is to 'understand the whole range of effects, how they vary among recipients of the intervention... and causes of that variation.' Linked to this is the question of 'how the intervention works, in other words, what are the active ingredients within the intervention and how are they exerting their effect?'¹⁹¹ Accordingly, if a patient says they felt the support of a chaplain had helped 'relieve their sadness,' was it the prayers and ritual, or the manner and bearing of the chaplain, or a combination of both that caused the effect? This suggested that my schedule of questions should provide space for parents to talk more generally about the support provided by chaplains, before asking more direct questions regarding the use of liturgy and ritual.

Reflecting a broad understanding in change management that ownership empowers,¹⁹² Kelly's findings highlighted the value parents found in the co-

¹⁸⁹ Kelly, Marking Short Lives, 156.

¹⁹⁰ Peter Craig et al., Developing and Evaluating Complex Interventions: New Guidance (London: MRC, 2008).

¹⁹¹ Craig et al., Developing and Evaluating Complex Interventions, 7.

¹⁹² Cf. for example, Michael Beer and Anna Elise Walton, 'Organization Change and Development', Annual review of psychology 38, no. 1 (1987).

creation of ritual. To investigate this concept further, it would be important that my schedule asked questions as to the input parents had into rituals, and how they perceived such rituals helping them. The contrast between expectations and actual experience of chaplaincy support illustrated by Kelly indicate that this would be a further fruitful area to explore. Accordingly, as I started my interviews, alongside the wider objective of evidencing the benefit of chaplaincy support, I had the following three aims in mind:

- 1. To see if Kelly's findings, particularly regarding co-creation, could be replicated or if they needed challenging or nuancing.
- 2. To discern if particular parts of chaplaincy support were more important than others, i.e. whether there is there an 'active ingredient.'
- 3. To attempt to understand better the beliefs and expectations that parents hold about who a chaplain is and what a chaplain might do.

My findings in relations to these aims are addressed in the chapters five and six. Before turning to them, however, I first set out and discuss my methodology.

4 <u>Methodological Considerations</u>

The past three chapters have detailed my journey to carrying out research with parents. Before I turn to my findings, this chapter describes the methodologies that lie behind this research project and details the study design used for the empirical research. In *section 4.1.1* I begin by outlining how I have used a version of the pastoral cycle as a driver for my thinking and to give shape to the project. This is followed in *section 4.1.2* by comments on why hermeneutic phenomenology is a particularly appropriate methodology for evidencing lived experience. I then in *section 4.2* go into greater detail over the method the empirical research followed. Having described the interview process, I comment on issues around sample size and saturation before in *section 4.2.1* relating how participants were recruited and selected. The chapter concludes with *section 4.2.2* providing a short discussion of my personal reflexivity and possible methodological limitations that have not been mentioned in the proceeding text.

4.1 Overall Methodology

4.1.1 The pastoral cycle

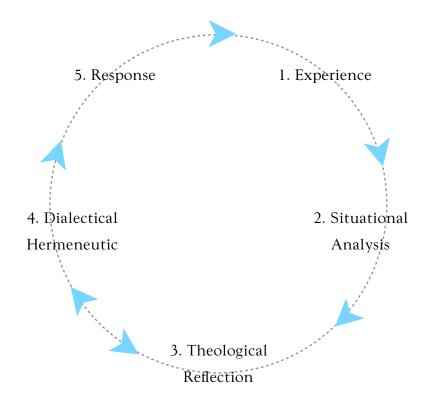
At the heart of much, if not all, practical theology research lies the pastoral cycle. The cycle is frequently referred to as the circle of praxis, because of the way 'it emphasizes the on-going relationship between reflection and action.'¹⁹³ As the methodology underpinning my whole research, I decided to follow a modified version of Emmanuel Lartey's pastoral cycle. This itself appears to be strongly based on Thomas Groome's 'shared Christian praxis' method of Christian formation.¹⁹⁴ Groome's model is a particularly appropriate starting point because it is designed to facilitate the 'intersection of narrative and action to empower renewed action consciously and deliberately chosen.'¹⁹⁵ The cycle can be represented thus:

¹⁹⁵ Neville Clement, 'Thomas Groome and the Intersection of Narrative and Action: Praxis, Dialectic and Hermeneutics', *Australian eJournal of Theology* 10, no. 1 (2007), paragraph 1, <u>http://aejt.com.au/__data/assets/pdf_file/0007/378106/</u>

¹⁹³ Joe Holland and Peter Hennot, Social Analysis: Linking Faith and Justice (MaryKnoll NY: Orbis Books, rev. ed. 1983), 8.

¹⁹⁴ Emmanuel Lartey, 'Practical Theology as a Theological Form', in David Willows and John Swinton (eds.), Spiritual Dimensions of Pastoral Care: Practical Theology in a Multidisciplinary Context (London: Jessica Kingsley, 2001), 72-77.

AEJT_10.6_Clement_Thomas_Groome.pdf.[accessed 23 April 2012]



The entry into stage one of the cycle is my experience of working as a chaplain. This led to my desire to explore how the benefit of chaplaincy work might best be evidenced. Having decided to look at chaplaincy work with parents, stage two, the situational analysis, consisted of an exploration of the relevant literature, presented in the previous chapter, and the empirical research undertaken. As with the purpose of Groome's stage two, the intention of the research was the creation of narratives with which to dialogue in the later stages of the cycle. In stages three and four these narratives were reflected on and brought into conversation with my understanding of chaplaincy and the related literature. As indicated by the arrows facing in opposing directions, it is difficult to separate out stages three and four. Lastly, stage five sets out my response in terms of conclusions and recommendations.

In my use of the cycle it should be noted, as Lartey writes of his pastoral cycle, that theology implicitly influences the whole cycle not just the stage within it labelled as such.¹⁹⁶ For example, a theological understanding lies behind my belief in the importance of spiritual care as part of holistic care. This does not mean that the conclusions can only be reached theologically. It may be possible to arrive at similar conclusions from other directions. However, within the research I view theology as bringing a renewed perspective and thus

¹⁹⁶ Lartey, 'Practical Theology', 76.

enriching the framework of reference. Robin Gill writes that 'public theology has, I believe, a threefold critical role, criticising, deepening and widening the ethical debate in society at large.'¹⁹⁷ I would want to suggest that, alongside the critical role, theology can affirm good practice and creatively re-imagine alternative ways forward, for example, bringing a transcendent dimension to the experience of loss and suggesting understandings of humanity that challenge individual and reductionist accounts.

4.1.2 Hermeneutic phenomenology

For the empirical research, within the time constraints of the Doctor of Theology and Ministry programme (DThM), I chose to follow as closely as possible the methodology of Kelly and the DIPEx Charity. The DIPEx methodology has been recommended by the NHS National Knowledge Service as the 'gold standard' for research into patient experiences.¹⁹⁸ Both of these studies utilise hermeneutic phenomenology for their analysis. Swinton and Mowat describe hermeneutic phenomenology as having 'both descriptive and interpretive elements.'199 The Stanford Encyclopaedia of Philosophy describes phenomenology as 'the study of the meanings things have in our experience. Phenomenology studies conscious experience as experienced from the subjective or first person point of view.²⁰⁰ Hermeneutics is the theory of the interpretation and understanding of texts. In contrast to phenomenology, interpretation is always from a particular position or perspective. Thus, it is an approach that rejects the idea of suspending our preconceptions and positioning ourselves outside the study and, instead, allows 'the researcher to adopt a more active role in the interpretation process bringing into the study his/her experiences.'201

Put together, hermeneutic phenomenology is the attempt to both see and understand what is going on in a given situation by developing a rich description of the phenomenon being investigated. This makes it a particularly

¹⁹⁷ Robin Gill, *Health Care and Christian Ethics* (Cambridge: Cambridge University Press, 2006), 175.

¹⁹⁸ DIPEx, 'Overview of Dipex Research Methodology' (Information Paper), 2. ¹⁹⁹ Swinton and Mowat, *Practical Theology*, 107.

²⁰⁰ David Woodruff Smith, 'Phenomenology', *The Stanford Encyclopedia of Philosophy* (Fall 2011 *Edition*), Edward N. Zalta (ed.), section 1, <u>http://plato.stanford.edu/archives/fall2011/entries/phenomenology</u>. [accessed 13 March 2012]

²⁰¹ Andreas Charalambous, (I)Rena Papadopoulos, and Alan Beadsmoore, 'Ricoeur's Hermeneutic Phenomenology: An Implication for Nursing Research', *Scandinavian Journal of Caring Sciences* 22, no. 4 (2008), 640.

appropriate methodology for not only exploring the spiritual needs of parents, but also for evidencing the work of chaplains. The descriptive phenomenological element is concerned with lived experience and aims to allow things to speak for themselves. Accordingly, semi-structured interviews which allow participants to tell their story are a particularly appropriate methodology. As the main focus of phenomenology is with pre-reflective experiences and feelings, it becomes hermeneutical when its method is taken to be interpretive rather than purely descriptive. Hermeneutics 'adds the interpretive element to explicate meanings and assumptions in the participants' texts that participants themselves may have difficulty in articulating.²⁰² At its heart is a 'listening to the Other, in give-and-take, or, more strictly, a triadic relation between the Other, the self, and a content that emerges from the dialogue.²⁰³ Hermeneutics has benefits over other approaches as it takes into account beliefs and culture and allows contrasting ways of understanding our experience. As Andreas Charalambous, Rene Papadopoulos, and Alan Beadsmoore conclude, 'hermeneutic phenomenology integrates all the necessary elements for conducting a successful qualitative study based on the lived experiences of the participants.'204

4.2 Study Design

Ethical approval for the study was given by Leeds Central NHS Research Ethics Committee and the Department of Theology and Religion Departmental Ethics Committee at Durham University. The research took the form of informal interviews and my interview schedule can be seen in *Appendix I*. It should be noted that parts in brackets provide example prompts that might be used if participants were unsure what I meant by a question and that the questions were not read slavishly, but adapted to the flow of the interviews. The use of semi-structured interviews allowed participants the freedom to narrate their experiences without being tied down to specific answers and thus provided a greater breadth and richness to the data than might be possible with structured interviews. Whilst allowing freedom of narration, in having a number of

²⁰² Rola Ajjawi and Joy Higgs, 'Using Hermeneutic Phenomenology to Investigate How Experienced Practitioners Learn to Communicate Clinical Reasoning', *The Qualitative Report* 12, no. 4 (2007), 616.

²⁰³ Roger Lundin, Clarence Walhout, and Anthony C. Thiselton, *The Promise of Hermeneutics* (Carlisle: Paternoster Press, 1999), 133.

²⁰⁴ Charalambous, Papadopoulos, and Beadsmoore, 'Ricoeur's Hermeneutic Phenomenology', 641.

standard questions, semi-structured interviews enable greater comparison of interviews than with an unstructured approach.

My interview questions were not independently validated. However, the results of numerous studies indicate that asking people to tell their story and following up with appropriate prompts produces data suitable for analysis using hermeneutical phenomenology. At the conclusion of the interview, parents were asked to fill in the self-report RFQ. This is a validated measurement tool designed to measure strength of belief. It was chosen to provide the wider context of the nature and strength of belief to accompany the data produced though the interviews. In their systematic review of research looking at the effect of spiritual or religious beliefs on bereavement, Becker *et al.* regret that very few studies used validated measurement tools to evaluate religiosity or spirituality.²⁰⁵

The interviews were carried out retrospectively. I chose to interview parents at a minimum of three months post the death of their baby. This decision was made in light of reading through the previously mentioned DIPEx research concerning the experience of terminating a pregnancy due to fetal abnormality. In the comments made by participants it was noticeable that they saw both naming and blessings, and funerals, as part of a continuous process of saying goodbye to their baby. The remarks also suggested that such services and ceremonies had an ongoing aspect beyond the actual time of the intervention. Interviewing a minimum of three months after a funeral allowed both the whole patient experience, and emergent insights, to be taken into account.

I digitally recorded the interviews and then transcribed them verbatim. The data was analysed using constant comparison. This is a form of grounded theory where analysis is highly inductive with a systematic interaction existing 'between data and ideas as well as the emergent properties of research design and data analysis.'²⁰⁶ As that suggests, data collection and analysis takes place simultaneously as new data is compared with existing data and categories. New and emergent categories are developed to incorporate and accommodate data

²⁰⁵ Becker et al., 'Do Religious or Spiritual Beliefs Influence Bereavement?', 215.

²⁰⁶ Paul Atkinson and Sara Delamont, 'Analytic Perspectives', in Norman K. Denzin and Yvonna S. Lincoln (eds.), *Collecting and Interpreting Qualitative Materials* (Thousand Oaks CA: Sage, 3rd ed. 2008), 300.

and, where needed, existing categories are modified until all data is accounted for. It is sometimes suggested that in grounded theory themes emerge from the data rather than being imposed upon it by the researcher. While this is true at one level, as Carol Bailey describes:

One does not search through one's qualitative garden at the right time of year and find themes like daffodils emerging from the ground. Qualitative researchers actively create the final product that they believe adequately represents their observations and interactions. The initial idea, the research questions, data collection, coding, interpretation, and writing of the final manuscript are all functions of the researchers' decisions and actions. Thus, themes do not wait in the data to emerge so that we all can see them.²⁰⁷

As I will later describe, there were two waves of recruitment for the study. This provided the opportunity for themes identified in the first to be checked and clarified in the second. To help facilitate analysis the data was coded for different meanings, feelings, and actions, etc. This was done using N-Vivo software. The software removes many of the manual tasks associated with analysis, such as classifying, sorting and arranging information, making it easier to explore trends and test theories. In grounded theory it would be normal to keep collecting data until theoretical saturation is reached. Due to time constraints I stopped interviewing after twelve interviews. As four couples wished to be interviewed together this gave me a total of sixteen participants. This I believe is a sufficient sample size to draw conclusions. Exploring the concept of satiation and sample size Mark Mason mentions research where the researchers carried out a systematic analysis of their own data to assess when it ceased returning new codes. From the thirty-six codes they identified, thirtyfour were developed from their first six interviews, and thirty-five after twelve suggesting that 'data saturation had occurred at a very early stage.'²⁰⁸ Looking from the other direction there is the question of how to prove a claim to have achieved saturation. Despite common characteristics being identified, it is often stated that everyone grieves differently. If each person's experience is uniquely important then saturation may be viewed as only existing in the eye of the researcher. Ultimately, given the link between the skill of the interviewer and

²⁰⁷ Carol A. Bailey, A Guide to Qualitative Field Research (Thousand Oaks CA: Pine Forge Press, 2nd ed. 2007), 127-28.

²⁰⁸ Mark Mason, 'Sample Size and Saturation in PhD Studies Using Qualitative Interviews', *Forum: Qualitative Social Research*, 11, no. 3 (2010), section 1.3, <u>http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027</u>. [accessed 4 May 2012].

the richness of the data, 'the sample size becomes irrelevant as the quality of data is the measurement of its value.'²⁰⁹

4.2.1 Recruitment and participant selection

I chose purposeful selection as my recruitment strategy. This is used in qualitative research to obtain a set of information-rich-cases for in-depth analysis. Within this strategy I used an approach called expert or criterion sampling. This involves recruiting a sample of participants who have a particular experience, in this instance having been supported by a chaplain following the death of a baby. My inclusion and exclusion criteria were as follows:

Inclusion criteria:

- Parents over the age of 18 who had suffered a miscarriage, stillbirth, neonatal death or had a termination due to fetal abnormalities since the year 2003 at Sheffield Teaching Hospitals NHS Foundation Trust.
- . In relation to the death of their baby, parents were supported by a chaplain who was part of a team signed up to the Cooperative Agreement for the Sheffield City-Wide On-Call Chaplaincy Service.
- . Parents who were able to give written informed consent.

Exclusion Criteria:

- . Any parent bereaved less than three months before the point of interview.
- Any parent unable to understand the information sheet or complete the consent form.
- . Any parent where there was on-going pastoral care being provided by the principal investigator.
- . Any other concern that was deemed to render the potential participants ineligible by the principal investigator, for example, a need for the provision of pastoral care that developed as part of an interview.

The chaplaincy electronic database recording those patients with chaplaincy involvement began in 2003. For ease of confirming chaplaincy support, parents bereaved before 2003 were therefore excluded from the study. It might be suggested that participants' memories would have faded over the years

²⁰⁹ Mason, 'Sample Size and Saturation', section 4.

following a bereavement. However, as previously noted, it is increasingly argued that parental grief has an on-going aspect. In support of this, the DIPEx research included fifteen participants who had been bereaved for over five years. Similarly, retrospective research into the needs of parents in a paediatric intensive care unit in the USA noted 'how vivid and long-lasting parents' memories of specific aspects of their child's death can be, and how such memories continue to play an active role in their bereavement over time.'²¹⁰

Alongside parents supported by other chaplains I made the decision to include parents who I had supported within the study. This is in contrast to the decision made by Kelly.²¹¹ Kelly suggested that there could be confusion for both parents and himself between the supportive role of chaplain and that of the researcher. This approach is suggestive of the split between pastoral care and critical theological thinking that I quoted Cobb warning about in *section* 2.1.5. Moreover, such a view comes close to falling into the delusion that researchers stand outside the research field and have no effect on that which they study. As James Holstein and Jaber Gubrium write:

Both parties to the interview are necessarily and unavoidably active. Each is involved in meaning-making work. Meaning is not merely elicited by apt questioning nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter.²¹²

Accordingly, the fact that I had been a chaplain to some parents could convey positive advantages in facilitating trust and confidence in the researchparticipant relationship. As previously mentioned, I chose to interview at a minimum of three months post bereavement and chaplaincy support. This should have helped make it clear that I was interviewing participants in the role of researcher, rather than offering support as a chaplain.

Kelly was also concerned about participants wishing to please him, referencing an article by Nicky Britten that suggests a patient being interviewed by their doctor may wish to please them by giving the responses he or she thinks the

²¹⁰ Kathleen L. Meert *et al.*, 'Examining the Needs of Bereaved Parents in the Pediatric Intensive Care Unit: A Qualitative Study', *Death Studies* 33, no. 8 (2009), 737.

²¹¹ Kelly, Marking Short Lives, 251.

²¹² James. A. Holstein and Jaber. F. Gubrium, *The Active Interview* (Thousand Oaks CA: Sage, 1995), 4.

doctor wants.²¹³ Britten offers no evidence for such an opinion. There is no reason to suppose that a participant supported by another chaplain would want to please me any more than a participant supported by myself. To help minimise any such potential bias I deliberately did not ask participants to rate chaplains, but simply to tell their story of what happened, what they valued and what they might have liked done differently. Particularly when exploring negative experiences of chaplaincy, it was important that I had good personal and epistemological reflexivity. Here, my experience as a chaplain in looking for congruence within a person, for example a patient saying they are not upset while visibly crying, was of help within the research process.

Kelly's final reason was that, due to his previous involvement, he would have developed particular assumptions about how a participant understood or experienced ritual and these would stop him listening fully to what was said. I would challenge this from several directions. It must be presumed that Kelly has general assumptions about how people understand and experience ritual. Are these less likely to affect his listening? Given the idea behind grounded theory, that data and ideas are in constant dialogue, with appropriate reflexivity, might not such assumptions be helpful? Writing about carrying out in-depth interviews, Susan Chase suggests that the aim should be to transform the interviewee-interviewer relationship into that of narrator and listener. When this happens, she suggests that:

In speaking from and about biographical particulars, a narrator may disrupt the assumptions that the interviewer brings to the research relationship. Thus, narrative interviewing involves a paradox. On the one hand, a researcher needs to be well prepared to ask good questions that will invite the other's particular story; on the other hand, the very idea of a particular story is that it cannot be known, predicted, or prepared for in advance.²¹⁴

The above points are not to suggest that Kelly's concerns are without merit. Each is indeed a potential pitfall. Instead, by drawing attention to them my aim is twofold: first, to show that I am aware of the issues and so better placed to mitigate them; and second, to recognise that alongside the dangers, interviewing participants whom I had supported could also confer considerable

²¹³ Nicky Britten, 'Qualitative Research: Qualitative Interviews in Medical Research', BMJ 311, no. 6999 (1995).

²¹⁴ Susan E. Chase, 'Narrative Inquiry: Multiple Lenses, Approaches, Voices', in Norman K. Denzin and Yvonna S. Lincoln (eds.), *Collecting and Interpreting Qualitative Materials*, 72.

advantage. As a possible example of this, in the discussion of demographic differences within *section* 5.1 I note the involvement of parents who are both younger and live in areas of greater deprivation than Kelly's participants. In the majority of cases these were parents I had been involved in supporting.

Routinely at STH, following the death of a baby, parents are given details of the annual baby memorial service and asked to return the reply slip if they are interested in attending. Those who attend the service are given a feedback form where they can indicate that they no-longer wish to receive information. A couple of months before the service, a letter confirming details of the service are sent to all those who have expressed an interest in attending. Within the 2010 mailing I included a short letter introducing the research, a reply slip for indicating interest, and a self-addressed envelope. Assuming respondents fitted the inclusion/exclusion criteria, I made contact with them to explain more about the research. If they continued to express interest in participating, I proceeded to arrange a convenient time for them to be interviewed. Before commencing the interview I checked that they had read the information sheet and then asked them to sign the consent forms. A second wave of recruitment was carried out a year later by including a letter of invitation within the order of service for the 2011 memorial service.

Parents who agreed to be interviewed were offered the choice of using the multi-faith room in the chapel of the Royal Hallamshire Hospital or another quiet room within the hospital if they were not comfortable coming into the chapel. Although some parents did not wish to return to the Jessop Wing maternity unit, all were comfortable using the multi-faith room. Parents were offered ten pounds towards travel and parking expenses. I travelled to see one parent who lived a considerable distance outside of Sheffield. While research has suggested that parents have often found telling their story beneficial, the primary risk for participants was the reliving of distressing emotions. To help minimise distress I took advice from the principal researcher behind the DIPEx research into terminations due to fetal abnormalities. Following her advice I offered participants a drink on arrival and had tissues available in the interview room. The information leaflet also made clear that parents were able to take a break from the interview, move on from a particular question, or withdraw from the research altogether if they felt too distressed. While some parents were

emotional in the interviews, no one asked to take a break, move on, or withdraw from the interview.

4.2.2 Personal reflexivity, bias and other limitations

Before turning to my findings I will briefly discuss issues around personal reflexivity and possible methodological limitations beyond those already discussed. It is impossible to detail my reflexivity at every stage of the research but I would like to explore key issues demonstrating awareness of my bias and how I have attempted to minimise this. I will begin by looking at the issue of power relating to my demographic, then discuss how my beliefs about chaplaincy and personal experience interplayed with the research.

As I noted in section 1.2, I am white, ordained and male. Theologically, while it might sound contradictory, I would describe myself as a liberal evangelical. By this I mean that I take a liberal critical approach to scripture and, in terms of salvation, lean towards universalism. At the same time, I continue to believe that Christianity is 'good news' and has a message worth sharing in the present. Even if historic deference to religious figures has waned recently, I am still aware of the privileged and powerful position those three descriptors at the beginning of this paragraph can place me in. Because, as described in section 4.2.1, parents came into the chapel, my territory, it was particularly important to be alert to this when interviewing. In several interviews I was aware of parents' hesitancy to be critical and was careful to explain that part of the aim of the research was to learn how we could do things better and this could only be done if they shared less than good experiences. Beyond making parents tentative to criticise, being on 'my territory' may have put other parents off participating altogether. However, it cannot be assumed that interviewing them at home would have removed such power dynamics. Rather than feeling they were offering hospitality, it could be that parents would feel they were being assessed with a home visit. Related to this, Kelly chose to interview parents in their home and, as discussed in section 5.1.2, it is noticeable that parents from the lowest social deprivation categories are missing from his participants.

In chapter two I stated that chaplains need to be skilled in handling liturgy and ritual. This is not just a theoretic position, but comes from my own experience of being, what might be termed, a labourer of liturgy and ritual. From this practical perspective I understand liturgy as involving more than just reading words off a page. It also includes 'holding a space' so that it feels safe and/or sacred for those involved. Ritual I view as formal action within that space; for example, within the context of this thesis, the signing of the cross on a baby's forehead or the scattering of tiny stars into a graveside. As part of section 2.1.4 I make clear my view that the chaplain's ability to use liturgy and ritual is unique within a healthcare setting. Accordingly, when interviewing it was important that I did not appear more interested in participants' comments about valuing liturgy and ritual. To do so may have encouraged them to talk more about this, rather than any other aspect of the support provided. Similarly, when analysing the interview transcripts it was important not to be blinded to views that were other than that which I expected. As illustrative of such reflexivity I draw the reader's attention to two sections. First, in section 8.4.7, I relate surprise that parents did not pick out individual moments as being of greater importance than others. Second, I dedicate the major part of chapter six to looking at the value ascribed to the presence of a chaplain alongside liturgy and ritual.

Lastly in terms of reflexivity, my thesis is dedicated to a friend who died while pregnant and whose baby subsequently also died. This was the third death of a friend within a nine-month period. Echoing my inclusion and exclusion criteria, of only interviewing parents who had been bereaved for over three months, I took the decision not to analyse any transcripts during the three months following each of these deaths. This was done for two related reasons. First, to give myself space to grieve and second to lessen the possibility of superimposing my grief experience onto the comments made by parents.

One other important limitation I would like to mention relates to recruitment. As described, my recruitment pool was parents who either attended, or had expressed an interest in attending, the baby memorial service. Given that members of the chaplaincy team both lead the service and are involved in its planning, it may be that parents who were unsatisfied with chaplaincy support are less likely to attend. This could, in part, have been mitigated by the fact that the invitation to attend the service comes from the bereavement manager at the Jessop Wing and not the chaplaincy department. However, even if parents dissatisfied with chaplaincy support attended, the fact that it was a chaplain carrying out the interview may have discouraged them from participating. In addition, the decision to attend a memorial service could indicate that parents find liturgy and ritual helpful. Accordingly, the recruiting pool may be biased towards parents who appreciated this kind of chaplaincy support.

5. <u>The Spiritual Needs of Bereaved Parents and How</u> <u>Chaplains Help Meet that Need</u>

I turn now to what is at the heart of my thesis, the exploration of the spiritual needs of parents and the way in which chaplains help meet that need. Given that one of my aims was to provide a critical appreciation of Kelly's conclusions, the chapter begins in *section* 5.1 by comparing and contrasting the demographic details of our respective participants. This includes, in *section* 5.1.5, a discussion of the findings from the RFQ. I turn in *section* 5.2 to discuss the spiritual needs described by my participants before relating, in *section* 5.3, how the liturgy and ritual provided by chaplains helped meet this need. In both sections I draw attention to how my findings support or nuance Kelly's.

Following this I look at what becomes a developing theme through this thesis, the way in which chaplains relate to parents. In *section 5.4* I demonstrate that there is not a one size fits all response and that chaplains need to quickly establish what type of support parents want. Having described the disturbingly poor expectations of chaplains in *section 5.5*, I continue by exploring, in *section 5.6*, the question of why parents wish for chaplaincy support in the first place. Finally, *sections 5.7 and 5.8* draw the chapter to a close by considering how the work of anthropologists investigating ritual may shed light on aspects of the chaplains role and identity and discussing the use of intuition.

5.1 Demographics

As I related in chapter three, UK based published evidence for the value of chaplains' work with parents is largely limited to the work of Kelly. As such, his study is the key text with which to compare my findings. Because of this, it is important to be clear how our respective participant groups differ and how this may affect our findings. The RFQ provides me with details about how my participants understand their lives in terms of religious and spiritual outlook, how strongly they hold to their beliefs and what significance these beliefs have on a day-to-day basis. Information provided by the questionnaire and participant demographics will be alluded to, as appropriate, through the next two chapters. Demographic details of participants in my study can be seen in *Appendix II*. My participants included those of white British and black African

descent. In order to help preserve anonymity I have not identified participants ethnicity.

5.1.1 Age of participants

The majority of parents I interviewed were aged over thirty with a further two aged twenty-nine leaving just three in their early to mid-twenties. This gives an average age of thirty-three and a half years, which is not much lower than the thirty-five and a quarter years of Kelly's participants. When detailing the age spread of parents he interviewed Kelly references research with bereaved fathers that similarly had a majority in their thirties or forties.²¹⁵ In light of this lack of younger participants Kelly wonders if, among other things, issues of perceived power and authority associated with him as a representative of church, university and hospital prevented younger parents from participating.²¹⁶ In support of this, all the participants under thirty in my study were those I had supported as chaplain, suggesting that they had trust and confidence in me. However, there is also a good medical reason why studies of pregnancy loss are likely to have increased numbers of older participants. As Ling Huang *et al.* in their systematic review demonstrate, 'women with advanced maternal age have a significantly increased risk of stillbirth.'²¹⁷

5.1.2 Level of social deprivation

While the ages of Kelly's and my participants are relatively similar, there is a striking difference in levels of social deprivation. Some caution must be expressed about this analysis. I mapped the postcode of my participants to Lower Layer Super Output Areas (LSOA) which are government defined geographical areas used for small area statistics. LOSAs were created from the 2001 census data and take into account geographical area and social homogeneity.²¹⁸ Kelly also used postcode data. Postcodes, which derive from the walking routes of mail-carriers, are a purely logistical categorisation and so there will inevitably be socio-cultural variance within them.²¹⁹ Because of this

²¹⁵ Kelly, Marking Short Lives, 259.

²¹⁶ Kelly, Marking Short Lives, 259-60.

 ²¹⁷ Ling Huang et al., 'Maternal Age and Risk of Stillbirth: A Systematic Review', Canadian Medical Association Journal 178, no. 2 (2008), 171.
 ²¹⁸ 'Office for National Statistics, 'Super Output Area's Explained', (January 2007), http://

www.neighbourhood.statistics.gov.uk/dissemination/Info.do?page=nessgeography/ superoutputareasexplained/output-areas-explained.htm. [accessed 21 February 2012] ²¹⁹ Sijmen A. Reijneveld, Robert A. Verheij, and Dinny H. de Bakker, 'The Impact of Area Deprivation on Differences in Health: Does the Choice of the Geographical Classification Matter?', Journal of Epidemiology and Community Health 54, no. 4 (2000), 306.

the level of social deprivation should not be viewed as definitive for each participant's background. Comparison is also hampered by the fact that Kelly and I used different measures. I used data from the English Indices of Deprivation which are based on seven domains: income, employment, health and disability, education skills and training, barriers to housing and services, living environment, crime.²²⁰ Kelly used a Scottish measure, the Carstairs and Morris Index, which is based on four variables: overcrowding, male unemployment, social class 4 or 5, and having no car.²²¹ To compound things further the two indices are scaled differently, Carstairs using a seven point scale and the English Indices of Deprivation a ten point scale.

Despite this, I still feel it is worth drawing comparisons. This is because a range of research evidence indicates that greater social deprivation, compounded by associated factors such as smoking and poor nutrition, is correlated with increased risk of stillbirth and perinatal mortality.²²² In line with this, the majority of my participants lived in areas of high deprivation, with several marked as coming from the most deprived category. Surprisingly, there is real disparity between my and Kelly's participants. None of the parents he interviewed are from an area of greatest deprivation. Indeed, half are in lower deprivation categories with several living in areas marked as the least deprived. I do not know how the socio-economic catchments areas of the respective hospitals may vary. However, if Kelly is right in speculating that issues of perceived power hindered younger parents from participating, were similar issues at play when it came to social background? As previously noted, it is interesting to observe that I had been involved as a chaplain with most of those participants who came from the areas of highest social deprivation.

²²⁰ Department for Communities and Local Government, 'The English Indices of Deprivation 2010' (March 2011), <u>http://www.communities.gov.uk/publications/corporate/statistics/indices2010</u>. [accessed 24 April 2012]

²²¹ NHS Scotland, 'Deprivation Background', section 2.9, (July 2002) <u>http://</u> www.show.scot.nhs.uk/publications/isd/deprivation_and_health/background.HTM. [accessed 24 April 2012]

 ²²⁷ April 2012]
 ²²² Cf., for example, Sarah Earle *et al.*, 'The Social Dimensions of Reproductive Loss', *Practising Midwife* 10, no. 6 (2007); Paul Haggarty *et al.*, 'Diet and Deprivation in Pregnancy', *British journal of nutrition* 102, no. 10 (2009); David Taylor-Robinson *et al.*, 'Quantifying the Impact of Deprivation on Preterm Births: A Retrospective Cohort Study', *PLoS ONE* 6, no. 8 (2011), http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0023163. [accessed 17 April 2012]

5.1.3 Time factors

There are a few other distinctions relating to demographics that are worth briefly picking up on. Although Kelly and I both interviewed retrospectively, our recruitment methods resulted in a considerable difference in the length of time parents had been bereaved. Over half the parents I interviewed had been bereaved for more than a year, with several over four years post bereavement. In contrast, all Kelly's participants were interviewed between three and six months after the death of their baby.²²³ Possible outcomes of this variance are discussed in *section* 5.2.3.

While I do not know about the length of some relationships, at the time of interview all bar Wendy, who spoke about a divorce following her baby loss, were still with the partner who suffered the loss with them. There is a strong correlation here with parents interviewed by Kelly who were all in secure longterm relationships.²²⁴ Reasons for the absence of single parents are unclear. Telling the story of their loss was an emotional experience for all parents interviewed. It is possible that parents who had split from a partner did not want to have to re-live this as well. Another possibility is that partners were able to discuss together the pros and cons of participating in a way that a single parent could not. However, the lack of a partner did not stop Wendy from participating and, given that Chloe stated about her husband, 'I didn't get any support from that end', it is unlikely they discussed her participation in the study. As speculation, there may be a link between the absence of single parents and younger parents. Various longitudinal studies have identified an increase in relationship break-up following pregnancy loss.²²⁵ In particular, a national US study found that statistically significant risk factors for break-up included 'lower maternal age... and shorter duration of relationship.'226

5.1.4 Nature of baby loss

Out of my twelve interviews, two were with people who had a miscarriage, one with a person who had a termination for fetal abnormalities, five with people who experienced a stillbirth, and four with people who had what was classified

²²³ Kelly, Marking Short Lives, 254.

²²⁴ Kelly, Marking Short Lives, 261.

²²⁵ William Badenhorst and Patricia Hughes, 'Psychological Aspects of Perinatal Loss', Best Practice & Research Clinical Obstetrics & Gynaecology 21, no. 2 (2007), 252.

²²⁶ Katherine J. Gold, Amanda Sen, and Rodney A. Hayward, 'Marriage and Cohabitation Outcomes after Pregnancy Loss', *Pediatrics* 125, no. 5 (2010), 1204.

as a neonatal death, i.e. their baby was born alive. Of the neonatal deaths, two babies only lived for a few hours, and one for three days. The remaining participant had twins. One survived for a day and the other for four months. Originally, like me, Kelly planned to interview a range of parents. However, he was unable to recruit participants who had experienced a neonatal death. As a result, he suggests that more research should be carried out as to whether it is 'more distressing experiencing the death of a baby who had lived, with whom parents had formed different types of relationship than with a baby who died in utero.'227 I agree with the need for further research around how gestation and type of loss impact on parental grief. I am not, though, convinced that this was the reason Kelly did not recruit from this group. Although he does not comment on it, he only recruited one participant whose baby died at term; the rest all died at less than twenty-six weeks gestation. On this basis he could have also asked whether going to term is more distressing and so put parents off participating. However, the broad spread of my participants suggests this is not so. Instead, introducing an argument I make in section 5.2.3, I believe that an individual's personality, rather than the type of death, is more likely to affect whether parents talk about their loss.

5.1.5 Religious and spiritual belief and practice

Following their interview, participants completed the RFQ. Within the questions answered in the RFQ on an eleven-point ratings scale I have taken seven and above to refer to a high score, and three and below to indicate a low score. The use of the RFQ provides a useful insight as to how, and at what level, religion and spirituality play a part in participants' lives. Kelly only records parents' religious affiliation as belonging to a denomination, linked to a denomination but non-active, or having no religious affiliation.²²⁸ This gives no indication of spiritual belief beyond religion, nor any detail of spiritual or religious practices participants engage in. Moreover, as can be seen in what follows, people who choose the same general category can have vastly differing beliefs in practice. I therefore have greater contextual information with which to interpret my interviews.

²²⁷ Kelly, Marking Short Lives, 262.

²²⁸ Kelly, Marking Short Lives, 270.

In using the word *religion*, we mean the actual practice of a faith, e.g. going to a temple, mosque, or church or synagogue. Some people do not follow a specific religion but do have *spiritual* beliefs or experiences. For example, they may believe that there is some power or force other than themselves that might influence their life. Some people think of this as God or gods, others do not. Some people make sense of their lives without any religious or spiritual belief.²²⁹

Answering a question about having a specific religion, six of my parents said that they did not observe a religion. Of these, when describing the understanding of their life, one chose religious,²³⁰ four spiritual,²³¹ and one neither religious nor spiritual.²³² Three of the people who described themselves as having a spiritual understanding, and the person with a religious understanding, had medium to low scores in answer to questions about whether a power or force other than themselves might influence what happened to them day to day, or enable them to cope. The person who chose neither, Craig, had a low score for those questions. All five stated that they did not take part in activities traditionally associated with religious practice. Contrastingly, the remaining person with a spiritual understanding, Sarah, had higher scores for questions about influence and enabling, indicated that she prayed and meditated, and that this was important in her day-to-day life. Interestingly, four of these six people stated that they believed we exist in some form after death, with three describing the form. Sarah thought we existed in the memory of others. Katy, who had a spiritual understanding, believed people go to heaven. Craig, with neither a religious nor spiritual understanding, stated that we exist as energy. Both the other two people were unsure if we existed after our death.

The remaining ten participants indicated that they had a specific religion. Describing their understanding of life, three chose religious,²³³ two spiritual,²³⁴ and four both religious and spiritual.²³⁵ Confusingly, despite identifying with a specific religion, the Church of England, Julia, chose the understanding neither

²²⁹ King, Speck, and Thomas, 'The Royal Free Interview', 1021.

²³⁰ Adam ČR02a.

²³¹ Claire CR04b, Thomas CR10a, Katy CR10b, Sarah CR11.

²³² Craig CR04a.

²³³ Jenny CR02b, Martin CR03, Liz CR05.

²³⁴ Diane CR06b, Chloe CR12.

²³⁵ Lewis CR01, Alistair CR06a, Wendy CR07, Olivia CR08.

religious nor spiritual.²³⁶ She had a low score for a power or force influencing what happens to her, and a middling score for it helping her to cope. While she did not engage in any religious practices, she did record communicating with a spiritual power through a medium. Eight of these ten people stated that they prayed,²³⁷ with several also participating in other religious practices. Intriguingly Diane, who chose a spiritual understanding of life, alongside prayer also indicated that she used a medium. Seven of the eight who prayed had high scores for influence and enabling, with five signalling higher and two middling importance regarding the day to day practice of religious belief. Each of these held strongly to their religious/spiritual view of life. Jenny, who put herself in the religious category, had low scores relating to influence and enabling, and a medium score for day to day importance. Olivia, who chose a religious and spiritual understanding of life, ticked only contact with a religious leader when it came to religious practice. She had medium scores for the three questions discussed above. Two people with a religious understanding, Jenny and Liz, along with Julia who chose neither, were unsure about life after death. The remainder thought that we would exist. Martin and Chloe, who described what that form would be, both indicated it would be spiritual rather than physical.

This brief discussion of the RFQ responses presents a syncretic picture, with some participants seeming to hold rather contradictory positions. This could be put down to difficulties understanding terms and definitions. However, it should be remembered that it is a validated tool which would militate against such misunderstandings. Instead, it seems likely that such results correlate with wider trends within society that see people taking a much more individual and subjective approach to life, with individuals constructing a spirituality that works for them.²³⁸ While wishing to argue that such approaches to spirituality are less unambiguously individualistic and more socially and publicly significant than sociologists often acknowledge, Stef Aupers and Dick Houtman nevertheless state 'there is, in short, no reason to deny the prominence of "bricolage" in the spiritual milieu.²³⁹ Within this, sometimes termed 'pick-and-mix', approach to spirituality, differing beliefs are often held in creative tension.

²³⁶ Julia CR09.

²³⁷ All but Olivia CR08 and Julia CR09.

²³⁸ Cf. particularly the work of Heelas and Woodhead, The Spiritual Revolution.

²³⁹ Stef Aupers and Dick Houtman, 'Beyond the Spiritual Supermarket: The Social and Public Significance of New Age Spirituality', *Journal of Contemporary Religion* 21, no. 2 (2006), 203.

A good example of this is provided by belief in reincarnation. The European Values Survey suggested that, in 1990, approximately a quarter of all British people believed in reincarnation.²⁴⁰ While Davies found a smaller percentage, his account of contemporary belief in life after death likewise notes that 'even the churchgoer may entertain firm ideas about reincarnation or the finality of death.'241 Exploring this phenomenon with those with strong church connections, Helen Waterhouse and Tony Walter's state 'as we have seen, for some of our informants, belief in reincarnation does not form part of a coherent world-view but is instead creatively mixed with, or held in tension with, mainstream Christian theology.'242 From a different direction, based on research investigating the spirituality of non-churchgoers, Kate Hunt relates how people struggle to find the right language with which to describe their spiritual experiences and beliefs. Accordingly, it is of little surprise she found that 'people's conversations are filled with contradictions, incoherence and frustration, as they attempt to describe the indescribable.'243

In outlining the religious and spiritual beliefs of parents in my study I noted the increased information I have in comparison to Kelly. As wider context, these beliefs are alluded to through the rest of the thesis. The preceding discussion of demographics identified three main areas where my participants differ from Kelly's: level of social deprivation, time since bereavement, and gestation of loss. These factors may contribute to differences in our findings, and I will discuss this at several points. With these notions in mind, I turn now to look at themes arising from my interviews.

5.2 The Spiritual Need of Bereaved Parents

As I outlined in *section 4.2*, within grounded theory there is a continuous interaction between new research data and existing ideas and categories. Through chapter three I alluded to literature that provides good insight into

²⁴⁰ Sheena Ashford and Noel Timms, What Europe Thinks: A Study of Western European Values (Aldershot: Dartmouth, 1992).

²⁴¹ Douglas J. Davies, 'Contemporary Belief in Life after Death', in Peter C. Jupp and Tony Rovers (eds.), Interpreting Death: Christian Theology and Pastoral Practice (London: Cassell, 1997), 137.

²⁴² Helen Waterhouse and Tony Walter, 'Reincarnation Belief and the Christian Churches in Contemporary England', *Theology* 106, no. 829 (2003), 25.

²⁴³Kate Hunt, 'Understanding the Spirituality of People Who Do Not Go to Church', in G. Davie, L. Woodhead, and P. Heelas (eds.), *Predicting Religion: Christian, Secular, and Alternative Futures* (Aldershot: Ashgate, 2003), 163.

pregnancy loss from clinical, psychological and anthropological perspectives. My research interest, however, is with an area where there is far less evidence, that of a spiritual perspective and support provided by a chaplain. Accordingly, in analysing my transcripts my attention was less towards the wider story of parents' loss and well established psychological categories, such as guilt, but more towards the less explored spiritual categories and the story of how the support of a chaplain had affected this. Consequently, in starting to analyse my data I had in mind the four themes of spiritual need identified by Kelly: social isolation, a loss of meaning and purpose, a loss of control, and a loss of self-worth. I found strong parallels for all but social isolation. In addition, I suggest a further common theme, the desire to do something. While the themes I have identified have been separated out in what follows, I would want to stress that the spiritual needs identified were often highly intertwined. It is also important to reinforce comments made by various researchers that each parent is an individual and should be responded to as such.

5.2.1 Loss of control

I would argue that underlying all other spiritual need was the loss of control that parents experienced. Parents spoke about a sense of events happening over which they no-longer had any influence. As Chloe described, 'I don't think it was in my control at all; it was external.'²⁴⁴ This was exacerbated by the fact that, much as they might wish otherwise, there was nothing parents could do to alter the events in progress:

It's that horrible bit it's like... on the telly episodes of *Casualty* where they say can you wait outside while we try and save this person's life. You know, you just feel really helpless and you can't really do anything, but... that's that.²⁴⁵

As in Kelly's research, fathers felt an inability to play the male protective role particularly acutely:

I felt isolated, I felt I was trying to be dad [and] partner in the relationship. I was trying to be that stereotype if you like and..., for the first time in my life, I was out of my comfort zone because... I do try and offer a positive male role model to that kind of environment and do the best that I can and the responsibilities I feel that I've got... as a

²⁴⁴ Chloe CR12.

²⁴⁵ Craig CR04a.

male parent and... I'd kind of lost that. There were so many things out of my control I was powerless in a lot of senses.²⁴⁶

These feelings of helplessness and lack of control were caused by several factors. As I suggested earlier, expectations are for a normal healthy delivery. The possibility of pregnancy loss was, therefore, not something parents had contemplated. Two quotes illustrate this well. 'Obviously when you go through a pregnancy you don't expect to be then going through... a funeral.'247 'I mean, the last thing you think is to obviously bury your child.'248 This sense of shock was shared by other family members. Claire described how her mum had left messages on her partner's phone saying, 'is this really true because she couldn't believe it, 'cos we all expected that day we were going to have the baby.'249 Again, as Kelly found, a lack of cultural norms further increased these feelings. Having 'never been in that position before'250 nor, in most cases, was it a situation that 'close friends or relatives have been either',²⁵¹ meant that parents did not 'know where to go... didn't know what to do really.'252 As a result, parents described being in a strange situation where 'there's no kind of guidelines.²⁵³ Without such guiding principles, the prospect of having to make appropriate arrangements was often stressful: 'I was just worried what to do 'cos I think a funeral, I'm only twenty-two, I shouldn't have to organise one of them.'254

Remembering Koenig's concerns, outlined in section 2.2.2, that definitions of spirituality often include secular sources, it might be argued that a loss of control is a psychological rather than spiritual need. There is, however, a range of evidence that equates 'a loss of control with spiritual distress.'²⁵⁵ This is not surprising for, as Ronnie Janoff-Bulman states, most people believe that the world is benevolent, meaningful, and that the self is worthy.²⁵⁶ Accordingly, when these beliefs are shattered, people are faced with the challenge of

²⁵³ Alistair CR06a.

²⁴⁶ Lewis CR01. ²⁴⁷ Diane CR06b.

²⁴⁸ Claire CR04b.

²⁴⁹ Claire CR04b.

²⁵⁰ Liz CR05.

²⁵¹ Lewis CR01.

²⁵² Martin CR03.

²⁵⁴ Katy CR10b.

²⁵⁵ Cf. Adrian Edwards et al., 'Review: The Understanding of Spirituality and the Potential Role of Spiritual Care in End-of-Life and Palliative Care: A Meta-Study of Qualitative Research', Palliative Medicine 24, no. 8 (2010), 760.

²⁵⁶ Ronnie Janoff-Bulman, Shattered Assumptions: Towards a New Psychology of Trauma (New York: Free Press, 1992), 6.

reconstructing their assumptions about the world. As seen in *section* 6.3, several parents in my study spoke about how their experiences had led to a changed religious or spiritual perspective. Such findings echo a range of research that describes how parents undertake a spiritual quest to restructure their assumptions about self and meaning in the world.²⁵⁷

5.2.2 Loss of meaning and loss of self worth

In their interviews, parents spoke profoundly about the loss of meaning and purpose and, in some cases, of self worth that they experienced following the death of their baby. While they were clearly deeply moved, none spoke about suicidal impulses as contemplated by some mothers in Kelly's study.²⁵⁸ Feelings of emptiness are summed up in Craig's statement, 'when you're losing a child... it's all that..., it's like all these... broken dreams, it's stuff you're never going to have.'²⁵⁹ Jenny described how 'being a mother you always sort of blame yourself an' think there was something I should have done more.'²⁶⁰ As related above, fathers could also be left thinking 'I guess I failed.'²⁶¹

Where hopes and plans for the future had evaporated, it could be hard to find motivation for doing things: 'I [was] useless for doing anything else... I didn't go to work for nearly six weeks following that.'²⁶² Such feelings of hurt and loss continued to haunt parents, 'you know, obviously I still have bad, I have really bad day[s].'²⁶³ Children of friends or colleagues could also act as a reminder of the future parents had been deprived of: 'It's still very difficult, because now they are coming to work and they are talking about their little ones and I'm thinking... I could have been doing that and I can't.'²⁶⁴ While not directly a loss of meaning or self-worth, grief could have unexpected effects on parents' lives as Wendy outlined:

I stopped listening to music completely, couldn't even listen to music, any music came on I had to walk out it was terrible. We were... in Sheffield, it was the first time we'd gone out and... there was a pub on that corner and we went in there and they didn't have any music on

²⁵⁷ Robert Marrone, 'Dying, Mourning, and Spirituality: A Psychological Perspective', *Death Studies* 23, no. 6 (1999), 503-05.

²⁵⁸ Kelly, Marking Short Lives, 125.

²⁵⁹ Craig CR04a.

²⁶⁰ Jenny CR02b.

²⁶¹ Lewis CR01.

²⁶² Chloe CR12.

²⁶³ Jenny CR02b.

²⁶⁴ Chloe CR12.

and I was okay and we ordered some lunch and we sat down, music came on, burst into floods of tears. Had to walk out. It's taken me nearly three years to listen to music. It's amazing how these things touch you.²⁶⁵

5.2.3 Social isolation

This leaves us with the remaining spiritual need identified by Kelly, social isolation. Unlike the previous three, I found less evidence to support this theme. This is not to say that I found no comparable experiences. Clearly some parents did have a sense of being cut off. Particularly in the immediacy of their loss parents described how, 'you feel like you're on your own, you feel like you're isolated.'266 Where there was not 'people around you who understand where you're coming from',²⁶⁷ it was difficult for parents to talk about their feelings. Such loneliness could continue if parents found that other people did not know how to relate to them. Talking about their experiences was not always easy because 'nobody sort of asks' and people 'sort of shy away from it because they don't wanna bring things up.²⁶⁸ Even when friends and family did engage, their attempts in trying to help could be, at best 'quite crass sometimes', leaving parents thinking '[I] just can't believe you've just said that to me.²⁶⁹ For some parents this could be laughed off, but others reported how 'the things that people tell you in trying to comfort you do hurt you.'270

In light of Kelly's findings, and because pregnancy loss is often referred to as a 'hidden loss',²⁷¹ I was surprised by how many parents reported how they were able to 'talk openly as a family'272 or with 'close friends.'273 Julia described how 'I just feel comfort talking to other mums... 'cos they talk to me an' I talk to them and we're not afraid to say anything.²⁷⁴ In addition to this, several parents also found good support from beyond friends and family. Sarah described the help that came from a complete stranger:

I go to a playgroup with my older children and there's a lady there who... said to me, oh how did your twenty week scan go? An' I said no

²⁶⁵ Wendy CR07.

²⁶⁶ Lewis CR01.

²⁶⁷ Chloe CR12.

 ²⁶⁸ Jenny CR02b.
 ²⁶⁹ Sarah CR11.

²⁷⁰ Chloe CR12.

²⁷¹ Valerie Hey et al., (eds.), Hidden Loss: Miscarriage and Ectopic Pregnancy (London: The Women's Press, 2nd ed. 1996).

²⁷² Olivia CR08.

²⁷³ Alistair CR06a.

²⁷⁴ Julia CR09.

it was quite bad really, you know, this is what happened... She said I had exactly the same thing, an' she said oh my little boy died when he was twenty-three weeks... She was fantastic... She told me sort of all the things that she'd wished she'd done to make it really special... A complete stranger, you know, somebody that I'd never really spoken to before.275

In a related way, other parents described how they had been able to pass on help and advice:

A girl at work, her sister-in-law's just gave birth to a stillborn, went up to term, so some of the material that you had you passed on didn't you and I... relayed my, you know, that I'd had excellent experience with the chaplain, with the staff up at Jessops.²⁷⁶

As summarised in section 5.1.3, in contrast to parents in Kelly's study, various of my participants had been bereaved for a number of years. This provides one possible reason for the difference in sense of isolation found in both studies. As Lewis, who had been bereaved for over three years commented, 'I couldn't of had a conversation like this up until quite recently.'277 Also linked to timescale, most parents had attended at least one baby memorial service. The simple act of going to the service was used by parents as a way to talk about their loss. Olivia described how she was able to 'bring it into the conversation by saying we're going to this service today.²⁷⁸ Once at the service the number of similarly bereaved people attending left parents commenting that 'you don't feel like you were on your own in't world'279 and that they appreciated having 'people around you who understand where you're coming from.'280

However, along with being at different stages in their grieving process, I suspect that parents' particular personality traits also affected whether they had discussed their experiences with others. For example, despite thinking, 'there's still this taboo where you shouldn't talk about it,' Liz, bereaved for over three years, described how she had talked about her loss because 'you've got to talk to be able to cope with it.²⁸¹ Similarly, Jenny, bereaved for less than a year, commented 'like I said I'm the sort of person I like to talk about things and I

²⁷⁵ Sarah CR11.

²⁷⁶ Alistair CR06a.

²⁷⁷ Lewis CR01.

²⁷⁸ Olivia CR08. ²⁷⁹ Thomas CR10a.

²⁸⁰ Chloe CR12.

²⁸¹ Liz CR05.

like to sort of tell people how I feel an'... sometimes I'll just come out with it.'282 The suggestion that it is a combination of time and personality that affects the ability of parents to speak about their loss is supported by comments made by Wendy:

I talk more openly as time's gone on, I talk openly about the boys now so, for example, you know, people say ... you've only one [child], oh no... I had three but I lost two... But I think that you can only do that necessarily in time with healing... I'm not scared of talking about them, about what happens, so I suppose that's made it easier for me. There's some people who... don't like talking and perhaps slightly more shy or whatever and... then it would be difficult for them.²⁸³

A further possible reason for the difference is the rise of social networking websites since Kelly's research. While social networking websites have been around from 1997, it was only from 2003 onward that there was a real proliferation of websites opening up.²⁸⁴ Most started off with the aim of supporting pre-existing social networks. However, increasingly they have also enabled strangers to connect through shared interests, activities or experiences. Social networking had certainly helped one parent connect with others who had been through similar circumstances. I have met a few people who have lost children, I met one at the baby memorial service, I met her off Facebook.'285 Support groups such as Sands, Bliss, and the Miscarriage Association, along with national charities like Antenatal Results and Choices all have Facebook pages. Similarly, all the major pregnancy loss charities have internet support and discussion forums as part of their websites. Sands states that that seventeen stillbirths or neonatal deaths will occur every day in the United Kingdom.²⁸⁶ With early miscarriages included, some estimating that one in seven pregnancies ends in miscarriage, this figures rises. It may be that social networking is one of the reasons why, following their loss, parents realised that pregnancy loss is 'a lot more common than you think'287 and that nearly everyone they told knew someone who had 'been through something similar.²⁸⁸ Illustrative of the increasing use of the internet by bereaved parents,

²⁸² Jenny CR02b.

²⁸³ Wendy CR07.

²⁸⁴ Danah M. Boyd and Nicole .B. Ellison, 'Social Network Sites: Definition, History, and Scholarship', *Journal of Computer-Mediated Communication* 13, no. 1 (2007), The Early Years section, http://jcmc.indiana.edu/vol13/issue1/boyd.ellison.html. [accessed 17 April 2012] ²⁸⁵ Julia CR09.

²⁸⁶ Sands, 'About the Campaign: Why 17?', (April 2011), <u>http://www.why17.org/About-the-</u> Campaign.html. [accessed 20 February 2012] ²⁸⁷ Katy CR10b.

²⁸⁸ Thomas CR10a.

it is worth pointing out that Abigail McNiven, in researching how individuals recall and narrate their experiences of pregnancy loss, recruited participants for her study 'primarily through online support groups.'²⁸⁹

5.2.4 Desire to do something

Before I begin to explore how the support of a chaplain helped to meet spiritual need, I would like to outline one additional spiritual need shared by parents. This is that, in the face of the all the above, there was a desire to do something; either to do something for their baby, or to do something to mark what had happened. As Lewis put it, 'I feel like it was a small window of opportunity for me to do everything that I could for baby.'290 Often this desire to do something was intuitively felt by parents, even if they could not articulate exactly why. The same father described how he and his wife instinctively gravitated towards wanting their baby christened or blessed. Another mother records how on being offered chaplaincy support 'I just knew that it felt... the right thing to say yes to.'291 Likewise when a chaplain introduced the idea of a naming and blessing, Craig remembers 'it was... just doing something to, sort of, mark that Nathan... had come, so when the chaplain talked about that that sounded like the right thing to do.^{'292} This desire was shared by parents regardless of whether they described themselves as religious, spiritual, both or neither. It was also important to those who stated they belonged to a particular denomination and those who did not.

5.3 Meeting Spiritual Need: The Role of Liturgy and Ritual

It is clear from my interviews that the provision of liturgy and ritual following the death of a baby helped support parents in a number of different ways. Through this section I will expand upon this in relation to the categories of spiritual need just delineated as well as making reference to the importance parents placed on mementos. As before, this will include commenting on where my findings parallel or refine Kelly's conclusions.

²⁸⁹ Abigail McNiven, email to the author, 4 October 2011.

²⁹⁰ Lewis CR01.

²⁹¹ Olivia CR08.

²⁹² Craig CR04a.

5.3.1 Giving back control

I suggested above that underpinning all other spiritual need was the loss of control that parents sustained. Echoing Kelly's findings, the simple act of being able to choose to have a ceremony helped give an element of control back to parents. It is the choice that is crucial, as encapsulated in the following quotation from Olivia:

The blessing felt like we'd actually done something that we'd done with our other children, so that felt like it done one of the things we would have done with him. The funeral obviously was necessary... an' we're glad we had one where people came an' people had chance to speak an' our other children had chance to write things down an' speak, but didn't really want to be there... Definitely the bit in the hospital was what brings nicer memories back. The other... felt as if it was a necessity as opposed to something we'd chosen.²⁹³

It should be remembered here that for babies over twenty-four weeks gestation there is a legal requirement for a funeral. In this quotation, even though a funeral appears to have been well co-created, there is a strong sense that its necessity had contributed to this parent's feelings of powerlessness.

5.3.2 Affirming meaning and purpose

Operating at a number of different levels, liturgy and ritual also helped mitigate existential loss. This was the same both for those who had a particular faith and for those who did not. Particularly important was the way that ceremonies facilitated parents affirming their beliefs about the value of life, however brief: 'it's another sort of, you know, marker that, you know, our child's existed.'²⁹⁴ This was particularly important for Julia who had an early miscarriage and found some hospital staff unsupportive:

It were just like he's been recognised... The ward staff were... like bury him in your garden. It's like he's nothing... he's had a heart... he's been born, he's been living so it's still a human being, an' it were nice to have a proper funeral service and having the naming an' getting certificate for like recognition he is here, that means so much.²⁹⁵

The last two quotations come from parents who lost babies at twenty-two and sixteen weeks respectively. As such, they support Kelly's statement that, for parents whose baby died during the second trimester, 'ritual was felt to be the

²⁹³ Olivia CR08.

²⁹⁴ Sarah CR11.

²⁹⁵ Julia CR09.

only formal way parents could publicly recognise the life of their baby.²⁹⁶ This, though, should not be taken to suggest that ritual was any less important for parents whose baby died at later gestations. Craig, for example, who lost his baby at term spoke about the importance of doing something seemly to mark the reality of what had happened, 'It felt important to do... something proper, as it where... to mark that, you know, this person had, although he hadn't quite... made it in..., that he, you know..., was there.²⁹⁷ Likewise, parents whose baby died at twenty-seven weeks spoke about how, through the funeral service, the chaplain had helped affirm the reality of their baby:

They made him into a person. I mean he was a person, but obviously a lot of people don't always see that in the outside world do they... I think they were quite good at, sort of, making it real for us in that, you know, that he was important an' sort of bringing that across in the service that, you know, he was a person.²⁹⁸

5.3.3 Countering a loss of self worth

As I indicated in *section 5.2.2*, by grouping them together, a loss of meaning and purpose and a loss of self worth are closely linked. In that section I described the loss of self esteem that stemmed from participants blaming themselves or thinking they had failed as parents. The quotation from Olivia, in *section 5.3.1*, speaking of 'doing things we would have done with him' illustrates how liturgy and ritual could help assuage this. Kelly suggested that naming and blessings acted as symbolic gestures of intended parenting. I would argue that for some parents it was less emblematic, and more an act of actual parenting. As Lewis describes, this allowed him and his wife to do everything they now could for their child:

I've always had a faith... I felt blessing baby was important part of that. If there was anything I could do for his journey now it would be to set him on the right path... The comfort that did come from having him blessed, we were doing everything that we could both physically and spiritually for the baby so it came as a great comfort.²⁹⁹

This was more important for parents who identified with a particular faith. Although with differing strengths of belief, both Olivia and Lewis identified as having a religious and spiritual understanding of life and aligned themselves

²⁹⁶ Kelly, Marking Short Lives, 180.

²⁹⁷ Craig CR04a.

²⁹⁸ Diane CR06b.

²⁹⁹ Lewis CR01.

with the Church of England. Similar views about the importance of preparing their children for the afterlife were expressed by parents who had a baby baptised on the neonatal unit. Martin spoke about deciding to have his son baptised 'just in case of anything, so that you can also give him a chance to be able to, you know, be with his creator.'³⁰⁰ Echoing this, Wendy, whose previous premature baby had survived and was not baptised while on a neonatal unit, described how the prognosis for her babies affected her decision:

I think all you need for... that sort of situation, if you've got the consultant standing next to you, you just look into their eyes and you know whether you need to get that child sorted or not... Even though Jane was on a ventilator... she looked different at thirty-one weeks compared to twenty-four and I just said... well no... You can feel it in your heart if something's going to go right or wrong but with the boys I know when they said to me do you want, yes straight away that was it, yep yeah fine yes please yeah crack on.³⁰¹

Again, both these parents identified with particular denominations and each held strongly to their beliefs.

5.3.4 Providing mementos

As the quotation from Julia in *section* 5.3.2 alludes to, along with the actual ceremonies, parents cherished the naming and blessing certificates provided as evidence of the service. Kelly recorded how mementos such as cards and candles were used by parents to aid the continuing remembrance of their baby in the security and privacy of their homes.³⁰² This was certainly true for parents in my study:

Nathan has a box, a little box, it sounds quite weird..., of his stuff... like Brian and Andrew who we had after... They have bigger boxes that get... added to when there's some particularly amazing painting or some work of art they do... but Nathan, Nathan's box is only, you know, it's only going to be this size... In there there's like the... naming ceremony certificate an' the bits and bobs... We've found... having physical... things like that useful for... on the first anniversary... we could sit an'... look through these things... Just having something like that, you know, that you can sit and... talk about... it was just almost like having something that can act as a memory jog.³⁰³

³⁰⁰ Martin CR03.

³⁰¹ Wendy CR07.

³⁰² Kelly, Marking Short Lives, 153.

³⁰³ Craig CR04a.

I also found that parents valued certificates as physical and tangible evidence for the existence of their baby:

I got the certificate, that's the only recognition I have got of him. Obviously I don't get a birth certificate, I don't get a stillbirth certificate or a death certificate, there was nothing like that so that's my recognition that he was here.'³⁰⁴

In the above instance, Julia valued the items for herself. For Sarah, after a hugely emotional and disappointing time, there was something to show to others:

That night we had to leave hospital we had to leave our child an', you know, I had something to show, you know, my children an' my... own parents... It's have a look, you know, as know silly as it sounds, it's important to me... [I've] got it, obviously, you know, put away with a few other little things in this memory box, so the children look at them, yeah definitely that was very important.³⁰⁵

The depth of emotion that could be invested in such items is seen in the experience of two other parents. Lewis described how only after four years had he and his wife 'decided to bring his photographs out on his birthday, we've never looked at 'em just couldn't bring ourselves to look at 'em we remember him but... we just can't bring ourselves to look at him.'³⁰⁶ For Wendy, the importance of mementos is seen by the fact that at the annual memorial service she will 'pick up your little pieces' and take them home and put them 'straight into the box.' Yet, she too finds it to difficult to actually look at any of these items:

I have boxes for both of them and I haven't looked in them yet, was it four years later and I haven't quite got there yet. I can't look and I don't know if I'll ever be able to look in those boxes.³⁰⁷

5.3.5 Enabling the desire to do something

I suggested in *section* 5.2.4 that a common spiritual need of parents was an intuitively felt desire to do something. The way that liturgy and ritual facilitate this is implicit in much of the above discussion. However, given that parents often struggled to put into words their reasoning for such instinctive impulses,

³⁰⁴ Julia CR09.

³⁰⁵ Sarah CR11.

³⁰⁶ Lewis CR01.

³⁰⁷ Wendy CR07.

I will provide a couple of explicit examples. For some, as a counter to feelings of powerlessness and grief it was a way of marking what has happened and affirming the reality and significance of their baby:

We wanted to do the naming ceremony though. We wanted to when we had a chat about it. We decided we wanted to go ahead..., even though we're not actually that religious really, we wanted to do something to mark his, you know, his entry and his exit out of the world.³⁰⁸

Alternatively, in a situation where parents 'felt a massive sense of loss, cheated almost' it allowed them to do everything they now could for their child:

The immediacy of the having him blessed and having that kind of support in the hospital, you know, without it we'd have had nothing... We'd have had the baby there and, you know, I helped deliver him I cut his cord and I bathed him and dressed him, tried to keep it... as normal as... you will expect a birth but without that... [it] would have ended there and it'd have been like where do we go from here... So to have that support, to have that feeling of doing as much as we could for him..., an' giving him as much spiritual guidance as we could, you know, that... plays a massive part I think, a massive part.³⁰⁹

Within the above discussion of the role of liturgy and ritual, we see evidence for Rappaport's declaration, as outlined in *section 2.1.4*, that certain meanings and effects can only be expressed or achieved through ritual. In the context of parental loss, I would suggest that ritual's efficacy is less physical but more about providing meaning, grounded, as Rappaport writes, in 'principles of communication.' Significantly, regardless of how the efficacy of ritual is understood, in meeting spiritual need, it is a chaplain that arrives to deliver it. Given Kelly's finding that it is not just sharing in, but the co-creation of, ritual that parents valued, this is particularly important. Accordingly, the next section moves to investigate further the way that chaplains use liturgy and ritual to support parents.

³⁰⁸ Claire CR04b.

³⁰⁹ Lewis CR01.

5.4 Not One Size Fits All: Giving Options or Taking Authoritative Action

Lyall in his book *Integrity of Pastoral Care* describes pastoral care as 'a phenomenon which is both simple and complex.'³¹⁰ The work of chaplains with parents provides a good example of this. At first glance it is obvious why, as a chaplain, you have been called to this situation. You are there because a nurse or midwife has contacted chaplaincy and informed you that there are parents who would like a naming and blessing or baptism for their baby. So far it is simple. However, once you arrive to support parents, the situation rapidly becomes far more complex. Quite clearly there is not a 'one size fits all' response.

For many parents, in a situation where they felt out of control, it was important that a chaplain did not force them into doing particular things. In this situation, parents were grateful that the chaplain 'took on board what we wanted, they didn't, you know, like steam roller this is what you needed, this is what you want, which is what... you might expect.'³¹¹ Linked to this, for other parents it was important that the chaplain gave them options and helped them explore what it was they wanted:

They came in... an' the way that they judged what support we needed I thought was excellent because they just explained a little bit around... these are the things that are available to you and you can have as much or as little, you know, and just the way they did all of that... I thought was excellent.³¹²

They were using their experience but then not to influence us, but just to sort of like guide you on the pros and cons really of different things and trying to really dig down to... what meant more to us.³¹³

In complete contrast, for other parents, what was wanted was authoritative action. Here, options were the last thing the parents wanted, as Wendy describes in relation to the baptism of her baby:

When they said to me do you want, yes straight away that was it, yep yeah fine yes please yeah crack on, and so it was all organised for me and arranged for me which was what I needed because I couldn't, I was in this haze... sometimes you get to that stage where... you can only give

³¹⁰ Lyall, Integrity of Pastoral Care, 11.

³¹¹ Claire CR04b.

³¹² Alistair CR06a.

³¹³ Diane CR06b.

so much because you can't, there's nothing there to give and you're kind of like oh you want my views on something, I've absolutely no view on the moment or on anything other than just breathing.³¹⁴

The fact that they did not have to make certain decisions also provided comfort to other parents. Jenny spoke about the 'complete relief we didn't have to think about anything... but everybody just sort of took over and just did it.'³¹⁵ Chloe described how 'the other thing that did help was that... the hospital and the chaplaincy department arranged the funeral... That was a big help because I don't think I would have done it, no I don't think I would have done it.'³¹⁶ It is abundantly clear that in some instances the last thing that parents want from a chaplain is co-creation. This is a point Kelly recognises, commenting that 'parents who feel unable to take an active role in co-creation, or indeed to attend a ritual, should not be made to feel as if they have failed their baby for a second time.'³¹⁷ However, within a whole book endorsing the value of co-creating, this quotation comes as part of just one paragraph on sensitivity in offering it. Accordingly, I feel it should be reinforced that co-creation is not appropriate for every parent.

Feelings of grief, shock, anger and confusion create a situation that, as one parent described, is 'highly emotionally charged.'³¹⁸ Sometimes it might just be a single parent. At other times extended family crowd into a room. Entering into this environment, a chaplain has only a very short time to judge how to pitch the support they offer; i.e. does this parent or parents want options or action? On the rare occasion parents expressed some dissatisfaction with the support provided by a chaplain, it was clearly linked to the chaplain misjudging this. Diane and Alistair, as seen in the quotations above, wanted to have choices and options explained to them. They saw two different chaplains. The first carried out a naming and blessing and the second provided pastoral support and was involved in taking the funeral. The parents' description of the naming and blessing carries a real sense of being done to. Diane talked about being taken into a private room where 'they *did* a blessing.'³¹⁹ Likewise, Alistair

³¹⁴ Wendy CR07.

³¹⁵ Jenny CR02b.

³¹⁶ Chloe CR12.

³¹⁷ Kelly, Marking Short Lives, 188.

³¹⁸ Alistair CR06a.

³¹⁹ Diane CR06b. (emphasis added)

described how the chaplain came and 'they *did* a blessing for us didn't they... said a few words an' then we were... left on our own.'³²⁰

It seems likely that, entering into this emotive situation late in an evening, the chaplain judged that what was needed was for them to get on with things, and then to give the parents space for themselves. When asked to reflect on the difference between the two chaplaincy experiences, the parents felt that it was the judging of what was needed, as opposed to what was actually done, that was the main difference between the two experiences. Reflecting on the first chaplain they discuss:

It may have been more useful if the chaplain had of explained right... we'll do the blessing now and even myself or one of my colleagues... will come across and have a, you know, have more of a chat with you when you've recovered a little bit tomorrow or the next day.³²¹

Yeah I think... you're right there. It is the explaining bit because I think... the chaplain who came on the night was probably thinking right we'll do the blessing..., ten minutes, you obviously need time as a family together and that's probably what was going through their mind, but nobody actually, they didn't actually say or anybody explain it to us.³²²

At one level, the chaplain was probably right that time and space was what Diane and Alistair needed. Indeed, they themselves recognised that 'it wouldn't have been right to have sat us down at that point... an' had the chaplain chat that was the next morning, that would have been wrong.'³²³ However, in the situation where power had been largely taken out of their hands, rather than action, what they wanted was explanations and information that would help them to begin to take control again. Instead, their lack of control was reinforced leaving them to comment about the chaplain that they 'didn't get anything really out of their service'³²⁴ and that they 'didn't really feel like I got any comfort... from them.'³²⁵

Given the poor expectation of chaplains, which will be discussed in a moment, and a negative first experience, the second chaplain was at a considerable disadvantage as they began their interaction with the parents. As they walked,

³²⁰ Alistair CR06a. (emphasis added)

³²¹ Alistair CR06a.

³²² Diane CR06b.

³²³ Alistair CR06a.

³²⁴ Alistair CR06a.

³²⁵ Diane CR06b.

in Diane remembered thinking, 'oh I don't know if I can be doing with this at this moment.'³²⁶ Despite this, because the chaplain 'very quickly, realised how they should pitch their support' they found that they 'warmed to them instantly.'³²⁷ With regard to the relationship between chaplain and parent, Kelly suggests that co-construction gave parents the opportunity 'to weigh up the chaplain and allowed a relationship to be established between chaplain and parents prior to a ritual being shared.'³²⁸ As the antithesis to this, the above situation indicates that at times a chaplain needs to be able to develop an almost instant rapport. Here, rather than co-construction allowing the development of a relationship, co-creation only happened because the chaplain had rapidly established a relationship can be seen in this comment from Lewis:

It was a Methodist minister that took the funeral and their first words to me, I'll never forget them, was all children sit at the feet of God... Those opening words, I don't think that minister could have said anything better to me at that moment of time.³²⁹

Furthermore, sometimes an impression could be made even before a chaplain said anything. Sarah described how, when the chaplain came in, 'I thought yes, they're the right person to do it.'³³⁰ While recognising that this comment is made retrospectively, there is something indicative here of how, as discussed through chapter six, the bearing and presence of the chaplain is as important as their actions. Finally, as I have recounted, there are instances when the last thing that parents want from a chaplain is co-creation. Accordingly, it may be the very fact that a chaplain understands parents' need for them to 'crack on' that facilitates a relationship.

Within this section I have drawn attention to the fact that, in comparison to Kelly's findings, some parents clearly did not want co-creation and, for others, it followed the establishment of a relationship rather than facilitating it. One speculative reason for these differences comes from the socio-economic background of our participants. Coming largely from more deprived areas, it

³²⁶ Diane CR06b.

³²⁷ Alistair CR06a.

³²⁸ Kelly, Marking Short Lives, 190.

³²⁹ Lewis CR01.

³³⁰ Sarah CR11.

would be expected that my participants have lower educational attainment. Accordingly, they may have lacked the confidence to engage with a chaplain in co-creation until a relationship of trust had been established. In contrast, it is likely that Kelly's participants were better educated and may have felt greater self-assuredness in expressing their wishes from the beginning.

5.5 Parental Expectations of Chaplaincy Support

In *section* 5.2.4 I suggested that many parents shared a common desire to 'do something' in response to their loss. The intensity of this desire is shown by the fact that, despite extremely poor expectations of chaplains, parents are prepared to risk having a chaplain come and carry out these rites and rituals. All but one parent had no idea what type of support a chaplain might be able to provide or that such provision might exist: 'it's a service that I first of all I didn't expect.'³³¹ Typical comments were that parents 'didn't really know what to expect did we'³³² or that they 'didn't really know what whoever came would actually say to us.'³³³ Noticeably, the one exception was Julia, whose understanding of the support a chaplain might provide was based on previous experience. She described how 'I did see a chaplain a few years back. Obviously, they just do come round on wards and we had a chat - I forgot what I was in for - so I knew they were there to sit and listen.'³³⁴

Problematically, when parents' presumptions were explored, it was typical that they 'didn't really have high expectations'³³⁵ of the chaplain. Such findings replicate those of Kelly discussed in *section* 3.2.2. Kelly summarises the assumptions his participants had of chaplains as being 'inappropriately formal, detached and paternalistic.'³³⁶ As a damning indictment of the perception the church is held in by those outside it, all three of these descriptors can be seen in my interviews. For Lewis this took the form of expecting the chaplain to be unnecessarily churchy in appearance. He described how 'I expected kind of a robed gown something like that... I think I did expect robes walking through the door.'³³⁷ For others, the concern was that the chaplain would be excessively

³³¹ Martin CR03.

³³² Adam CR02a.

³³³ Sarah CR11.

³³⁴ Julia CR09.

³³⁵ Alistair CR06a.

³³⁶ Kelly, Marking Short Lives, 137.

³³⁷ Lewis CR01.

churchy in conduct. When you remember the context, these are parents who have just lost a baby, it is quite shocking to hear them say how, 'prior to that happened to me I would have thought the chaplain would come and preach to me and I'd be like [sigh] I don't, sort of, need this.'³³⁸ This expectation was not unique. Worrying that she would offend me, Sarah related how:

I didn't really have any expectations at all but I was [sigh] I was possibly a little bit concerned that somebody might come and, you know, an' then maybe use something from the Bible that might suggest that it was like, you know, something that we may have, you know.'³³⁹

With some gentle prompting she confirmed that her concern was that a chaplain would insinuate, or worse make quite plain, that the loss of their baby was entirely her and her partner's fault; presumably because they did not attend church or were not married. Given such a negative expectation, it is of little surprise that, before the offer of chaplaincy support, Sarah felt that a chaplain would want nothing to do with her:

I just assumed that really, because I hadn't been christened, that I couldn't really christen my children or I couldn't really have anything an' a chaplain probably wouldn't want to have any, that sounds awful, wouldn't want to have... any role in, sort of, in our family set up... So, no offence at all to you, but... I just assumed that wouldn't be something that was open... to us.³⁴⁰

For a church where mission and outreach are high priorities, the sense that, even in this traumatic situation, its representatives would want nothing to do with them, apart from judging them, should be exceedingly perturbing.

5.6 Balancing Openness and Authority

Thankfully, parents' actual experiences of chaplaincy support were that chaplains went 'above an' beyond' so that their expectations were 'completely surpassed.'³⁴¹ Rather than aloof religiosity, parents spoke about how the chaplain was 'just like a person'³⁴² and how they provided care 'in a way that was suitable for us.'³⁴³ The fitting of liturgy and ritual around their beliefs was

³³⁸ Alistair CR06a.

³³⁹ Sarah CR11.

³⁴⁰ Sarah CR11.

³⁴¹ Alistair CR06a.

³⁴² Craig CR04a.

³⁴³ Sarah CR11.

particularly appreciated by parents. As Jenny put it, 'that made it more special... everything was just as perfect as it could have been.'³⁴⁴ In light of such low expectations, particularly the concerns about inappropriate behaviour and being judged, it is worth reflecting on why parents agreed to chaplaincy support in the first place.

5.6.1 The chaplain as an authority figure

The answer comes from two strongly related reasons. I noted in *sections* 5.2.4 *and* 5.3.5 the intensity of parents' desire to do something, and how liturgy and ritual facilitated this. In this desire we see an example of what Davies calls 'words against death.' Davies argues that, through funeral rites, we 'see how human cultures assert the ongoing power of human existence despite death's ravages' and 'how death rites influence and change human identity.'³⁴⁵ Given the desire to affirm the reality and significance of their baby, the role of death rites in affecting human identity is particularly important here. As I argued in *section* 2.1.4, one of the unique skills of the chaplains within the hospital is the ability to handle liturgy and ritual. Therefore, if parents want some form of ritual, unless they have links to someone appropriate from outside the hospital, it is to a chaplain that they must turn.

However, the answer goes deeper than just the skills of a chaplain. Having been advised at the twenty week scan to terminate the pregnancy, and that their little girl probably would not survive even if she reached forty weeks, Sarah spoke about how:

I wanted her to get to twenty-four weeks because I know I wanted her to be like a person an' be recorded an' have a birth certificate. I know it sounds really ridiculous an'... my partner laughed at me for that because... it doesn't really matter when it happens you know, we know, that... she's lived. But I was like oh I want other people to know as well an', you know, the chaplain offered to do that for us and obviously we've got a certificate. a bit like a birth certificate, you know, with her name on and somebody else has acknowledged that she exists. That's really important to me, ridiculous that might sound to other people, but.. it's very important to me that... somebody else had witnessed her birth.³⁴⁶

³⁴⁴ Jenny CR02b.

³⁴⁵ Davies, Death, Ritual and Belief, 4.

³⁴⁶ Sarah CR11.

Just as anybody can carry out an emergency baptism, so any other member of hospital staff could have issued a certificate with their baby's name on it. Similarly, surely the midwives and other staff members involved in Sarah's care were also witnesses to the birth? Indeed, as the chaplain came after the baby was delivered, when compared to the midwives who were there at delivery, the chaplain might be expected to be considered less of a witness. There would seem to be something different or 'other' about how the chaplain was perceived.

5.6.2 Performative utterances

Help in understanding what this difference may be comes from the philosopher Austin's concept of performative utterances. A performative utterance is a statement that not only describes a particular situation but that also affects and changes the situation. As Austin, writes there are times when 'to say something is to do something; or in which by saying or in saying something we are doing something.³⁴⁷ There is here, clearly, a link to Rappaport's understanding of ritual's efficacy being grounded in principles of communication. Indeed, Austin notes that 'it is very commonly necessary that either the speaker himself or other persons should also perform certain other actions.'348 In the paper that introduced his concept, Austin notes that one of the key markers of a performative utterance is the question of 'what was the force, as we may call it, of the utterance.'349 In setting out his understanding more fully, it is clear that one aspect of appropriate force is that the words must be said by a person viewed as being appropriately qualified to say them. Footnoting that issues of entitlement when naming a baby are even more complex, Austin describes how, if he named a ship, but was not the person chosen to name it, the action would be viewed as being void or without effect 'because I was not a proper person, had not the 'capacity', to perform it.'350

Consequently, for 'words against death' to do their work of marking the reality of their baby and affirming the significance that the baby has to them, parents want them to be said with appropriate force and authority. Something of this

³⁴⁷ John L. Austin, *How to Do Things with Words*, ed. James O. Urmson (Oxford: Clarendon Press, 1962), 12.

³⁴⁸ Austin, How to Do Things with Words, 8.

³⁴⁹ John L. Austin, 'Performative Utterances', in Robert J Stainton (ed.), *Perspectives in the Philosophy of Language: A Concise Anthology* (Peterborough ON: Broadview Press, 2000), 252.

³⁵⁰ Austin, How to Do Things with Words, 23.

desire for statements and support to have a certain status can be seen in Alistair's earlier comment that it was important to do something 'proper' to recognise his son's birth. Against such a view it might be argued that witnessing a birth or giving a certificate are not words against death or performative utterances. To counter this I would draw attention to Austin's comment that words and actions conjoin in performative utterances, as well as Davies's belief that words against death can be 'both literal and metaphorical.'³⁵¹ Further support would also come from the way that, as discussed in *section* 8.4.5, parents understood the support of a chaplain in terms of a whole, rather than as separate episodes.

5.6.3 Religious or spiritual authority

In my outlining of the role of a chaplain in section 2.1.5, I referenced the many unspoken signals that are at play within any chaplain-patient encounter. As Steve Nolan writes, 'chaplains begin their relationship as an evocative presence, which is rooted in the transferential response that characterizes all human contact.'352 Even if they are sometimes unconscious, one of these influences is the representative associations that a parent makes with the word chaplain. In light of his findings, Kelly writes 'in matters of ritual efficacy, where the eternal destiny of a dead baby is concerned, church representatives are perceived to have immense authority by a number of parents.'353 That their baby would go to a safe and happy place was important for various parents in my study. Attempting to explain how the liturgy and ritual had helped her, Liz responded 'I just think it gave me a sense of peace... I had to believe that he was in a better place, you know, nobody could hurt him now.'354 Yet, alongside having authority in relation to heavenly realms, I wish to suggest that there is another realm where chaplains are perceived to have authority. This, as can be seen in sections 5.3.2, 5.3.4 and 5.5 is to do with matters of meaning, purpose, personhood and identity. Efficacy concerning the eternal destiny of a baby is perhaps best understood in terms of providing religious care. In contrast, notions of relational meaning and identity fit much more with the understanding of spiritual care I outlined in section 2.2.2.

³⁵¹ Davies, Death, Ritual and Belief, 4.

³⁵² Steve Nolan, 'Hope Beyond (Redundant) Hope: How Chaplains Work with Dying Patients', *Palliative Medicine* 25, no. 1 (2011), 23.

³⁵³ Kelly, Marking Short Lives, 213.

³⁵⁴ Liz CR05.

As recognised by the Church of England's review of the work of its Hospital Chaplaincies Council, there is considerable tension and dispute as to how chaplains should to respond to the changing context they face.³⁵⁵ Part of this centres around whether chaplains are providers of religious care, or a more widely focused spiritual care. Reflecting on his auto-ethnography - the ethnographic study of his own chaplaincy work - Swift states that 'scratch below the surface and the reality of what chaplains do appears to remain resiliently religious - albeit in a more fragmented and less prescriptive manner.'356 As a result, he wondered if spiritual care has been written about far more than it has been enacted.³⁵⁷ I am sympathetic to Swift's contention. An analysis of the comments made by parents in their interviews, alongside answers given in the RFQ, in the vast majority of cases, supports this. For example, Sarah, in section 5.5, was concerned about affirming the personhood of her baby; something I have suggested relates to spiritual care. Furthermore, she described herself as having a spiritual understanding of life and not identifying with a specific religion. However, in relation to the care provided, she talks about how the chaplain provided 'religious support... but in a way that was suitable for us.³⁵⁸ Another example, looking from a different perspective, comes from parents who described themselves as non-religious in understanding, did not identify with a particular religion, and did not engage in any religious practices. Yet, indicative of a desire for 'religious' care, in their interviews they spoke about concerns over the eternal destiny of their babies.³⁵⁹ Only in one interview, with Craig and Claire, is there a sense that it was entirely spiritual care, rather than religious care, that was provided. Such findings support Swift's assertion, mentioned in section 2.1.3, that it is religious authority rather than religion itself that people have rejected. Building on this, I would suggest that, in many cases, good non-dogmatic religious care helps meet spiritual need. Such flexibility in listening to, discerning and responding to the need of parents requires, as Andrew Todd states, 'considerable openness on the part of

³⁵⁵ Church of England, 'Health Care Chaplaincy and the Church of England: A Review of the Work of the Hospital Chaplaincies Council' (Report, London, 2010), section 7, <u>http://www.nhs-chaplaincy-spiritualcare.org.uk/HCC%20Review%20-%20Final%2031.3.10.pdf</u>. [accessed 4 June 2012]

³⁵⁶ Swift, Hospital Chaplaincy, 142.

³⁵⁷ Swift, Hospital Chaplaincy, 143.

³⁵⁸ Sarah CR11.

³⁵⁹ Cf in particularly parents CR10a and CR10b and, to a lesser extent CR02a.

the chaplain as well as the wisdom to know when a particular spiritual need requires referral to another practitioner.³⁶⁰

Drawing the above paragraphs together I contend that, paradoxically, the main reason that parents are willing to risk 'Bible-bashing' and judgement is because, alongside a skill in liturgy and ritual, they see chaplains as representing a form of authority, be that religious, spiritual, or a combination of both. This leaves the intriguing question of where the source of this authority stems from. Is it, for example, because chaplains are seen a being authorised in some way by the faith community? Alternatively, is it because they are viewed as a member of that community and, therefore, understood to hold certain beliefs and partake of certain practices? Although I do not have the evidence to discern an answer, my instinct is that it is the latter. As recently noted, it appears that it is religious authority rather than religion that people have rejected. Accordingly, it seems unlikely that parents would desire 'the church' to validate the reality and significance of their baby. Instead, it seems more likely that chaplains' authority derives from an understanding that they have reflected on the meaning and purpose of life and so hold certain beliefs that parents may wish to ascribe to, but be uncertain about. We see an example of this in the concern various parents showed over eternal destiny of their baby despite, in their RFQ answers, not being sure about the existence of life after death.

There is a tension between parents worrying about being the recipient of paternalistic and judgemental attitudes while, at the same time, wanting authoritative statements and recognition. In the mêlée of emotions that parents go through, such incongruences are not really surprising. Paradoxical need has been found in other bereavement research. For example, when examining the needs of parents in a paediatric intensive care unit in Michigan, Kathleen Meert *et al.* describe how often 'within individual narratives dynamic and conflicting needs were evident.'³⁶¹ This understanding of contradictory need, and of chaplains having to make subtle and almost instant judgements of what support is wanted, may help explain an early chaplaincy experience of mine. One afternoon in February 2007 I was called to the labour ward to see parents who had suffered a stillbirth. Before going in to see the parents, I was informed

³⁶⁰ Andrew Todd, 'Responding to Diversity: Chaplaincy in a Multi-Faith Context', in Threlfall-Holmes and Newitt (eds.), *Being a Chaplain*, 97.

³⁶¹ Meert *et al.*, 'Examining the Needs of Bereaved Parents ', 723.

by the midwife that they were not religious. Having entered the room, from my initial conversation with them, it was clear that they were uncomfortable with references to God occurring within a naming ceremony. My only resource at that point was a liturgy for naming, blessing and commending a baby to God. Consequently, before carrying out the ceremony, I spent time with them going through the constituent parts of this service and asking where they might want some of the language used changed, or removed altogether. It was later fed back to me that, when it came to the funeral, the parents had requested a different chaplain because they thought I was too unsure of myself. Rather than cocreation, it may be that what those parents were wanting was for decisions to be taken out of their hands and for me to simply get on with things. Linked to that, despite not being religious, they may well have preferred a liturgy with religious content if it meant someone was acting with an appropriate authority to lend gravitas and meaning to the situation.

5.7 Ritual Communitas and Koinonia

In section 2.1.1 I noted literature that described a lack of clarity among chaplains as to role and identity. The paradoxical context described above, of a society that has rejected religious authority, and yet of parents wanting liturgy and ritual led authoritatively, may be one reason for this. On several occasions I have heard chaplains wondering if, at times, they act as something akin to a shaman or witch doctor. Indeed, reflecting on the diversity of roles which a chaplain is perceived to enact and embody by parents, Kelly writes of the chaplain acting as a shaman. He relates this to the need for a chaplain during ritual to 'be touched and moved and run the risk of being overwhelmed.'362 It is not clear where Kelly takes his understanding of a shaman being overwhelmed from. I presume he derives it from the way shaman undertake a mystical journey through entering a trance state. Whether shaman are 'overwhelmed' or not may be a moot point. However, I am not convinced that Kelly evidences notions that chaplains run the risk of being overwhelmed nor, from personal experience, do I think it true that they do. That said, a chaplain being emotionally overwhelmed at a baby's funeral is so far removed from a shaman's ecstatic trance that it is debatable whether the comparison really gets off the ground in the first place. Moreover, there are good anthropological

³⁶² Kelly, Marking Short Lives, 222.

reasons why it is not a helpful analogy to pursue. Firstly, shamanism as a category 'simply does not exist in a unitary and homogeneous form.'³⁶³ This can lead to the confusing situation where 'terms such as shaman, medicine man, diviner, witch doctor, medium, healer, and others are often used interchangeably and without specification of the assumed common characteristics or consideration of the possible differences among such practitioners.'364 Secondly, when classifying magico-religious practitioners, despite certain overlapping characteristics, anthropologists find good ethnographic evidence to group shamans and priests separately.³⁶⁵ Unsurprisingly, given that many chaplains are ordained or licensed ministers of one type or another, there is greater similarity between chaplains and priests than between chaplains and shamans. The principal difference is that shamans work in another reality, generally through entering ecstatic or meditative trance states, while priests work in ordinary reality.³⁶⁶ Another difference is that, rather than a shaman's 'divine stroke' and personal communication with a supernatural being, priestly authority is derived from competence with codified and standardised ritual knowledge.367 While there is no set liturgy for various of the situations chaplains encounter, in co-creating rites they are likely to follow similar patterns and draw on the 'deep structure' of ritual to generate fresh manifestations.

As I stated in *section* 2.1.4 my purpose in this thesis has not been to investigate the nature of ritual. However, a brief exploration of some anthropological insights will help illuminate aspects of the chaplain's role and identity. The notion of a 'deep structure' to ritual can be traced back to the work of the anthropologist Arnold van Gennep who argued that there was a basic threefold pattern behind the wide range of human rituals 'which accompany a passage from one situation to another or from one cosmic or social world to another.'³⁶⁸ Using the Latin term *limen*, meaning threshold, these 'rites of passage' were described by him as preliminal rites (rites of separation), liminal rites (rites of

Study of Their Origins, Nature, and Social Transformations', *Ethos* 18, no. 3 (1990), 309.

³⁶⁵ Cf. for example, David Hicks, (ed.), *Ritual and Belief: Readings in the Anthropology of Religion*, (Plymouth: AltaMira Press, 2010), 133; Winkelman, 'Shamans', 312.

³⁶⁷ Victor W. Turner, 'Religious Specialists', in David Hicks (ed.), *Ritual and Belief: Readings in the Anthropology of Religion*, (Plymouth: AltaMira Press, 3rd ed. 2010), 140.

 ³⁶³ Jane Monnig Atkinson, 'Shamanisms Today', Annual Review of Anthropology 21 (1992), 308.
 ³⁶⁴ Michael James Winkelman, 'Shamans and Other "Magico-Religious" Healers: A Cross-Cultural

³⁶⁶ Merete Demant Jakobsen, Shamanism: Traditional and Contemporary Approaches to the Mastery of Spirits and Healing (New York: Berghahn Books, 1999), 8.

³⁶⁸ Arnold van Gennep, *The Rites of Passage*, trans. Monika B. Vizedom and Gabrielle L. Caffee (London: Routledge & Kegan Paul Ltd, 1960), 10.

transition), and postliminal rites (rites of incorporation).³⁶⁹ As Davies comments, rather than rites of passage, van Gennep might have called not just the middle stage but the overall pattern 'rites of transition' as transition is the key term with ritual activity helping people forge a new sense of purpose, duty, or status.³⁷⁰ At a simple level this can be seen in the concern of some parents that their baby is transferred safely to the heavenly realms. It is also possible to understand a process of transformation being at work in the situations where parents valued ritual for affirming the reality of their baby.

Although all three phases are normally part of a ritual they are not necessarily equally important or elaborated. Van Gennep argued that liminal rites are dominant within funeral rites.³⁷¹ Victor Turner, for whom the liminal stage was a particular interest, suggests that 'being in a tunnel' might better describe the often hidden nature and mysterious darkness of the liminal phase.³⁷² Aspects of this can be seen in the comments by parents in section 5.2.1 about feeling isolated, there being no guidelines and not knowing what to do next. From his studies of times of liminality Turner developed the notion of communitas 'as the experience of those in the state of liminality.'373 Turner argued that in the transition from one position, structure or status to another there are moments when hierarchy, rank and class marks disappear, resulting in a 'spontaneously generated relationship between leveled and equal total and individuated human beings.'374 The rapid forming of a deep bond between parents and the chaplain that supported them, explored in section 6.2, provides a good example of *communitas*. Davies suggests that the anthropological term communitas has much in common with the theological term koinonia, describing communitas as 'a natural sacrament of koinonia.'375 Biblically, as a concept, koinonia embraces notions of community, sharing and intimacy.³⁷⁶ Indicative of this, within their interviews several parents spoke about how the ritual ceremony brought them closer together as a family. Lewis, for example, described how his 'parents came in and... it unified us as we all stood round...

³⁶⁹ Gennep, The Rites of Passage, 11.

³⁷⁰ Davies, Anthropology and Theology, 123.

³⁷¹ Gennep, The Rites of Passage, 146.

³⁷² Victor W. Turner, Dramas, Fields, and Metaphors: Symbolic Action in Human Society (London: Cornell University Press, 1974), 232.

³⁷³ Davies, Davies, Anthropology and Theology, 124.

³⁷⁴ Turner, Dramas, Fields, and Metaphors, 238.

³⁷⁵ Davies, Anthropology and Theology, 129.

³⁷⁶ Wesley J. Perschbacher, (ed.), *The New Analytical Greek Lexicon*, (Peabody MA: Hendrickson, 1990), 242.

an' blessed him.'³⁷⁷ In *section 5.4*, I questioned whether co-creation leads to trust or trust enables co-creation. It is interesting, therefore, to note Davies's statement that 'trust typifies both *communitas* and *koinonia*.'³⁷⁸ Indeed, the cocreation of ritual and liturgy strongly resonates with his comment that it 'is as creatures of God, made in the divine social image, that people and priest reach out to help one another.'³⁷⁹

I have elsewhere written about the various ways that chaplaincy may be understood in terms of marginality and liminality.³⁸⁰ As Threlfall-Holmes and I comment at that point, the terms marginal and liminal are often used interchangeably, with various distinct yet overlapping meanings. As Davies notes, care should be taken not to confuse a more permanent marginality with the temporary being 'on the border or edge of mainstream social life' of liminality.³⁸¹ It is the former, more permanent isolation, I suspect that Swift has in mind when he describes how chaplains occupy multiple marginalities:

Not simply on the margins between the parochial system central to diocese and the medical paradigm that dominates the hospital, but between life and death... a Christendom past and a contemporary spirituality that has rejected the rights of external authority.³⁸²

In relation to the medical paradigm, Frances Norwood writes of chaplains being marginalised in a manner that is,

communicated in multiple ways, from the structural (e.g., spatial arrangement of hospital space and staff hierarchies that limit chaplain contact with patients) to the ideological (e.g., staff stereotypes and assumptions of chaplains and chaplain[cy] work that limit their inclusion in hospital routines).³⁸³

While that may be true, much of a chaplain's support of bereaved parents can be perceived in terms of liminality; be that helping parents confront the threshold between life and death or by their very presence opening up the

- ³⁸¹ Davies, Anthropology and Theology, 124.
- ³⁸² Swift, Hospital Chaplaincy, 173.

³⁷⁷ Lewis CR01.

³⁷⁸ Davies, Anthropology and Theology, 129.

³⁷⁹ Davies, Anthropology and Theology, 129.

³⁸⁰ Miranda Threlfall-Holmes and Mark Newitt, 'Introduction', in Miranda Threlfall-Holmes and Mark Newitt (eds.), Being a Chaplain, (London: SPCK, 2011), xv-xvi.

³⁸³ Frances Norwood, 'The Ambivalent Chaplain: Negotiating Structural and Ideological Difference on the Margins of Modern-Day Hospital Medicine', *Medical Anthropology* 25, no. 1 (2006), 16.

possibility of an encounter with the transcendent. Given this, a lack of clarity among chaplains as to role and identity is not surprising, for, as Turner writes, the characteristics of 'threshold people' are:

necessarily ambiguous, since this condition and these persons elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, connection, and ceremonial.³⁸⁴

Whether a result of liminality or marginality, being perceived as on the border or edge of mainstream hospital life does bring potential benefits. Several parents expressed a view of chaplains as part of the hospital, but separate from all that was happening to them medically, grateful that 'somebody from the outside was able to comfort us.'³⁸⁵ Linked to this, and supporting my earlier contention that chaplains are able to listen in a different way to other health professionals, one interviewee, Claire, related how she appreciated that the chaplain 'wasn't like... a nurse or somebody, that wasn't going to... give you [laughs] injections, or it wasn't a doctor that was going to prod you.'³⁸⁶

5.8 Chaplains and intuition

In *section 2.2.3*, I stated that, amongst other skills, chaplains make use of intuition and compassion. Intuition may be understood as 'the immediate apprehension of an object by the mind without the intervention of any reasoning process.'³⁸⁷ The inclusion of bypassing reasoning within that definition is interesting as research has shown that processing emotions is quicker than reasoning processes.³⁸⁸ Accordingly, the use of intuition may be particularly important in helping chaplains make the almost instant decisions needed when supporting parents. While the use of emotions is discussed within *section 7.2.2*, I will briefly explore how intuition might function.

As a topic, intuition has received considerable debate within nursing literature. Typically the term is 'linked to expertise and is often defined as a characteristic

³⁸⁴ Victor W. Turner, *The Ritual Process: Structure and Anti-Structure* (London: Penguin Books, 1969), 81.

³⁸⁵ Liz CR05.

³⁸⁶ Claire CR04b.

³⁸⁷ OED Online, March 2012, s.v. 'intuition, n.', <u>http://www.oed.com/view/Entry/98794?</u> <u>redirectedFrom=intuition</u> [accessed 27 April 2012].

³⁸⁸ John McKinnon, 'Feeling and Knowing: Neural Scientific Perspectives on Intuitive Practice', Nursing standard 20, no. 1 (2005).

trait of the expert nurse.'389 It would not be appropriate, within the scope of this study, to explore all the argument around nursing intuition. However, I do find helpful Judith Effken's suggestion that nursing intuition is a form of what James Gibson in The Ecological Approach to Visual Perception termed 'direct perception.' This is the belief that:

The array of information in our sensory receptors, including the sensory context, is all we need to perceive anything. In other words, we do not need higher cognitive processes or anything else to mediate between our sensory experience and our perceptions. Existing beliefs or higher-level inferential thought processes are not necessary for perception.³⁹⁰

Importantly, perception is not limited to the physical world. Instead, the richest and most elaborate information may actually come from other people. As Gibson writes, 'sexual behaviour, nurturing behaviour, fighting behaviour, cooperative behaviour, economic behaviour, political behaviour - all depend on the perceiving of what another person or other persons afford, or sometimes on the misperceiving of it.³⁹¹ I find this view attractive for a couple of reasons. Firstly, it means that intuition is 'no longer focused solely on the expert's cognitive (or perceptual) processes, but also on the information provided by the patient and the context of care.'392 As a result, within chaplaincy, as Anita Smith states of nursing, while experience is an influential factor in the skilful use and application of intuition, it may be used by practitioners of all levels.³⁹³ This understanding recognises that 'although some aspects of direct perception are hard-wired through evolution, much of perception, and by extension, intuition, is learned through years of practice.'394 In section 2.1.2 I described the giving of attention as one of a chaplains skills. Noticeably, in light of this, perceptual learning is viewed 'as the education of attention.'395

³⁸⁹ Anita Smith, 'Exploring the Legitimacy of Intuition as a Form of Nursing Knowledge', Nursing standard 23, no. 40 (2009), 35.

³⁹⁰ Robert J. Sternberg, Cognitive Psychology (Belmont CA: Wadsworth Cengage Learning, 5th ed. 2009), 101.

³⁹¹ James J. Gibson, The Ecological Approach to Visual Perception (Hillsdale NJ: Lawrence Erlbaum, 1986), 135.

³⁹² Judith A. Effken, 'Informational Basis for Expert Intuition', Journal of advanced nursing 34, no. 2 (2001), 252.

³⁹³ Smith, 'Exploring the Legitimacy of Intuition', 37.

³⁹⁴ Effken, 'Informational Basis for Expert Intuition', 247.
³⁹⁵ Effken, 'Informational Basis for Expert Intuition', 251.

5.9 Summary

In chronicling the spiritual needs of parents, I have suggested that underlying all other need was a loss of control. Alongside this I identified three further themes: a loss of meaning and purpose, a loss of self worth, and a desire to do something. This latter theme is a new theme arising from this study while the other themes confirm the findings of Kelly. With regard to social isolation, another of Kelly's themes, fewer comparable experiences were found. I suggested that this was due to both individual personality traits and greater time post-bereavement of my participants. The liturgy and ritual provided by chaplains was shown to help meet each of the spiritual needs identified. In addition, I drew attention to the way in which parents valued mementos, such as certificates of naming and blessing, that were given following ceremonies.

It is clear that chaplaincy support to parents does not fit a one size fits all response. While some parents appreciated the giving of information and options, others simply wanted the chaplain to take authoritative action. Consequently, I highlighted the fact that co-creation may not always be appropriate. Almost universally, participants in this study had limited or poor expectations about the support chaplains would provide. In light of such expectation, I suggested two reasons why parents wanted chaplaincy support. Alongside the ability to handle ritual and liturgy, chaplains were regarded as authoritative in both religious matters concerning the eternal destiny of babies, and also in spiritual questions of meaning and identity. I continued by postulating that a lack of clarity among chaplains as to their role may, in part, be due to the contradictory tensions arising from a society that has rejected religious authority, and yet of parents wanting authoritative action. In seeking greater comprehension about role and identity, I argue that insights from anthropologists concerning ritual are more helpful than seeing the chaplain as analogous to a shaman. Lastly, I found value in the suggestion of intuition as a form of direct perception rather than an expert trait.

Implicit within much of this chapter's discussion is the notion that the bearing and presence of the chaplain in being with parents is as important as the liturgy and ritual that they carried out. I now turn to explore the different ways that parents valued the presence of a chaplain.

6. <u>More than Marking Short Lives: Valuing the</u> <u>Presence of a Chaplain and Faith Development</u>

Inherent within various of the concepts discussed in the last chapter was the notion that the liturgy and ritual performed by chaplains was most meaningful to parents when it was accompanied by the chaplain relating well to them. This perception is developed and explored through the first two sections of this chapter. *Section* 6.1 begins with a discussion of the various ways in which parents valued the presence of a chaplain. Drawing on both attachment and community theories, *section* 6.2 continues by examining reasons for the depth of relationship that could be formed between parents and chaplains. Related to this, *section* 6.2.3 notes the need for chaplains to 'let go' of parents they have supported previously in order to avoid burnout. The last part of the chapter, *section* 6.3 acts as an excursus exploring the unexpected finding that various parents spoke of the development of religious or spiritual belief.

6.1 Chaplaincy Presence

6.1.1 Presence as attentive listening

Alongside the liturgy and ritual that a chaplain carried out, parents also valued the presence of the chaplain being with them. This took a number of different though related forms, with parents principally valuing the presence of the chaplain in listening. Parents spoke about how a chaplain 'just sat there and listened to me'³⁹⁶ or how when a chaplain came into the room 'they sat down an' they listened.'³⁹⁷ As with the use of liturgy and ritual and some parents wanting options while others wished for authoritative action, there is not a one size fits all response to the presence of a chaplain. Diane described how the chaplain was 'there a good hour that first day I'm sure.' ³⁹⁸ Likewise, Wendy spoke of how the chaplain 'just sat and listened to me again and again and again, which was brilliant.'³⁹⁹ In contrast, Olivia recounted how the chaplain was not there for very long. This, though, was entirely apposite because, as she notes, 'I mean..., I don't think I'd have wanted them there for

³⁹⁶ Julia CR09.

³⁹⁷ Diane CR06b.

³⁹⁸ Diane CR06b.

³⁹⁹ Wendy CR07.

ages but the length of time they were there was right.⁴⁰⁰ The appropriateness here, of the chaplain arriving, carrying out the ritual and fairly quickly departing, can be contrasted with the discussion in *section 5.4* where a chaplain doing something very similar was clearly wrong for those parents.

Reflecting the DIPEx findings quoted in chapter five concerning the ability of chaplains to take on others' sadness without trying to fix everything, Claire described how the chaplain 'could be supportive without even talking, you know, that's the sort of support they give you... some of... the silence was like, you know, effective.'⁴⁰¹ In outlining the skills of a chaplain, in *section 2.1.2* I drew a link between listening and attending. The depth of the attending by chaplains to the parents' situation and story helped them to feel that they mattered, that they were worthy of attention. Diane described how the chaplain 'was definitely interested in us as people an', as I said, really listened... They weren't just going through the motions.'⁴⁰² For some parents this attention was in direct contrast to their perceptions of other staff. Julia stated how 'with the chaplains... I got tret better than I did by the hospital staff', and how her treatment by one member of staff left her thinking 'you've got no feeling.'⁴⁰³ A lack of empathy was also commented on by Liz:

At the time, how can I put this without sounding, [laughs] at the time I thought, particularly the nurses, I thought because they'd probably seen it that often it's like goes over their head and sometimes they come across like, well you know, it's happened an' just get on with it... it's a bit raw it's just happened an', you know, they don't seem too concerned.⁴⁰⁴

The use of words or phrases within funerals that chaplains had picked up on by careful listening was commented on by several parents:

I really noticed, we both, well we all noticed an' all our family did, when the chaplain... were, like, saying what they needed to say they picked up all little things about him like we called him grumpy bum. We never told the chaplain that we called him that, just how they picked up on that... were right nice weren't it. ⁴⁰⁵

⁴⁰⁰ Olivia CR08.

⁴⁰¹ Claire CR04a.

⁴⁰² Diane CR06b.

⁴⁰³ Julia CR09.

⁴⁰⁴ Liz CR05.

⁴⁰⁵ Katy CR10b.

Yeah, through us talking... it's just showing that they're caring and they're listening and that [it's not] just through one ear and out the other, do you know what I mean, nice to know that people listen to you. 406

This helped give parents a further sense that chaplains were not just going through the motions. 'I could tell by like the words they were saying at the funeral that they, you know, they had listened to us talking to them, they weren't just reeling off some standard spiel.'⁴⁰⁷ The fact that several parents mention the idea of a standard spiel or going through the motions hints at further poor expectations that chaplains would be cold and insensitive with just a stock response that they trotted out. Instead, parents were grateful that chaplains 'treat us individual instead of like, you know what I mean don't ya.'⁴⁰⁸

6.1.2 The chaplain as a constant and/or consistent presence

Perhaps not surprisingly, for Wendy, who had a long stay of about seven weeks on the neonatal unit, the chaplain became a consistent point of contact and she greatly valued having the same person supporting her:

I think the one of the import things is having the same face... and obviously people need days off [laughs] I appreciate that, but at the same time... they... became the one constant. Whereas the nursing staff and the medical staff, you know, the doctors were to a certain extent rotating... and there are some people that sometimes you'll see people and sometimes you won't, but that was kind of like one constant... and then the chaplain saw us all the way through.⁴⁰⁹

Similar comments, though, were made by parents who were in hospital for a shorter time. Craig described how there were so many midwives, which meant 'constantly it's someone new and you're having to explain, again an' you just get sick of that.'⁴¹⁰ They therefore greatly appreciated having the hospital chaplain that did the naming and blessing doing the funeral:

Having the consistency... of it being the same person I think that was a big help. Probably more than anything actually having it be the same person 'cos you see that many midwives... an' things an' in that

⁴⁰⁶ Thomas CR10a.

⁴⁰⁷ Craig CR04a.

⁴⁰⁸ Thomas CR10a.

⁴⁰⁹ Wendy CR07.

⁴¹⁰ Craig CR04a.

particularly experience it's just you need, I think you benefit from some sort of constant.'411

The same sentiments were shared by Martin, although, unfortunately, it was not possible because the chaplain was away on annual leave:

My son's baptism it was done by the chaplain and after that... we wanted them also to be to be present in our son's burial but... they informed us that probably wouldn't be around by then, but they arranged for somebody else to take over.⁴¹²

When speaking about the chaplain as a consistent or constant presence, clearly the chaplain was not with these parents all the time. Alongside the quality of attentive listening, the chaplain's availability when needed was important. Katy described how 'it were nice that the chaplain were there whenever we needed them, we could just ask for them and they were here.'⁴¹³ Speaking with a sense that this was not always the case with other staff, Diane described how the chaplain:

Phoned when they said they were going to phone. They were there when they said they would be so there was no, like, [sigh] I can't get hold of the chaplain... If they were out, obviously couldn't be on call night or day, but if they were they would phone back in the time that they said they would phone back.⁴¹⁴

There is a strong sense here of Martin Israel's statement that 'the best way of healing a person in spiritual distress is to be with him constantly.'⁴¹⁵ Noticeably, in light of the experiences just commented on, Israel continues by noting that this does not mean never leaving their side. Instead, what he suggests is needed is holding the person in prayer and being available to them in direct encounter and by telephone when needed.

6.1.3 Presence as comfort and strength

Writing about the availability of the chaplain, Kelly comments that 'the natural attributes of the chaplain and how he or she utilised these in relation to parents was of profound significance to them.'⁴¹⁶ Although I do not think

⁴¹¹ Craig CR04a.

⁴¹² Martin CR03.

⁴¹³ Katy CR10b.

⁴¹⁴ Diane CR06b.

⁴¹⁵ Martin Israel, The Pain That Heals: The Place of Suffering in the Growth of the Person (London: Continuum, 2001), 180.

⁴¹⁶ Kelly, Marking Short Lives, 200.

this is how Kelly intends it, this statement could be taken to indicate that the different personal attributes of individual chaplains were key to the relationship they made with a parent. Clearly, chaplains are all individuals and, as a result, may well 'hit it off' better with some people than others. However, I would argue that personal attributes, or to pre-empt the discussion in chapter seven, 'virtues' such as empathy, compassion and integrity should be generic to all chaplains. Accordingly, it should not matter which chaplain a parent is supported by; provided the chaplain accurately judges what support is needed, they will be able to establish a therapeutic relationship. This is implied in the common valuing of different chaplains made by parents in my interviews, but made particularly clear in the experience of Martin. As seen in the quotation from his interview above, the chaplain who baptised his son was not available to carry out the funeral and a different chaplain carried out this service. Alongside those two chaplains, Martin also saw a third chaplain, the on-call chaplain who came and said prayers of commendation when treatment was withdrawn. In his interview Martin stated that 'the presence of the chaplaincy [was] really... very vital and it helped me quite a lot.'417 On further questioning, he names specific attributes he found helpful in the chaplaincy team, but does not link them to individual chaplains:

I can't name individual circumstances but in general... I can just record very well because it happened, I think it should be about six months ago now... if I can recall, it's just a feeling of comfort really and a feeling of... confidence that, you know, irrespective of what has gone on there was somebody there... to, sort of, be there for us in terms of... emotional... I found a lot of compassion in it anyway and a lot of understanding.⁴¹⁸

The comfort Martin describes being brought by chaplaincy support is implicit in all the interviews and can be sensed in many of the quotations above. Comfort obtained by the presence of a chaplain is an important theme in the Nolan's recent work researching hospice chaplaincy. As an accompanier, Nolan suggests that chaplains bring comfort 'not in an anodyne, "tea and sympathy" sense, but in the original Latin sense of *confortare* - "to strengthen".' ⁴¹⁹ Something of this is reflected in Thomas's description of how the presence of the chaplain made it possible for him to tell his partner that their baby had

⁴¹⁷ Martin CR03.

⁴¹⁸ Martin CR03.

⁴¹⁹ Nolan, 'Hope Beyond (Redundant) Hope', 24.

died, 'yeah they made it a bit easier for me to tell Katy what happened an' what have you 'cos they were there, I don't think I could... have done that on my own to be honest.'⁴²⁰ A further sense of the strengthening comfort brought by chaplains can perhaps be seen in the embodiment of hope that some parents describe. This is picked up further in *section* 7.4 as part of the discussion of chaplaincy virtues in chapter seven.

6.2 A Relationship of Depth

Unsurprisingly, given the comments in section 6.1.2 regarding the chaplain as a constant, several parents spoke about a real depth of relationship with the chaplain who supported them. Diane and Alistair, for example, described how 'we've never forgot the chaplain have we'⁴²¹ and how, following the funeral, they had commented that it was 'really sad that we won't see the chaplain again... because they went, almost felt like they went through that with us, you know..., they felt really close to us.'422 Echoing those sentiments Jenny spoke about how she felt really close to the chaplain because 'they've seen her, they've, you know..., sort of sent her on her way.'423 In other interviews, even if not directly mentioned, it was clear that a strong bond had often formed from the way that parents could remember the name of the chaplain who had provided them with the majority of their support. Likely reasons for the depth of these relationships being formed, in what was often a short space of time, are provided by concepts within both community and attachment theories. Those from attachment theory will be discussed first, and then insights from theories of community building.

6.2.1 Attachment theory

Attachment theory was developed by John Bowlby and refers to 'the propensity of human beings to make strong affectional bonds to particular others.'⁴²⁴ Bowlby's work was developed by others, particularly Mary Ainsworth, whose major contribution was 'the explanation of individual differences in

⁴²⁰ Thomas CR10a.

⁴²¹ Diane CR06b.

⁴²² Alistair CR06a.

⁴²³ Jenny CR02b.

⁴²⁴ John Bowlby, 'The Making and Breaking of Affectional Bonds. I. Aetiology and Psychopathology in the Light of Attachment Theory. An Expanded Version of the Fiftieth Maudsley Lecture, Delivered before the Royal College of Psychiatrists, 19 November 1976', *The British Journal of Psychiatry* 130, no. 3 (1977), 201.

attachment relations and the concept of the caregiver as secure base.^{'425} In terms of caregiver as secure base, Ainsworth's point was that a mother figure 'need not be the natural mother but can be anyone who plays the role of principal caregiver.^{'426} This is because a baby will become attached to any adult who is sensitive and responsive towards them on a consistent basis. With regard to adults, Ainsworth suggests that people who might act as a surrogate attachment figure 'include mentors, priests or pastors, or therapists.'⁴²⁷ Such a view is backed up by Ann Masten and Jelena Obradovic who, drawing on research looking at resilience, state that 'humans appear to form attachment-like relationships with spiritual figures and religious leaders that may provide a secure base analogous to a parent attachment.'⁴²⁸ Importantly, secondary or supplementary attachments may differ from primary attachments in the length of time that they last. Ainsworth makes this point in relation to therapeutic relationships:

It may be very influential for a limited period in a person's life, but when therapy has been terminated, the active relationship usually ceases. To be sure, the therapist and his or her influence may continue to be valued, and the representational model of the relationship may persist. In that sense the attachment continues, even if the active connection has ceased.⁴²⁹

That the influence continues to be valued after the active relationship has ceased is evident in several parents' comments. It is particularly well described by Wendy as she recalled seeing the chaplain that supported her at the annual baby memorial service:

Again it was that... bond that we had... and that's something I still cling to because that's a part of my, part of their, memory, part of that little world that I only saw for a short time in theory, but it's still there and it's still important to me.⁴³⁰

⁴²⁵ Inge Bretherton, 'The Roots and Growing Points of Attachment Theory', in Colin Murray Parkes, Joan Stevenson-Hinde, and Peter Marris (eds.), *Attachment across the Life Cycle* (London: Routledge, 1991), 9.

⁴²⁶ Mary D. Salter Ainsworth, 'Infant-Mother Attachment', American psychologist 34, no. 10 (1979), 932.

⁴²⁷ Mary D. Salter Ainsworth, 'Attachments Beyond Infancy', American Psychologist 44, no. 4 (1989), 711.

⁴²⁸ Ann S. Masten and Jelena Obradovic, 'Disaster Preparation and Recovery: Lessons from Research on Resilience in Human Development', *Ecology and Society* 13, no. 1 (2008), macrosystems section, <u>http://www.ecologyandsociety.org/vol13/iss1/art9/</u>.[accessed 21 May 2012]

 ⁴²⁹ Mary D. Salter Ainsworth, 'Attachments and Other Affectional Bonds across the Life Cycle', in Parkes, Stevenson-Hinde, and Marris (eds.), *Attachment across the Life Cycle*, 37.
 ⁴³⁰ Wendy CR07.

Community theory 6.2.2

In relation to patterns of mothering, Robert Hinde and Joan Stevenson-Hinde write that 'at a general level, sensitive responsiveness is likely to be a precursor to security or attachment.^{'431} If this applies to other relationships as well, we can see how, in a time of crisis when they feel out of control, the care and sensitivity shown by chaplains towards parents facilitates the development of bonds of attachment. The reason for the strength of these bonds can be seen by looking at theories of community. In their definition and theory of a sense of community, David McMillan and David Chavis set out four elements. The last of these is a shared emotional connection.⁴³² Two of the features that go towards expanding this element are particularly important to our consideration of the bond between a parent and a chaplain. The first is what they term the 'quality of interaction', noting how 'the more positive the experience and the relationships, the greater the bond. Success facilitates cohesion.'433 We can see a clear example of this in the connection made by Diane and Alistair with one chaplain and not another, as discussed in section 5.4. The second feature is what McMillan and Chavis call 'shared valent event hypothesis.' This rather strange term denotes the simple principle that 'the more important the shared event is to those involved, the greater the community bond. For example, there appears to be a tremendous bonding among people who experience a crisis together.'434 It seems rather redundant to say that the loss of a baby is hugely significant to parents. Within this experience chaplains are, as Kelly notes, among the few people who will have seen a parent's baby and, perhaps more importantly, acknowledged and validated the depth of attachment and loss they felt.⁴³⁵ In saying this, I am not suggesting that strong bonds might not be formed by parents with other members of staff who also provide sensitive and responsive care. However, through the planning and leading of liturgy and ritual, chaplains accompany parents through the process of saying goodbye to their baby in a way that other staff do not. Something of this can be seen in Wendy's description of how her bond with the chaplain means she looks back at her time in the hospital as 'that whole little world... all sort of sacred and

⁴³¹ Robert A. Hinde and Joan Stevenson-Hinde, 'Perspectives on Attachment', in Parkes,

Stevenson-Hinde, and Marris (eds.), Attachment across the Life Cycle, 60.

⁴³² David W. McMillan and David M. Chavis, 'Sense of Community: A Definition and Theory', Journal of community psychology 14, no. 1 (1986), 9.

 ⁴³³ McMillan and Chavis, 'Sense of Community', 13.
 ⁴³⁴ McMillan and Chavis, 'Sense of Community', 14.

⁴³⁵ Kelly, Marking Short Lives, 195.

special.'⁴³⁶ To the suggestion that this was because she and the chaplain had shared something profound, she responded 'absolutely, but you can't do [that] with anybody else, and you hope you never do with anybody else, because you don't want anybody else to have gone through it.'⁴³⁷ Similarly, quotations from Diane, Alistair and Jenny at the beginning of this section speak about the chaplain being present throughout and going through the process with them. Furthermore, as described in *section* 5.7, chaplains can also be perceived differently to other medically focused staff.

6.2.3 The need for chaplains to 'let go' of parents

Given the depth of relationships established, it was perhaps to be expected that, following their interview, several parents asked me to pass on their greetings to the chaplain who had supported them. When I did so, it often took a little while for the chaplain to bring the parents to mind. In a similar way, it was sometimes only as parents began to tell their story that I realised that I had been the chaplain who supported them. This could be viewed as being bad form on behalf of the chaplain, as suggestive that they were only going through the motions. I disagree. Instead, I believe that the inability to instantly recall parents is indicative of chaplains undertaking the important task of self-care. Looking at the chaplaincy patient records for the past three years, the colleague and I based on the site with the maternity wing have each carried out, on average, a naming and blessing or baptism and a funeral every three weeks.⁴³⁸ If a chaplain could instantly remember names and details of many of the parents they had helped support, I would be concerned about the possibility of burnout or compassion fatigue. Burnout is 'a state of physical, emotional, and mental exhaustion caused by long term involvement in emotionally demanding situations.^{'439} Compassion fatigue is a form of burnout and may be described as 'an extreme state of tension and preoccupation with the suffering of those being helped to the degree that it is traumatizing for the

⁴³⁶ Wendy CR07.

⁴³⁷ Wendy CR07.

⁴³⁸ Not all naming and blessings or baptisms match to a funeral. As seen in the experience of Martin, chaplains cannot always do the funeral. Also, some parents will return out of area for the funeral, or the funeral will be carried out by local clergy were there is an established relationship. Similarly, parents may have declined, or not been asked about, a naming and blessing and only met a chaplain when planning the funeral.

⁴³⁹ Ayala Pines and Elliot Aronson, Career Burnout: Causes and Cures (New York: Free Press, 1988), 9.

helper.'⁴⁴⁰ There is a range of good evidence that those working in caring and helping professions are subject to unique stressors that may lead to burnout. Highlighting the danger for chaplains, such research suggests that those who work with dying or bereaved individuals are particularly at risk.⁴⁴¹ Drawing on other research, Wendy Lum notes that 'therapists at risk for burnout are too emotionally involved with their clients.'⁴⁴² Writing about ways of recognising and preventing compassion fatigue, Charles Figley highlights the importance of being able to disengage from those you have been supporting. This, he states, requires a conscious rational effort to 'let go' of the thoughts, feelings and sensations associated with support of the client.⁴⁴³ There is, here, a certain reciprocity in that the chaplain who helps the parents 'let go', then needs to 'let go' them self.

Through the last two sections I have identified various ways that parents valued the presence of the chaplain alongside the liturgy and ritual they provided. Within this there is a strong sense that parents appreciated the chaplain *being* with them as much as their *doing*. There is here an obvious connection with notions of the importance of character within virtue ethics. This will be explored further in the next chapter. Before that, I turn to a final section of findings which relate to parents' comments about being opened up to greater religious belief or spiritual awareness.

6.3 Faith Development

Commenting on how ritual might be significant to parents, Kelly argues that one important factor is that it provided 'a touching point with transcendence.'⁴⁴⁴ Exploring this further, Kelly outlines how 'parents, whether they considered themselves religious or not, found they were, in the context of ritual, put in touch with a dimension which transcended the distress and pain

www.medscape.com/viewarticle/513615. [accessed 15 April 2012]

⁴⁴⁰ Medscape News, 'Compassion Fatigue: An Expert Interview With Charles R. Figley, MS, PhD.', Medscape Psychiatry & Mental Health (October 2005), first answer, <u>http://</u>

⁴⁴¹ Jason M. Holland and Robert A. Neimeyer, 'Reducing the Risk of Burnout in End-of-Life Care Settings: The Role of Daily Spiritual Experiences and Training', *Palliative and Supportive Care 3*, no. 3 (2005), 174.

⁴⁴² Wendy Lum, 'The Use of Self of the Therapist', Contemporary Family Therapy 24, no. 1 (2002), 185.

⁴⁴³ Charles R. Figley, 'Compassion Fatigue: Psychotherapists' Chronic Lack of Self Care', *Journal of Clinical Psychology* 58, no. 11 (2002), 1438.

⁴⁴⁴ Kelly, Marking Short Lives, 174.

of their situation.'445 It is clear from my interviews that parents in my study similarly found moments of serenity within the context of their pain and loss. Furthermore, I wish to suggest that, for some parents, there was the potential for this 'putting in touch with another dimension' to become the beginning of a renewed journey of faith. Without it being the focus of any of my questioning, several interviewees spoke about how their experiences had led to the development of religious or spiritual belief. In what follows it may be helpful to think of faith less in terms of particular religions, but in more universal and inclusive terms, as described by Fowler, as 'the most fundamental category in the human quest for relation to transcendence... a universal feature of human living.'446 Understood this way, faith, similar to the definition of spirituality presented in section 2.2.2, is 'foundational to social relations, to personal identity, and to the making of personal and cultural meanings.'447

6.3.1 Religious and spiritual development

For Liz, this faith development was very clearly expressed in terms of religious belief. In response to the question of whether chaplaincy support had helped in any way, she describes how, 'I did find faith, which is very strange 'cos most people seems to go the other way don't they.'448 The fact that this is a religious faith is made clear later in the interview when she spoke about how, even though she could not describe how and why, she had 'started attending church an' it seemed to help.'449 Contrastingly, for Jenny, a new awareness of another dimension was described in much more spiritual and experiential terms:

I don't know, not that I believe, I just, I don't know, I feel more at ease with things. I don't feel as frightened. I know that sounds daft, you know, if it's good enough for her and everything, was just how it was and, yeah, you know..., it did change me it changed me a lot, definitely.

Like I said, it was when I was with her, and I've never been with anybody that's passed away, but I knew she'd gone... an' I felt she was safe and that she's being looked after. But I can't describe how it is. It's just something inside an' it was the whole situation..., it's so hard to

⁴⁴⁵ Kelly, Marking Short Lives, 175.

⁴⁴⁶ James W. Fowler, Stages of Faith: The Psychology of Human Development and the Quest for Meaning (San Francisco: Harper & Row, 1981), 14.

⁴⁴⁷ James W. Fowler and Mary Lynn Dell, 'Stages of Faith from Infancy through Adolescence: Reflections on Three Decades of Faith Development Theory', in Eugene C. Roehlkepartain, et al. (eds.), The Handbook of Spiritual Development in Childhood and Adolescence (Thousand Oaks CA: Sage, 2006), 36. 448 Liz CR05.

put into words... it's more of a feeling from inside that, definitely, an' I do believe that I'm gonna be with her again, definitely.⁴⁵⁰

As before, it is difficult to separate out factors relating to liturgy and ritual, and those relating to the presence of the chaplain. Suggesting the importance of the ritual, early in the interview Jenny spoke about how, when the chaplain blessed her baby, she said to her partner 'she's gone and... it was just, I don't know where it came from, but I just felt like she'd, yeah she alright, she's gone now.'⁴⁵¹ Yet, towards the end of the interview, she also highlights the significance of the chaplain's manner of being with her:

The chaplain was so calm with it and, like, you know people, they weren't reacting oooh, you know, like people do... They were just so calm with it an', you know, it that's what's put me at, like I said, put me at ease.⁴⁵²

The role that the chaplain's manner might play in bringing faith to expression is evidenced by the comments of other parents. In contrast to their expectations, the sympathetic and selfless approach of the chaplain led Diane and Alistair to comment that 'if anything it actually makes you believe more',⁴⁵³ and that 'it makes you believe, it makes your faith stronger.'⁴⁵⁴ Similarly, to repeat Wendy's comments, the depth of relationship mentioned in *section* 6.2 could also lead to an ongoing sense of spiritual awareness:

Again it was that... bond that we had... and that's something I still cling to because that's a part of my, part of their, memory, part of that little world that I only saw for a short time in theory, but it's still there and it's still important to me... in my mind it's that whole little world... it's all sort of sacred and special.⁴⁵⁵

It is worth reiterating the fact that parents filled out the RFQ at the end of their interview. Accordingly, notions of religious and spiritual belief were not introduced before they relayed their experiences. It is possible that had there been a more explicit question around development of faith, whether relating to religious belief or spiritual awareness, other parents might have expressed similar experiences. In support of this, having filled out the RFQ, a couple of

⁴⁵⁰ Jenny CR02b.

⁴⁵¹ Jenny CR02b.

⁴⁵² Jenny CR02b.

⁴⁵³ Diane CR06b.

⁴⁵⁴ Alistair CR06a.

⁴⁵⁵ Wendy CR07.

other parents made comments regarding faith and belief that, while not recorded, I noted down when they had left. In relation to her loss, Katy spoke about how, 'when it first happens you think how can God let this happen, but then you also want to think that your baby is being looked after.'⁴⁵⁶ Echoing the fact that the experience had raised existential questions, Lewis described how the whole situation made him think and that his faith had developed and that he now held onto his beliefs more strongly.⁴⁵⁷ As with other findings, these experiences were shared by participants who scored themselves very differently on the RFQ. For example, Lewis held strong views that were essential in his day-to-day life. In contrast, Jenny recorded medium scores for those questions. Parents' comments about the development of faith and greater spiritual awareness lead to the intriguing but unanswerable question of how participants might have scored themselves on the RFQ before their loss.

6.3.2 Stages of faith development

Liz, quoted at the beginning of the last section, expressed surprise at her development of faith. Reflecting similar sentiments, after describing how her link with church had helped her enormously, Wendy stated that she 'could understand why people would turn away from the church rather than go towards it.'⁴⁵⁸ As this theme began to emerge, my initial reaction was also one of surprise. However, as I started to reflect more deeply on it, I realised that the notion that faith and spiritual awareness might develop out of suffering was not so shocking. As I write this, within the Church's year it is the season of Lent. In the Judeo-Christian tradition, acts of fasting and self-denial are traditionally seen as ways of deepening and developing one's spiritual life. Nicholas Lash beautifully encapsulates this insight when he writes, 'The search for God is not the search for comfort or tranquillity, but for truth, for justice, faithfulness, integrity; these, as the prophets tirelessly reiterated, are the forms of God's appearance in the world.'⁴⁵⁹ Noticeably, Lash continues by quoting from Friedrich von Hügel, stating that accordingly it is,

not the smoother, easier times and circumstances in the lives of individuals and of peoples, but on the contrary, the harder and hardest trials of every conceivable kind, and the unshrinking, full acceptance of

⁴⁵⁶ Katy CR10b.

⁴⁵⁷ Lewis CR01.

⁴⁵⁸ Wendy CR07.

⁴⁵⁹ Nicholas Lash, The Beginning and the End of Religion (Cambridge: Cambridge University Press, 1996), 179.

these, as part of the price of conscience and of its growing light, [that] have ever been the occasions of the deepest trust in and love of God to which man has attained.⁴⁶⁰

Such an understanding is echoed by Weil. In an essay entitled *Forms of the Implicit Love of God*, Weil writes about the transformation needed to empty ourselves of our false divinity and to 'awaken to what is real and eternal, to see the true light and hear the true silence.'⁴⁶¹ Weil continues by suggesting that:

The beauty of the world is the mouth of a labyrinth. The unwary individual who on entering takes a few steps is soon unable to find the opening. Worn out, with nothing to eat or drink, in the dark, separated from his dear ones, and from everything he loves and is accustomed to, he walks on without knowing anything or hoping anything, incapable even of discovering whether he is really going forward or merely turning round on the same spot. But this affliction is as nothing compared with the danger threatening him. For if he does not lose courage, if he goes on walking, it is absolutely certain that he will finally arrive at the center of the labyrinth. And there God is waiting to eat him. Later he will go out again, but he will be changed, he will have become different, after being eaten and digested by God.⁴⁶²

Weil is writing about how a sense of beauty creates this opening. Interestingly, having given the above quotation in his opening lecture to the 2010 DThM Summer School, rather than relating it to a sense of beauty, Mark McIntosh develops it by stating:

There are places and times in one's life, Weil seems to be saying, when we are lured beyond our customary view of the world. We become entranced by a poet, or a child we know approaches death... in such moments a journey may begin from which we will never come back as we used to be.⁴⁶³

Within that idea of beginning a journey there is something of Fowler's theory of faith development. First published in 1981 as *Stages of Faith*, Fowler's six stages is probably the most widely cited theory of faith development. In referencing it I am aware of strong support and criticism.⁴⁶⁴ Key among the

⁴⁶⁰ Friedrich von Hügel, The Mystical Element of Religion as Studied in Saint Catherine of Genoa and her Friends (London: JM Dent and sons, 2nd ed. 1923), 291-2.

⁴⁶¹ Weil, Waiting for God, 100.

⁴⁶² Weil, Waiting for God, 103.

 ⁴⁶³ Mark A. McIntosh 'Scholarship, Theology, and Spirituality.' Opening Lecture to DThM Summer School, (Ushaw College: Ushaw, 13 September 2010). [no source available in the public domain]
 ⁴⁶⁴ For a recent overview of criticisms cf. Adrian Coyle, 'Critical Responses to Faith

⁴⁶⁴ For a recent overview of criticisms cf. Adrian Coyle, 'Critical Responses to Faith Development Theory: A Useful Agenda for Change?', Archive for the Psychology of Religion 33, no. 3 (2011).

criticisms, as postmodernism has largely rejected the quest for meta-narratives, is a critique of the stage structure and its invariant, sequential and hierarchical nature. However, as David Heywood puts it:

The abandonment of Fowler's explanation for what he calls 'faith development' does not entail abandoning the observation that people construct the meaning of their lives and faith in different ways, that these constructions may change in significant ways during the course of their lives, nor that they display regularities which may profitably be compared.465

It may be helpful to think about faith development as a little like grieving. By this I mean that while it may be a non-linear process, it remains helpful to group and categorise similar understandings, even though flexibility between such groupings must be maintained. Accordingly, we might substitute the word 'stage' for that of 'task' when Worden writes of his grief tasks that, 'tasks can be revisited and worked through again and again over time. Various tasks can also be worked on at the same time.'466

Even, assuming that some that some classification is accepted as possible, I do not have enough information to even estimate what stage, or stages, parents in my study might be at. Going with Fowler for a moment, he suggests many, particularly younger, adults will be found in Stage 3.467 In this stage, while faith synthesises values and information, there is a 'dependence on significant others for confirmation and clarity about one's identity and meaning to them.'468 One of the essential features of Stage 4 is a 'critical distancing from one's previous assumptive value system.'469 In Stage 4 'for the first time we explicitly and consciously take charge of, and accept responsibility for, out commitments, evaluations and world-view.'470 The transition to Stage 4, is often precipitated by major upsets. Echoing the notion of being lured beyond our customary view, Fowler states that 'frequently the experience of "leaving home" - emotionally or physically, or both - precipitates the kind of examination of self, background, and lifeguiding values that gives rise to stage transition at this

⁴⁶⁷ Richard Osmer and James W. Fowler, 'Childhood and Adolescence - a Faith Development Perspective', in Robert J Wicks, Richard D. Parsons, and Donald Capps (eds.), Clinical Handbook of Pastoral Counseling Volume 1 (Mahwah NJ: Paulist Press, Expanded ed. 1993), 185. ⁴⁶⁸ Fowler and Dell, 'Stages of Faith', 40.
⁴⁶⁹ Fowler, *Stages of Faith*, 179.

⁴⁶⁵ David Heywood, 'Faith development theory: A case for paradigm change', Journal of Beliefs & Values, 29, no.3 (2008) 264.

⁴⁶⁶ Worden, Grief Counselling and Grief Therapy, 4th ed., 53,

⁴⁷⁰ Astley, 'Learning in the Way', 133.

point.'⁴⁷¹ Whatever view of Fowler's theory is taken, it is not hard to see how the loss of a baby may have triggered parents to question their fundamental beliefs about the universe.

While that understanding makes sense for some of the comments above, it does not really answer why liturgy and ritual or the presence of the chaplain may have played a part. Writing generally, without reference to particular stages, James Fowler and Mary Dell state that:

Faith, taken in this broad sense, is a common feature of human beings. In the language of child psychiatrist Erik Erikson, faith begins with basic trust, as the child forms bonds with the mother and other intimate caregivers. As the child matures, physically and emotionally, faith accommodates the development of an expanding range of object relations, and exposure to religious symbols and practices may nurture a sense of relatedness to the transcendent.⁴⁷²

The preceding analysis has argued that chaplains may act as temporary surrogate attachment figures. In addition, I have earlier described how parents' expectations of chaplains were vastly at odds with their actual experience. As Astley *et al.* write, 'it is new experience that often leads to faith stage change.'⁴⁷³ It may be that, in forming an unexpected bond with a chaplain, parents' beliefs and stereotypes are challenged, beginning the process of a stage transition. Furthermore, from the RFQ, we can see that various parents described themselves as not religious and very few participated in communal religious activity. Accordingly, whether co-created or not, the liturgy and ritual carried out by a chaplain may have been the first exposure to religious symbols and practice that parents had had for some time. The nurturing of a renewed relatedness to the transcendent can be seen very well in Jenny's descriptions of chaplaincy support outlined in *section* 6.3.1.

In relation to a person transitioning between stages, Astley *et al.*, drawing on Fowler, write that faith:

is like a shawl (of meaning) that we knit and wrap around ourselves. It is not the job of the pastor or educator to slash at this with a knife or rip it from a person's shoulders. But sometimes the shawl starts to

⁴⁷¹ Fowler, Stages of Faith, 173.

⁴⁷² Fowler and Dell, 'Stages of Faith', 36.

⁴⁷³ Astley et al., How Faith Grows, 41.

unravel of its own accord. And then we should step in to help: not by darning up the loose ends, but by rolling up the wool, standing by the wearer in his nakedness, and then encouraging him to knit a new shawl for himself. ⁴⁷⁴

In 'standing by the wearer in his nakedness' there is a strong resonance with the chaplain being present, sitting with parents' pain and not rushing to fix everything. This, I believe, requires a level of maturity that might be equated with Fowler's Stage 5. In this stage a person is alive to paradox and 'accepts as axiomatic that truth is more multidimensional and organically interdependent than most theories or accounts of truth can grasp.'475 Further evidence for chaplains needing the maturity of Stage 5 comes from the depiction in section 5.6 of how chaplains did not impose their own views, but met parents where they were, adapting liturgy and ritual to fit with their beliefs. Such openness resonates with the comments of Astley et al. that in this stage 'the self has started to know what it is truly to give to others. It is more and more willing to suspend its own views.'476 As an interesting observation, Fowler states that a person at Stage 5 'is ready to spend and be spent for the cause of conserving and cultivating the possibility of others' generating identity and meaning.'477 On several occasions through this thesis I have written about the chaplain working in such a way. For example, in section 2.1 I wrote that the chaplain helps people seek meaning and in section 5.3.5 I described how liturgy and ritual aided parents to affirm the reality of their baby. As Fowler perhaps hints at with the terms 'spend and be spent', such support can be costly. This notion is further discussed in terms of character virtues section 7.5.3.

6.4 Summary

The value placed by parents on the presence of the chaplain in being with them makes it clear that chaplains need more than just the ability to handle liturgy and ritual. Of particular importance to parents was the ability of the chaplain to draw alongside them through attentive listening. This made parents feel respected, that chaplains were giving them individual attention, and brought them comfort and strength. As a contrast to the rotation of nurses

⁴⁷⁴ Astley *et al.*, How Faith Grows, 41.

⁴⁷⁵ Fowler, Stages of Faith, 186.

⁴⁷⁶ Astley *et al.*, How Faith Grows, 32.

⁴⁷⁷ Fowler, Stages of Faith, 198.

and doctors, parents also appreciated the consistency of seeing the same face. Within a short space of time several parents had developed a deep relationship with the chaplain who supported them. Exploring how this came about, I noted the significance of a sensitive and responsive attitude in developing bonds, and that in accompanying parents chaplains had shared an emotional connection. As a result of the collective valuing of individual chaplains by parents, I argued that the skills needed to provide a supportive presence should be core to all chaplains.

An unanticipated finding was the way in which some parents spoke about or intimated religious or spiritual growth. On reflection, recognising that there is a strong theme within Judeo-Christian spirituality that times of testing lead to growth, this should not be so surprising. Acknowledging criticisms, and noting a non-hierarchical approach valuing it as a way of classifying beliefs, I related this to Fowler's stages of faith development and proposed that, alongside losing a baby, both the experience of liturgy and ritual and the sensitive presence of a chaplain could be factors that precipitate parents questioning previously held life views. Further drawing on Fowler, I mooted that in supporting parents chaplains need to exhibit the maturity of faith described in Stage 5.

Throughout this chapter at various points, in relation to the work of chaplains, I have drawn attention to the concept of character and virtue ethics. This is something that I believe has a great potential to inform the work, training and continuing development of chaplains. Accordingly, the next chapter explores virtue ethics and chaplaincy in more detail.

7 <u>Chaplaincy Among the Virtues?</u>

Both implicitly and explicitly in chapters five and six I have argued that the way in which a chaplain relates to parents is as important as the liturgy and ritual they carry out. Within this there is, it strikes me, an obvious connection with virtue ethics for those who defend virtue ethics argue 'that how one does what one does is as important as what one does.^{'478} Exploring this connection, this chapter begins in section 7.1 by outlining what I mean by a 'virtue-based' approach to chaplaincy and defining several key terms within virtue ethics. Having done this, noting the way character acts as a driver for action and the valuing of emotions, section 7.2 sets out in more detail why I see merit in a virtue-based approach. This is followed by section 7.3, which introduces the concept of a regulative ideal, and section 7.4 which suggests 'engendering an encounter with hope' as a regulative ideal for chaplains supporting parents. Section 7.5 then offers three virtues - attentiveness, openness and probity - that, alongside practical wisdom, I believe are important to the character of a chaplain. Finally, in highlighting the importance of mentoring and shadowing, section 7.6 explores how taking a virtue-based approach might affect the training and continuing professional development of chaplains.

7.1 Understanding a Virtue-Based Approach to Chaplaincy

The renewed interest in virtue ethics within contemporary ethical theory is usually traced back to an article written by Elizabeth Anscombe in 1958 criticising deontological and consequentialist ethical approaches.⁴⁷⁹ It was, however, really only after the publication of Alasdair MacIntyre's *After Virtue* in the 1980s that both philosophical and theological engagement with virtue took off. There is now an ever expanding range of approaches that view themselves as forms of virtue ethics. While each differs in their varying ways, at the heart of all forms of virtue ethics is a claim 'about the primacy of *character* in the justification of right action.'⁴⁸⁰ This leads to the central, if slightly convoluted, statement that an action is right if and only if it is what an agent with virtuous character would do in the circumstances. Put a different way, in practice this

⁴⁷⁸ Stanley M. Hauerwas, 'Virtue and Character', in Stephen G. Post (ed.), *Encyclopedia of Bioethics* (New York: Macmillian, 3rd ed. 2003), 2551.

⁴⁷⁹ G. E. M. Anscombe, 'Modern Moral Philosophy', Philosophy 33, no. 124 (1958).

⁴⁸⁰ Justin Oakley and Dean Cocking, Virtue Ethics and Professional Roles (Cambridge: Cambridge University Press, 2001), 9.

means that within virtue ethics 'people's selves or characters, rather than their actions or the consequences that flow from those actions, are at the centre of moral assessment.'⁴⁸¹

The title of this chapter derives from Stanley Hauerwas and Charles Pinches' book Christians Among the Virtues. Within the book they wish to argue 'that the virtues Christianly considered are in fundamental ways different from the virtues associated with quite different practices, communities, and narratives.'⁴⁸² While I am sympathetic to such a notion, I do not aim to critique or defend their viewpoint. Neither do I wish to outline a version of virtue ethics that is distinctive to chaplaincy. Equally, I am not proposing that chaplains, in preference to any other ethical system, should adopt a virtue ethics approach to their life. Instead, what I am suggesting is that because the character of a chaplain is important, chaplaincy would benefit and learn from an engagement with virtue ethics. Following Sarah Banks and Ann Gallager, this might best be thought of as taking a 'virtue-based' approach with the aim of exploring questions such as what kinds of moral qualities a chaplain might 'exhibit and aspire to; how these are manifested in their professional commitments, relationships and actions; and how these qualities can be promoted and developed through professional practice and education.'⁴⁸³ I do not believe that this has been done by anyone else writing about chaplaincy.

7.1.1 Virtue

Before continuing, it is worth outlining how a number of key words within the field of virtue ethics are generally understood, in particular virtue and character. The word virtue comes from the Latin *vir* meaning 'man' and originally related to manliness. While the chauvinist association has been dropped, the notion of marking a quality remains. *Vir* is the Latin translation of the Greek term *arete*, from which the notion of virtue in Western thought stems. *Arete* means excellence and relates to 'a quality possessed by something which helps it fulfil its function well.'⁴⁸⁴ The most commonly given example of

⁴⁸¹ Jennifer Radden and John Z. Sadler, 'Character Virtues in Psychiatric Practice', Harvard Review of Psychiatry 16, no. 6 (2008), 373.

⁴⁸² Stanley M. Hauerwas and Charles R. Pinches, *Christians among the Virtues: Theological Conversations with Ancient and Modern Ethics* (Notre Dame, IN: University of Notre Dame Press, 1997), x.

⁴⁸³ Sarah Banks and Ann Gallagher, *Ethics in Professional Life: Virtues for Health and Social Care* (Basingstoke: Palgrave Macmillan, 2009), 7-8.

⁴⁸⁴ Peter Allmark, 'Is Caring a Virtue?', Journal of Advanced Nursing 28, no. 3 (1998), 467.

this is of the *arete* of a knife being its sharpness. Accordingly, a human virtue may be thought of as 'any one of a set of interdependent traits which, as a set, adapt a person for living an ideally human life and express the proper human potential.⁴⁸⁵ The word interdependent reminds us that a single virtue does not work in isolation. Rather, as Rosalind Hursthouse describes, it will be concerned with other actions, emotions and emotional reactions, choices, values, desires, perceptions, attitudes, interests, expectations and sensibilities. Accordingly, 'to possess a virtue is to be a certain sort of person with a certain complex mindset.'⁴⁸⁶ It is also important to recognise the potential impact of a person's context on a virtue. As Banks and Gallagher rightly state, 'the individual dispositions of the professional and the features of the situation are both relevant to the doing of and the explaining of good actions.^{'487} For example, as they illustrate, a person considered trustworthy by work colleagues might be thought untrustworthy by friends because they are persistently late for social engagements. However, there might be extenuating circumstances to the social context, such as a commitments to elderly relatives. Therefore, rather than viewing the person as not trustworthy, we recognise that the persons behaviour is situation-specific.

7.1.2 Character

The word character derives from a Greek word *charakter* meaning to scratch or engrave; hence letters of the alphabet being termed characters. A person's character is often thought of as something robust and stable with the etymology of engraving suggesting 'something enduring and brought about by some activity.'⁴⁸⁸ As the word activity indicates, virtues are traits which 'are acquired through habituation; they are habits of mind as much as behaviour.'⁴⁸⁹ Within discussions of virtue ethics the term 'character trait' is sometimes used interchangeably with virtue when referring to particular or individual dispositions. However, when virtue ethics is said to be characterdriven, the word character refers to the way a person's virtues or traits act out together. This does not mean that character is simply the sum of the individual

⁴⁸⁵ Richard C. Chewning, 'Virtue, Virtues', in David J. Atkinson and David H. Field (eds.), New Dictionary of Christian Ethics & Pastoral Theology (Downers Grove IL: Inter-Varsity Press, 1995), 881.

⁴⁸⁶ Rosalind Hursthouse, 'Virtue Ethics', *The Stanford Encyclopedia of Philosophy* (Spring 2012 *Edition*), Edward N. Zalta (ed.), section 2, <u>http://plato.stanford.edu/archives/spr2012/entries/</u> <u>ethics-virtue/</u>. [accessed 29 April 2012]

⁴⁸⁷ Banks and Gallagher, Ethics in Professional Life, 55.

⁴⁸⁸ Banks and Gallagher, Ethics in Professional Life, 52.

⁴⁸⁹ Radden and Sadler, 'Character Virtues', 374.

virtues. Instead, character 'indicates the stability that is necessary so that the various virtues are acquired in a lasting way.'⁴⁹⁰

7.1.3 Eudaimonia

It is difficult to write of virtue, character, and notions such as human potential and ideal lives, without making reference to another Greek term, *eudaimonia*. This was a key term in ancient Greek moral philosophy and is usually translated as flourishing, happiness, or occasionally well-being. Conceptually, virtue and *eudaimonia* are linked. While the exact nature of the link is a matter of opinion and conjecture, 'all usual versions of virtue ethics agree that living a life in accordance with virtue is necessary for *eudaimonia*.'⁴⁹¹ Of course, there is also disagreement and debate over exactly what such happiness or flourishing might look like in practice. Ultimately, this is what is at the centre of Hauerwas and Pinches' claim for the distinctiveness of Christian virtues. As they describe, the difference between Aristotle and Christianity is not that one teaches happiness and the other does not, 'rather, it is to be found in the differing accounts of the kind of person we must be if we are to be genuinely happy.'⁴⁹²

7.2 The Value of a Virtue-Based Approach

I would hope that it is obvious why a virtue-based approach might have much to offer chaplaincy. I will, however, explain my thinking. The two other major ethical approaches, deontology and consequentialism, are based on principles of action. Deontological approaches, based on notions of duty, seek rules or principles by which to judge an action. For example, based on the principle of patient choice, a deontologist might say that a chaplain was right to offer choices rather than take authoritative action when supporting parents. However, as I described in *section 5.4*, there are times when choice is the last thing that a parent wants. Given the complex and sometimes paradoxical need, it is hard to see how any rule or principle might be consistently applied. When assessing the rightness of an action consequentialism, of which utilitarianism is the best known example, looks to a good outcome or the maximum overall happiness; it is sometimes described as the greatest good for the greatest number of people. As before, a consequentialist might say that a chaplain was

⁴⁹⁰ Hauerwas, 'Virtue and Character', 2550.

⁴⁹¹ Hursthouse, 'Virtue Ethics', section 2.

⁴⁹² Hauerwas and Pinches, Christians among the Virtues, 15.

right to offer choices, but this time because it is what the parents wanted and led to their comfort. However, while this approach recognises that appropriate action will differ according to the situation, it is not clear how, in the short time available, a chaplain might decide how to act. In short, as Daniel Statman writes:

Principles are just too abstract to provide helpful guidance in the complicated situations met in everyday ethics. These situations typically involve conflicting considerations, to which principle-ethics either offers no solution, or formulates higher order principles of preference, which, again, are too abstract and vague to offer any real help.⁴⁹³

7.2.1 Character as the driver for action

In contrast, within a virtue-based approach, rather than following set rules or attempting to judge the outcome of their actions, the chaplain's character is viewed as the driver for how they relate to parents. Here, the understanding is that the set of virtues which make up a chaplain's character form them to know the right way to respond. When it comes to making decisions, this can produce the paradoxical effect that:

the good person may well find herself having to decide with progressive infrequency, for she knows the good and does it joyfully, with little deliberation. This is not because she is unschooled in its art. To the contrary, it is because she has learned over time and partly by the practice of deliberation to recognize readily what should be done.⁴⁹⁴

In relation to this notion, I would propose that the habituation of virtues necessary to the formation of character may be a helpful way to understand the use of intuition discussed in *section* 5.8. Drawing on notions of improvisation with drama and the theatre, Samuel Wells writes:

The Bible is not so much a script that the church learns and performs as it is a training school that shapes the habits and practices of a community. This community learns to take the right things for granted, and on the basis of this faithfulness, it trusts itself to improvise within its tradition. Improvisation means a community formed in the right habits trusting itself to embody its tradition in new and often challenging circumstances.⁴⁹⁵

⁴⁹³ Daniel Statman, 'Introduction to Virtue Ethics', in Daniel Statman (ed.), Virtue Ethics: A Critical Reader (Edinburgh: Edinburgh University Press, 1997), 6.

⁴⁹⁴ Hauerwas and Pinches, Christians among the Virtues, 19.

⁴⁹⁵ Samuel Wells, Improvisation: The Drama of Christian Ethics (London: SPCK, 2004), 12.

As chaplains gain experience it must be hoped that they also develop greater habituation of the virtues, leading to increased use of, and confidence in, their intuition; 'they learn to act from habit in ways appropriate to the circumstances.'⁴⁹⁶ At the same time, this does not deny that newer chaplains may already have formed the appropriate character that enables them to intuit the correct way to respond.

7.2.2 Valuing emotions

I will look at how notions of character in decision-making might work in practice in a moment. Before doing so I will outline the other main attraction of a virtue-based approach. This is the value that it can place on the emotions in ethical decision-making. As Ronald de Sousa writes, emotions have held an unsettled place in the history of ethics, often being regarded as 'a dangerous threat to morality and rationality.'497 Stereotypically, deontological and consequentialist approaches would be seen to distrust emotions. Even when attempting to defend Kant from accusations that he is the 'enemy-of-theemotions', Robert Louden notes Kant's view that practical reason must always be in charge of the emotions and that part of a moral discipline is 'training the emotions so that they work with rather than against reason.'498 An exploration of the relation between emotion and reason would make a whole thesis in itself. As Randolph Cornelius writes, 'beyond acknowledging that emotions are multifaceted phenomena, there is often little agreement among psychologists as to what emotions, fundamentally, are all about.' ⁴⁹⁹ My understanding is that emotions are not irrational, but perhaps best thought of as alternatively rational. Supporting this there is a range of research showing that people with damage to the ventromedial prefrontal cortex, part of the brain associated with the processing of emotions, do not become more rational; instead the 'damage leads to pathological impairments in the decision-making process which seriously compromise the efficency [sic] of everyday-life decisions.⁵⁰⁰ Emotions, however understood, grab or channel our attention. They tell us what is important to us and how important it is. As Hursthouse writes:

⁴⁹⁶ Wells, Improvisation, 65.

⁴⁹⁷ Ronald de Sousa, 'Emotion', *The Stanford Encyclopedia of Philosophy* (Spring 2012 Edition), Edward N. Zalta (ed.), section 10, <u>http://plato.stanford.edu/archives/spr2012/entries/emotion/</u>. [accessed 2 April 2012]

⁴⁹⁸ Robert B. Louden, 'Kant's Virtue Ethics', Philosophy 61, no. 238 (1986), 488.

⁴⁹⁹ Randolph R. Cornelius, The Science of Emotion: Research and Tradition in the Psychology of Emotions (Upper Saddle River NJ: Prentice Hall, 1996), 10.

⁵⁰⁰ Antonie Bechara, Hanna Damasio, and Antonio R. Damasio, 'Emotion, Decision Making and the Orbitofrontal Cortex', *Cerebral cortex* 10, no. 3 (2000), 305.

The whole idea that a human agent *could* do what she should, in every particular instance, while her emotions are way out of line, is a complete fantasy. Our understanding of what will hurt, offend, damage, undermine, distress or reassure, help succour, support, or please our fellow human beings is as much emotional as it is theoretical.⁵⁰¹

Exploring emotions in relation to spirituality, and as a basic part of Christian moral character, Robert Roberts proposes that emotions are concern-based construals that provide a framework for interpreting a situation and responding to it:

To say that emotions are concern-based construals is to say that they are states in which the subject grasps, with a kind of perceptual immediacy, a significance of his or her situation. Emotions are interpretive in a broad and loose sense: two subjects with equally acute powers of sense perception and intellection may see the same situation in very different ways, experiencing widely different emotions in response to it.⁵⁰²

Angela Henderson describes how nurses 'not only experience strong emotions in the context of work but also consciously use those emotions to hone, refine and improve their practice.⁵⁰³ It may well be that, in a similar way, chaplains are able to use their emotions to help direct their care. In *section* 5.8 I noted how emotions may lead to the immediate 'gut feelings' associated with intuition. Outlining research that evidenced the perception of information through psychophysiologic systems outside conscious awareness, Smith describes how 'intuitive information is received by two organs: the heart and brain. These organs respond to this information and the heart appears to receive the information before the brain.⁵⁰⁴ The links between heart and brain are explored by Joseph Pearce who states that:

Neurocardiology, a new field of medical research, has discovered in our heart a major brain center that functions in dynamic with the fourfold brain in our head. Outside our conscious awareness, this heart-head dynamic reflects, determines, and affects the very nature of our resulting awareness even as it is, in turn, profoundly affected.'505

 ⁵⁰¹ Rosalind Hursthouse, On Virtue Ethics (New York: Oxford University Press, 1999), 118.
 ⁵⁰² Robert C. Roberts, Spiritual Emotions: A Psychology of Christian Virtues (Grand Rapids: Eerdmans, 2007), 11.

⁵⁰³ Angela Henderson, 'Emotional Labor and Nursing: An under-Appreciated Aspect of Caring Work', Nursing Inquiry 8, no. 2 (2001), 135.

⁵⁰⁴ Smith, 'Exploring the Legitimacy of Intuition', 36.

⁵⁰⁵ Joseph Chilton Pearce, The Biology of Transcendence: A Blueprint of the Human Spirit (Rochester VT: Park Street, 2004), 4.

It is interesting to reflect here that historically the heart has long been seen as the sacred seat of virtue.

7.2.3 Emotional labour

When it comes to getting our emotions 'in line' with the actions that are required of us, Arlie Hochschild introduced the notion of 'emotional labour.' This is a term that relates to 'the management of feeling to create a publicly observable facial and bodily display.⁵⁰⁶ Hochschild developed the concept out of her study of flight attendants and the requirement for them to be caring, attentive and compassionate in contexts where they might naturally respond otherwise. While one would hope that the situation of parents would incline chaplains to respond with care and compassion, as Hochschild notes of flight attendants, there may be a need to disguise fatigue and irritation. Calls can often come in the middle of the night and, at any time, a chaplain may have distractions they need to ignore. I have, for example, carried out the naming and blessing of a miscarried baby at the same time as my pregnant wife was having her twenty-week anomaly scan. Hochschild states that there are two different ways of managing emotions, surface acting and deep acting.⁵⁰⁷ Surface acting may be thought of as putting on a mask; simply modifying your facial expressions to those required. In contrast, deep acting requires a person to modify their inner feelings so that they express the desired emotion. While surface acting might seem to be more obviously faking, Alicia Grandey suggests that 'both forms of acting are internally false.'508 If this is the case, we might legitimately ask how emotional labour is compatible with virtues. My answer would be that, as Hochschild notes, emotional labour 'sometimes draws on a source of self that we honor as deep and integral to our individuality.⁵⁰⁹ The importance of self within emotional labour is also recounted by Nicky James who writes, 'emotional labour is hard work and can be sorrowful and difficult. It demands that the labourer gives personal attention which means they must give something of themselves, not just a formulaic response.'510 After exploring the concept of emotional labour, Banks and Gallagher suggest that it is

⁵⁰⁶ Arlie Russell Hochschild, *The Managed Heart: Commercialization of Human Feeling* (Berkeley: University of California Press, 2003), 7.

⁵⁰⁷ Hochschild, The Managed Heart: Commercialization of Human Feeling, 35.

⁵⁰⁸ Alicia A. Grandey, 'When "the Show Must Go On": Surface Acting and Deep Acting as Determinants of Emotional Exhaustion and Peer-Rated Service Delivery', *Academy of management Journal* 46, no. 1 (2003), 87.

⁵⁰⁹ Hochschild, The Managed Heart: Commercialization of Human Feeling, 7.

⁵¹⁰ Nicky James, 'Emotional Labour: Skill and Work in the Social Regulation of Feelings', The Sociological Review 37, no. 1 (1989), 19.

'arguably, part of the process of habituation necessary for the expression of and development of the virtues', concluding that:

Necessary conditions for emotional labour compatible with a virtue account would seem to include the ability to reflect on one's practice and to ask how this emotional labour relates to the narrative of one's overall character and to the *telos or ideal* of one's profession.⁵¹¹

Issues of the *telos* or aim of chaplaincy will be picked up in a moment. For now I return to issues of character and decision-making.

7.3 Character and Regulative Ideals

The most helpful way of understanding how character acts as a driver for decision-making, that I have seen, is given by Justin Oakley and Dean Cocking's notion of a regulative ideal:

To say that an agent has a regulative ideal is to say that they have internalised a certain conception of correctness or excellence, in such a way that they are able to adjust their motivations and conduct so that it conforms - or at least does not conflict - with that standard.⁵¹²

By the terms 'correctness' and 'excellence', Oakley and Cocking mean to indicate that a regulative ideal includes both normative dispositions that relate to standards - i.e. that can be classified as principles or rules - and those that go beyond notions of correct or incorrect behaviour. Accordingly, a regulative ideal for chaplains might be thought to include, but not be limited to, the code of conduct issued by the United Kingdom Board of Healthcare Chaplains (UKBHC).⁵¹³ Expounding their concept, Oakley and Cocking suggest that, 'regulative ideals may be general in scope, or they may be specific to certain domains.'⁵¹⁴ They further suggest that there is a hierarchy of regulative ideals whereby a particular regulative ideal relating to a particular virtue 'will itself be governed by a higher-order and more general regulative ideal, which functions so as to co-ordinate the interplay between the particular regulative ideals.'⁵¹⁵ Oakley and Cocking describe this general regulative ideal as being *phronesis*.⁵¹⁶

⁵¹¹ Banks and Gallagher, Ethics in Professional Life, 69.

⁵¹² Oakley and Cocking, Virtue Ethics and Professional Roles, 25.

⁵¹³ UKBHC, Code of Conduct for Healthcare Chaplains (Cambridge: UKBHC, 2010).

⁵¹⁴ Oakley and Cocking, Virtue Ethics and Professional Roles, 26.

⁵¹⁵ Oakley and Cocking, Virtue Ethics and Professional Roles, 29.

⁵¹⁶ Oakley and Cocking, Virtue Ethics and Professional Roles, 29-30.

Following Aristotle, *phronesis*, generally translated as practical wisdom or prudence, is usually seen as being one of the most significant intellectual virtues. However, even as an intellectual rather than moral virtue, *phronesis* is still widely viewed as having a regulative role where its task 'lies, in part, in determining which other virtues will be applicable in any particular circumstances.'⁵¹⁷

In relating the concept of a regulative ideal to a professional working in a particular profession, Oakley and Cocking argue that, 'the norms of the profession in question cannot simply be taken as given; rather they must be shown to reflect a commitment to an important substantive human good that contributes to our living a flourishing human life.⁵¹⁸ Such a viewpoint is echoed by Banks and Gallagher who state the need for professions to be 'understood more broadly as practices with a social purpose, which ultimately links them to some society-wide notion of the good life, or, more specifically, human flourishing.^{'519} Although not stemming from an exploration of the virtues, Cobb, writing from a chaplaincy perspective, in his contextual modal also recognises that, 'chaplains cannot simply go around claiming a particular identity: the communities they relate to and deal with must validate it.'520 How then, do the practices of chaplaincy fit with society-wide understandings of human flourishing? In 1977 George Engel proposed the biopsychosocial model for health.⁵²¹ Although spirituality is not explicitly mentioned, Engel viewed the social domain of the model as 'encompassing cultural, spiritual, and other broader issues.^{'522} Given the links between spirituality and health previously mentioned, at a broad level a chaplain's provision of spiritual care would fit with widely held notions of health and wellbeing. More particularly, I suspect that the provision of comfort to parents would also be widely seen as a commitment to a social good. Further, the co-creating of funerals may also have links to substantive human good. As Davies depicts, practically all human societies possess some form of formalised rites around death and, as far as archaeological evidence extends, humans have always dealt ritually with their

⁵¹⁷ Radden and Sadler, 'Character Virtues', 378.

⁵¹⁸ Oakley and Cocking, Virtue Ethics and Professional Roles, 75.

⁵¹⁹ Banks and Gallagher, Ethics in Professional Life, 49.

⁵²⁰ Mark Cobb, 'The Location and Identity of Chaplains: A Contextual Model', Scottish Journal of Healthcare Chaplaincy 7 (2004), 11.

⁵²¹ George L. Engel, 'The Need for a New Medical Model: A Challenge for Biomedicine', *Science* 196, no. 4286 (1977).

⁵²² Robert C. Smith, 'The Biopsychosocial Revolution', *Journal of general internal medicine* 17, no. 4 (2002), 310.

dead. Accordingly, it is likely that such rites 'have a positive adaptive significance, for if they possessed no such benefit they would have been abandoned long ago.'⁵²³ Following Cobb's contextual model, whilst these broad aims would doubtless be endorsed by the hospital community, the work of a chaplain needs to also be validated by the faith community. Moreover, if Hauerwas and Pinches are to be believed, then these aims should relate, not to society-wide understanding of flourishing but to what Christians hold as a substantive good.

7.4 Engendering an Encounter with Hope: A Regulative Ideal for Chaplaincy

Finding agreement on what constitutes a substantive Christian good might be thought difficult. However, I suggest that engendering an encounter with hope, one of the theological virtues, would not be contentious. Here, although the aim might be applicable more widely, I am applying it specifically to the supporting of parents. The *New Dictionary of Christian Ethics and Pastoral Theology* defines hope as 'a positive attitude or disposition towards the future' which, from a Christian perspective, relates to a 'confident expectation in God.'⁵²⁴ I discussed in *section* 6.3 notions of parents developing faith or, at least, being opened up to a greater awareness of another dimension. Often, though not always relating to that development, various of my interviewees spoke about how, in different ways, the support of a chaplain had helped them find hope for the future. Sometimes hope was directly mentioned, for example Lewis described how:

I'm a big chap, big stature. You could probably hit me with hammers all day and I'll take a certain degree of it before I fell down. This situation hit me like a steam-train and I've never felt pain like it before in my life. But... what the spiritual side brought to it was a massive comfort to me. It gave me some reassurance, it gave me some hope, and it kind of brought me out of it a little bit.'525

In other interviews hope was not explicitly mentioned, but it is clear that parents had gained a hopeful attitude or disposition. For example, as a result of

⁵²³ Davies, Death, Ritual and Belief, 6.

⁵²⁴ David W. Gill, 'Hope', in Atkinson and Field (eds.), New Dictionary of Christian Ethics & Pastoral Theology, 455.

⁵²⁵ Lewis CR01.

the chaplaincy support, parents spoke about 'having that optimism for the future'⁵²⁶ or of gaining 'closure' meaning that they could 'move on.'⁵²⁷

It is important to be clear here that, while such hope often included a sense that their baby 'might be in a better place where he ain't suffered' and that they were 'going to be with him one day',⁵²⁸ it is much more than the sop of 'pie in the sky when you die.' To open up the possibility of an encounter with hope is not to provide a quick fix. It is not something that suddenly makes everything better. As Chloe put it 'we cannot forget about that baby, the baby did exist and that's part of me, part of my flesh, it's part of my blood, I cannot forget the baby.'⁵²⁹ Recognising this, the encounter with hope that a chaplain offers has to be able to hold and acknowledge pain and brokenness, not simply plaster over it. Something of the encounter that I am suggesting chaplains offer is beautifully expressed in a poetic meditation based on George Frederic Watts's painting *Hope*:

You have gone in search of hope.

Since you were small you have been told of her grace, of her beauty and you want to see her with your own eyes.

You have been travelling for days, or maybe it is months, or perhaps even years, when finally you arrive.

And you see her.

Hunched, blindfolded, sitting atop the globe and playing the remaining strings on her harp. The strings are creating a sweet soft hum that you can barely hear.

And she is beautiful in her dress of ash.

And she is graceful.

But you think you must have come too late.

Something must have happened.

Stripped of colour, light, and life.

This is no scene of hope.

It feels desolate, forlorn, godforsaken.

Hope seems to be transfixed by the music, her head cocked to one side. You think she has not heard you come and so you decide to leave.

Then she speaks,

Come sit with me.

You have not travelled in vain.

Come, sit, and listen.

Sometimes hope is about the music that comes from the remaining chord.

And so you do.

⁵²⁶ Diane CR06b.

⁵²⁷ Jenny CR02b, Craig CR04a and Claire CR04b.

⁵²⁸ Thomas CR10a.

⁵²⁹ Chloe CR12.

You climb up the orb and sit by Hope.

The warmth of her body touching your weary bones.

And you listen to the sound of the remaining chord.

And in your own way, you start to make sense of why you have been sent here. Of why you craved to see her. Her blindfold, her harp, her dress of ash, her seat on the globe.⁵³⁰

7.4.1 Hope as presence

This concept of engendering an encounter with hope has some strong parallels with Nolan's theory of how a hospice chaplain 'may become a hopeful presence to those with whom they are able to work.⁵³¹ As a result of his research Nolan made the fascinating discovery that hope, as traditionally understood as futureorientated, did not feature in how hospice chaplains understood their work. Instead, he found that they fundamentally redefined the concept by speaking of hope as hope in the present.⁵³² Rather than having specific interventions that aimed to stop patients lose hope and fall into despair, Nolan describes how chaplains aimed to 'model a way of being-with patients that is itself a hopeful presence.'533 The purpose here was to 'enable that person to become hopeful not in the sense of helping them to reorient towards the future realization of an unfulfilled desire, but in the sense of living "in a hopeful manner".' 534 Although he was reluctant to label what he felt as hope, there is, perhaps, something of this in the words of Martin when he says 'the presence of a chaplaincy... especially [in] a time like this... gives people, I won't call it a bit of hope, but it gives people a good choice.' When asked to try and unpack this, it was not hope for the future that he described. Instead, among other things, almost paradoxically, he spoke about comfort coming from having 'time to absorb the impact, you know, to come and realise that actually our son had died.'535 In making this link I am aware of the difference between the work of the chaplains as described by Nolan and the support provided by chaplains in my study. Most obvious is that, when supporting parents, chaplains make use of specific interventions in the form of liturgy and ritual. However, as I have argued consistently through the past two chapters, parents valued the chaplain's presence as much as the liturgy and ritual that they carried out.

⁵³⁰ Written by Tess Keeble and used with permission. Noticeably, this conception of hope is written out of the experience of grief and loss; in December 2010 after just three years of marriage, Tess's husband Dan died.

⁵³¹ Steve Nolan, 'Chaplain as "Hopeful Presence": Working with Dying People', Practical Theology 4, no. 2 (2011), 169.

⁵³² Nolan, 'Chaplain as "Hopeful Presence", 169.

⁵³³ Nolan, 'Hope Beyond (Redundant) Hope', 24.

⁵³⁴ Nolan, 'Chaplain as "Hopeful Presence", 166.
⁵³⁵ Martin CR03.

7.4.1 Hope as quest

A further insight into understanding the offering of hope comes by relating it to the narratives described in Arthur Frank's book *The Wounded Storyteller*. Frank suggests that within illness there are three main types of story: restitution, chaos and quest. The plot of the restitution narrative has the basic storyline 'yesterday I was healthy, today I am sick, but tomorrow I will be healthy again.'⁵³⁶ A chaos narrative is in some ways an anti-narrative; due to the intensity of their illness 'suffering is too great for a self to be told.'⁵³⁷ Lastly, although 'what is quested for may never be wholly clear',⁵³⁸ quest narratives search for alternative ways of being ill or, as Sharon Kilty more helpfully puts it, 'alternative ways of being well.'⁵³⁹ A similar understanding of the need for an alternative way of being can be seen in the writing of Israel, who makes it clear that undertaking a quest is not a quick fix:

The resolution of life's tragedy is not a blissful return to the *status quo*, to the old times of childish abandon and irresponsible indulgence. These are past recall. What lies ahead is solid labour in the darkness of cold reality, but the end in distant view is a transformed life.⁵⁴⁰

As with the case of chronic illness explored by Frank, parents who have lost a baby know that things will not quickly return to how they were; there is no happy ending. The descriptions in *section* 5.2.1 of the loss of control that parents undergo sound very much like being in a place of chaos, a place where they do not have the words they need. In this chaotic and unknown land, it is of little surprise that, as well as listening, parents appreciated 'signposts which aided orientation in the dark landscape of grief and resources to help them verbalise their feelings and inner wrestling.'⁵⁴¹ Importantly, offering a signpost is not an attempt to fix everything, it simply indicates that someone has been this way before and offers up the possibility of a journey. To embark on this journey does not mean a sudden end to the chaos. Frank is clear that within any narrative all three types will be at work 'each perpetually interrupting the other two.'⁵⁴² Something of this can be seen clearly in my interviews where,

⁵³⁶ Arthur W. Frank, The Wounded Storyteller: Body, Illness, and Ethics (Chicago: University of Chicago Press, 1995), 77.

⁵³⁷ Frank, The Wounded Storyteller, 115.

⁵³⁸ Frank, The Wounded Storyteller, 115.

⁵³⁹ Sharon Kilty, 'Telling the Illness Story: The Healing Power of Words', *The Patient's Network* Winter, Vol. 5, no. 3 (2000), 18.

⁵⁴⁰ Israel, The Pain That Heals, 27.

⁵⁴¹ Kelly, Marking Short Lives, 202.

⁵⁴² Frank, The Wounded Storyteller, 76.

even many years post bereavement, parents continue to wrestle with and be affected by their loss. Furthermore, just as hope in Nolan's study was focused in the present rather than directed at the future realisation of desires, this journey does not have a particular destination. Instead, 'the meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking.'⁵⁴³ Reflecting on two different experiences, a bereaved parent with whom I consulted before making my ethics submission said, 'the support at the beginning sets the tone for the journey.' An example of this can be seen in comments of Sarah reflecting on the help of a stranger:

It's just knowing the right thing to say isn't it... an' that person, you know, sort of really helped me, helped us, 'cos, yeah, the right things at the right time means quite a lot as you do remember it.⁵⁴⁴

Writing about the moral life as a journey and the need for companions on the way, Hauerwas and Pinches remind us that 'true virtue is not something we have or do alone.' ⁵⁴⁵ It is, therefore, not surprising that alongside liturgy and ritual it is the presence of a chaplain that brings comfort and may engender an encounter with hope. Accordingly, it is to the virtues that a chaplain expresses in providing this support that I now turn.

7.5 The Virtues of a Chaplain

In suggesting virtues that might make up part of a chaplain's character, as previously stated, I am not aiming to provide an all-embracing virtue ethics theory for chaplaincy. In line with this, the following suggestions are intended not as the final word on chaplaincy virtues, but more simply as a conversation starter. A large range of character traits present themselves as possible virtues that a chaplain might exhibit when supporting parents. Likely choices include humility, gentleness, sensitivity, honesty, creativity, compassion, to name just a few. The situation is further confused by overlapping dispositions; defining the difference between trustworthy, truthful and honest, for example, might be a thesis in itself. Accordingly, I have picked just three virtues to explore. These are: attentiveness, openness, and probity. I have picked them because, alongside

⁵⁴³ Frank, The Wounded Storyteller, 117.

⁵⁴⁴ Sarah CR11.

⁵⁴⁵ Hauerwas and Pinches, Christians among the Virtues, 31.

phronesis, I believe they also perform a regulative function over other dispositions or virtues.

7.5.1 Attentiveness

Recognising that virtues are habits of mind as much as outward behaviour, Jennifer Radden and John Sadler write that 'possessing a virtue might affect not actions, but felt responses that find no immediate expression in action - habits of deliberation, concentration, imagination and attention.³⁴⁶ I suggested in section 2.1.2 that an important skill for chaplains was the gift of attending. The value of giving attention to patients was evidenced by my interviews where a chaplain's depth of attending led to the formation of strong relationships of trust with parents. Radden and Sadler continue by recognising that 'even when overt, what the practitioner does is often subtle, conveying warmth and understanding through words, demeanour, and body language, rather than through grosser motor action.'547 There is, in that description, a strong resonance with Peck's analogy, mentioned in section 2.1.2 in relation to chaplains being attentive listeners, of looking at someone with 'soft eyes.'

7.5.2 Openness

The importance of looking at people with respect relates to the virtue of openness. In his magnum opus Truth and Method, Hans Gadamer writes about the need for a fundamental openness within the practice of interpretation. This openness is extended to conversation where, Gadamer argues, genuine conversation requires accepting the validity of another person's point of view:

Conversation is a process of coming to an understanding. Thus it belongs to every true conversation that each person opens himself to the other, truly accepts his point of view as valid and transposes himself into the other to such an extent that he understands not the particular individual but what he says.548

Within the process of co-creation it is clear that chaplains met parents 'where they were' and respected their viewpoint and beliefs about the world. Alongside links to faith maturity discussed in section 6.3.2, this ability to suspend judgement would seem to have much in common with one of the

⁵⁴⁶ Radden and Sadler, 'Character Virtues', 375.
⁵⁴⁷ Radden and Sadler, 'Character Virtues', 375.
⁵⁴⁸ Hans Georg Gadamer, *Truth and Method*, trans. Joel Weinsheimer and Donald G. Marshall (London: Continuum, 2nd rev. ed. 2004), 387.

ways Roger Walton puts forward for using the Bible and tradition in theological reflection. Termed a 'mutual critique', this is where a dialectical critique is allowed between theology on the one side and practice and experience on the other that requires a willingness to suspend, at least temporarily, the privilege normally accorded to the Bible and tradition.⁵⁴⁹ As Walton notes, 'to engage in this pattern of theological reflection may require a mature self-confidence as well as considerable skill.'550

7.5.3 Probity

Part of that mature self-confidence will relate to probity. Within the chaplaincy code of conduct, probity is defined as 'the honesty, integrity and trustworthiness of chaplains in their professional duties and conduct.³⁵¹ As with psychiatrists, when dealing with people in vulnerable situations it is incumbent upon chaplains to avoid 'temptations to exploit the situation by indulging bias, whimsy, narcissism, and prejudice to preserve one's own selfesteem and psychological unity at the expense of the patient.⁵⁵² The last part of this quotation reminds us that, alongside questions of what human flourishing looks like, there is also the question of whose flourishing is being referenced. Writing about suffering and oppression, Lisa Tessman introduces the idea of a 'burdened virtue.' Here, as a virtue, attention to another's suffering has 'the unusual feature of being regularly disjoined from their bearer's own flourishing.⁵⁵³ Tessman suggests that a burdened virtue may be accepted 'if one is a direct victim of oppression, or one may choose to accept such a burden if one is committed to the liberatory struggle.³⁵⁴ I would suggest that supporting parents and not rushing to fix everything may similarly be thought of as a burdened virtue. Alternatively, we might conceive of it as a distinctive Christian virtue. As Hauerwas and Pinches make clear, contra Aristotle's understanding of friendship, 'there is no question, then, but that Christians must enter into suffering for their friends.'555

⁵⁴⁹ Roger Walton, 'Using the Bible and Christian Tradition in Theological Reflection', Journal of Adult Theological Education 13, no. 2 (2003), 147-48.

⁵⁵⁰ Walton, 'Using the Bible and Christian Tradition', 148.⁵⁵¹ UKBHC, Code of Conduct for Healthcare Chaplains, 6.

⁵⁵² Radden and Sadler, 'Character Virtues', 377.
⁵⁵³ Lisa Tessman, Burdened Virtues: Virtue Ethics for Liberatory Struggles (Oxford: Oxford) University Press, 2005), 160.

⁵⁵⁴ Tessman, Burdened Virtues, 95-96.

⁵⁵⁵ Hauerwas and Pinches, Christians among the Virtues, 48.

Whether understood as a Christian or burdened virtue, in the sorrow or pain that may be experienced through supporting and accompanying parents there is, perhaps, a link to notions of emotional labour discussed in section 7.2.3. The need for chaplains to disengage from parents to avoid burnout or compassion fatigue was noted in section 6.2.3. Alongside appropriate care of others, probity must also relate to chaplains taking care of themselves. Of particular concern is the possibility of disenfranchised grief. Disenfranchised grief refers to 'losses in the mourner's life of relationships that are not socially sanctioned.³⁵⁶ I have elsewhere written of the need for chaplains to work with spiritual directors and work mentors 'to reflect on spiritual and work life respectively.'557 If a chaplain is not appropriately working through the pain and sorrow they experience. they may be, quite literally, storing up trouble. As Danai Papadatou writes, 'quite often, the experience of burnout is the result of grief that has long been disenfranchised.⁵⁵⁸ Suggesting that disenfranchised grief may be an important concern to address in chaplaincy, research with chaplains in America found that twenty-one percent of chaplains felt that their grief was not supported and affirmed at work and sixty-three percent listed circumstances of death which they felt very uncomfortable either talking or hearing about.⁵⁵⁹ Such figures are a reminder that chaplains should, as Worden rightly states of all involved in grief work, know where they get emotional support, what their limitations are, and how to reach out for help when they need it.560

7.5.4 Practical wisdom

It would be difficult to write any account of chaplaincy virtues without exploring the notion of practical wisdom. While some philosophers have argued that *phronesis* is not necessary for every virtue or even redundant to an account of virtue altogether, Daniel Russell argues that, 'virtue ethics cannot establish an appropriate connection between having a virtue and doing what is right unless every virtue includes phronesis.'⁵⁶¹ Reflecting such a position, Banks and Gallagher state that 'without practical wisdom the other virtues

⁵⁵⁶ Worden, Grief Counselling and Grief Therapy, 4th ed., 3.

⁵⁵⁷ Newitt, 'The Role and Skills of a Chaplain', 111.

⁵⁵⁸ Danai Papadatou, 'Training Health Professionals in Caring for Dying Children and Grieving Families', *Death Studies* 21, no. 6 (1997), 589.

⁵⁵⁹ Steven Spidell *et al.*, 'Grief in Healthcare Chaplains: An Investigation of the Presence of Disenfranchised Grief', *Journal of Health Care Chaplaincy* 17, no. 1-2 (2011).

⁵⁶⁰ Worden, Grief Counselling and Grief Therapy, 4th ed., 256.

⁵⁶¹ Daniel C. Russell, Practical Intelligence and the Virtues (New York: Oxford University Press, 2009), 3.

would be rudderless.²⁶² Suggesting how such a rudder might steer the other virtues, Radden and Sadler describe practical wisdom as:

the set of capabilities that allow us to deliberate about things with ends or goals in mind, and to discern and enact right action, thus acknowledging the complexities involved in practical realities. The clinician must combine theoretical knowledge with the particularities of individual cases.⁵⁶³

It may be helpful here to think of the notion of 'reflection in action' which, akin to the reflexivity required of a researcher, 'involves recognising and thinking about a new situation while acting.'⁵⁶⁴ The importance of the situation for decision-making within virtue ethics is made forcefully by Devettere who, translating *phronesis* as prudence, writes:

Prudence is above all concerned with particulars - a particular person in a particular situation is making a particular decision about a particular action in an effort to achieve a particular life that will be good and bring personal happiness - and understanding particulars comes only from experience.⁵⁶⁵

A need for experience is echoed by Ann Begley who, writing about virtues from a nursing perspective, notes how 'the possession of *practical wisdom* leads to excellence in deliberation and... we need experience for understanding and being able to interpret situations: maturity is therefore essential.'⁵⁶⁶ We might think here of a chaplain supporting parents and having to make a decision about whether these particular parents want options or decisive action. I suggested previously that in such a situation there is a need to make subtle and almost instant judgements. If 'deliberation takes time, *until* a deliberative pattern becomes habitual',⁵⁶⁷ then we can see how maturity and experience are an important part of practical wisdom. Such a view would be endorsed, from a Christian viewpoint, by Wells who states that the improvisation mentioned in *section* 7.2.1 is not about being clever or witty or spontaneous 'but is in fact about long preparation before following instinct.' ⁵⁶⁸ Such an understanding

⁵⁶² Banks and Gallagher, Ethics in Professional Life, 78.

⁵⁶³ Radden and Sadler, 'Character Virtues', 377.

⁵⁶⁴ Banks and Gallagher, *Ethics in Professional Life*, 91.

⁵⁶⁵ Raymond J. Devettere, Introduction to Virtue Ethics: Insights of the Ancient Greeks (Washington DC: Georgetown University Press, 2002), 116.

⁵⁶⁶ Ann M. Begley, 'Facilitating the Development of Moral Insight in Practice: Teaching Ethics and Teaching Virtue', *Nursing Philosophy* 7, no. 4 (2006), 258.

⁵⁶⁷ Russell, Practical Intelligence and the Virtues, 13.

⁵⁶⁸ Wells, Improvisation, 80.

leaves us with the implicit question of how a new chaplain might develop practical wisdom, and what a virtue-based understanding of chaplaincy has to say regarding the training of chaplains, to which I now turn.

7.6 Virtues, Training and Continuing Professional Development

Given that, within virtue ethics, an action is right if and only if it is what an agent with virtuous character would do in the circumstances, it is not surprising that 'we understand what *phronesis* is and how it works by watching the *phronimoi*, the people who have it.'⁵⁶⁹ As Hauerwas notes, there is an inherently circular nature to this account of the virtues that cannot be avoided.⁵⁷⁰ This circularity lies behind part of Louden's critique of virtue ethics:

There is also an epistemological issue which becomes troublesome when one focuses on qualities of persons rather than on qualities of acts. Baldly put, the difficulty is that we do not seem to be able to know with any degree of certainty who really is virtuous and who vicious.⁵⁷¹

I would, however, contest Louden's statement. If asked about what acts make a person wise or holy or spiritual I would struggle to articulate them. By contrast, I would find it much easier to name a person whom I view as being wise, holy, or spiritual. In other words, it is the quality of character, not the quality of acts, that lies behind my understanding. Support for this viewpoint might come from the use of character references in job applications which indicate that the qualities of the person matter alongside the quality of their work. More pertinently, within training and education, the use of role models, mentors and exemplars is often used to provide students with a model of the type of person they should aspire to be. As Radden and Sadler state, 'the importance of this sort of learning has long been recognized in the apprenticeship, or practice-based, models of medical education.'⁵⁷² It is this fact that leads Hauerwas to conclude that 'medicine, because it remains a craft that requires apprenticeship, exemplifies how virtue can and should be taught.'⁵⁷³

⁵⁶⁹ Devettere, Introduction to Virtue Ethics, 111.

⁵⁷⁰ Hauerwas, 'Virtue and Character', 2553.

⁵⁷¹ Robert B. Louden, 'On Some Vices of Virtue Ethics', American Philosophical Quarterly 21, no. 3 (1984), 232.

⁵⁷² Radden and Sadler, 'Character Virtues', 380.

⁵⁷³ Hauerwas, 'Virtue and Character', 2553.

7.6.1 Mentoring and shadowing

Alongside medicine, apprenticeships and mentoring are also used within the training of nurses and other allied-health professionals. They are not, I suspect, widely used in chaplaincy training or continuing professional development. Currently the UKBHC website links to seven healthcare chaplaincy courses.⁵⁷⁴ Reading through the basic course details, only three appear to include a practical element alongside the theoretical work. More worryingly, although one mentions supervision, only one describes working with an experienced mentor. This is concerning for, as Begby writes of nursing, 'passing all examinations and demonstrating theoretical wisdom is no guarantee that the student will be a good nurse - there must be evidence that theoretical knowledge can be used to make sound judgements and to act appropriately.'575 I have to acknowledge here my own culpability. While I do not know exact numbers, in five plus years of chaplaincy work the number of times I have either shadowed another chaplain, or had another chaplain shadow me, probably only just reaches double figures. Part of the reason for this lack of shadowing stems from my own hesitancy. Until recently, I would have been one of those who might respond to suggestions of increased mentoring within chaplaincy training and assessment with the comment that it is not appropriate for sensitive one-to-one pastoral work. At a conference in Glasgow in March 2012, David Mitchell gave a workshop about the development of the Glasgow MSc in Healthcare Chaplaincy, the one course noted above that directly mentions mentoring. Mitchell described how many experienced chaplains expressed concerns about mentoring not being suitable within a pastoral encounter. However, he went on to share how feedback about the experience, from both mentor and mentee, was extremely positive. In contrast to their worries, mentors had found, in practice, that it did not detrimentally affect a chaplain's ability to support patients.⁵⁷⁶

⁵⁷⁵ Begley, 'Facilitating the Development of Moral Insight in Practice', 258.

⁵⁷⁶ David Mitchell, 'Integrating Professional Education in Spiritual Care within a Multidisciplinary MSc. Programme' (workshop given at the Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing, International Conference, Glasgow, March 13-14 2012), <u>http://www.nes.scot.nhs.uk/media/859374/david_mitchell.pdf</u>.[accessed 4 June 2012]

⁵⁷⁴ UKBHC 'Training and Education', (<u>http://www.ukbhc.org.uk/chaplains/training-and-education</u> [accessed 31 March 2012].

7.6.2 The black box of chaplaincy interventions

It is, perhaps, partly this lack of shadowing and mentoring that had led to, what I have heard Daniel Grossoehme⁵⁷⁷ refer to as, the 'black box' of chaplaincy interventions. By this I understand him to mean the simple fact that we have very little evidence for how chaplains actually carry out their interventions. Travelling home on the train from the Glasgow conference, I was near two surgeons. They spent part of the journey discussing how they performed a particular surgical procedure. I found myself reflecting that I have never had similar discussions with another chaplain about how they carry out a naming and blessing or a baptism. I do not know what practical actions another chaplain might perform; do they touch the baby? do they make the sign of the cross? do they invite others to carry out ritual action? what do they say as they leave? Given my argument that one of the skills of a chaplain is adjusting what they do to the situation, I have little idea how other chaplains make these more intangible or intuitive decisions. In light of this it is perhaps not surprising that, as part of his keynote address at the Glasgow conference, George Flitchet argued that, rather than random controlled trials, what chaplaincy needs at the moment is good case studies of our work.⁵⁷⁸ In his view, these case studies should provide detailed information about the person to whom care was provided, the spiritual care provided, and what happened as a result of that spiritual care. As I noted at the beginning of chapter two, there is little consensus as to 'what the chaplain comes for.' There is a desperate need for greater understanding of both what the chaplain comes for and what they actually do once they arrive at the bedside. As part of this, I would argue for increased shadowing and mentoring as part of chaplaincy training and continuing development.

7.7 Summary

In determining the correct way a chaplain should respond to the complex and sometimes paradoxical need of parents, I have argued that a virtue-based approach has much to commend it. Rather than the near-impossibility of creating rules or principles to follow, the character of the chaplain acts as the driver for the action they take. A virtue-based approach also has the advantage

⁵⁷⁷ Assistant Professor of Pediatrics at the University of Cincinnati College of Medicine and Staff Chaplain III in the Department of Pastoral Care at Cincinnati Children's Hospital Medical Center.

⁵⁷⁸ George Fitchett, 'Making Our Case(s)', Journal of Health Care Chaplaincy 17, no. 1 (2011).

of appreciating the way that emotions can contribute to our decision-making. Character is formed through the habituation of appropriate virtues. In understanding how it may guide decision-making, I suggested that a regulative ideal, a concept that incorporates but goes beyond codes of conduct, is particularly helpful. With regard to the work of chaplains with parents, I proposed that a Christian regulative ideal is the engendering of an encounter with hope. Far from being a platitude, such hope needs to be able to accommodate pain and brokenness. As metaphors for understanding how it may function, I identified hope as presence, and hope as quest.

My aim through this chapter has not been to set out the definitive understanding of chaplaincy virtue ethics but rather to open up discussion. Accordingly, rather than provide an exhaustive list of virtues, alongside practical wisdom, I set out three key virtues that might act to regulate other virtues or dispositions. These were attentiveness, openness, and probity. Importantly, I noted that probity relates not just to the safe and appropriate care of others, but also to the need for chaplains to exercise self-care. Lastly, because of the way virtues are learnt from studying the virtuous, I argued for the place of increased shadowing and mentoring within chaplaincy. Such a suggestion leads to my final chapter containing my conclusions and recommendations.

8. <u>Conclusions and Recommendations</u>

In chapter seven, whilst discussing regulative ideals, I alluded to Cobb's contextual model for the location and identity of chaplains. The model sets out the three principal communities that chaplains are associated with and participate in: the healthcare community, the faith community, and the professional chaplaincy community (referred to by Cobb as the disciplinary community).⁵⁷⁹ Although there is an inevitable overlap, my conclusions and recommendations will be set out in relation to the community to which they are most relevant. As all the conclusions stem from them, the chapter begins with a summary of the spiritual needs identified and the way in which chaplaincy support helped to meet that need.

8.1 Spiritual Need

Whether it was suffered as a miscarriage, stillbirth, termination for fetal abnormality, or neonatal death, the loss of their baby was experienced by parents as a devastating event. Each of their stories was unique. While I have identified common spiritual need arising from their loss, it must be remembered that each parent is an individual and requires responding to as such. As I have argued at a number of different points, there simply is not a one size fits all response.

I have suggested that the root of all other spiritual need was the loss of control that parents experienced as events transpired that they were powerless to halt. Some parents had warning that things were unlikely to turn out as they had hoped and had started to prepare themselves accordingly. However, for most parents pregnancy loss was not something they had anticipated and so came as a bolt from the blue. Alongside this overarching need, I distinguished three further themes. The first two of these were a loss of meaning and purpose, and a loss of self worth. Along with a loss of control, these were also themes identified by Kelly and so my research provides strong corroboration for his work. However, I found less substantiation for another of Kelly's themes, that of social isolation. One likely reason for this was the greater time post-bereavement of parents in my study. Based on their comments, I also argued that individual

⁵⁷⁹ Cobb, 'The Location and Identity of Chaplains', 11.

personality traits may have played a part in whether or not parents were able to talk about their loss. Accordingly, I recommend that further research with bereaved parents, particularly if it is looking at coping, should include some form of personality indicator.

As a new theme arising from my research, I noted parents' intuitively felt a desire to do something. In response to the instinctive need, liturgy and ritual allowed parents both to do all that they could for their baby and to mark what had happened. At a fundamental level, the fact that parents were able to choose to have some form of ceremony began to give them back an element of control. For parents with a particular faith, this was often expressed in terms of preparing their baby for the afterlife. Those who did not have a religious understanding of life tended to place greater importance on marking the reality of their baby. Along with the ceremonies, parents treasured mementos that were given following them, which acted both as a reminder of and evidence for the ceremony.

In helping counter spiritual distress, parents appreciated both the presence of a chaplain and the liturgy and ritual they performed. The presence of the chaplain was valued in a number of different ways by parents. Attentive listening gave parents a sense of dignity and helped them feel that they mattered as individuals. The presence of a chaplain also brought parents comfort in the form of strength and hope. As a result of sharing an intense part of their bereavement journey, parents could develop strong bonds with the chaplain who supported them. Seeing the same chaplain was greatly appreciated by several parents, who contrasted a sense of the chaplain as a constant with the rotation of other hospital staff.

8.2 Conclusions and Recommendations Pertaining to the Health Service

8.2.1 Need for training of healthcare staff due to poor expectations of chaplains.

In section 5.5 I described how all but one parent, who had previous experience of chaplaincy support, did not know what sort of care a chaplain would

provide. Perturbingly, parents' assumptions of how the chaplain would relate to them were wholly negative, expecting chaplains to be inappropriately churchy in appearance and conduct or, worse, judgemental. Thankfully, contrary to these presumptions, parents experienced chaplains as open and approachable. However, given these adverse expectations, it is likely that many parents will be hesitant about accepting the offer of chaplaincy support and some may even decline it. Nurses and midwives are widely regarded as the gatekeepers to patients. There is, therefore, an important role for them in providing reassurance to parents that chaplains will not arrive and preach at or judge them. Of course, if parents have poor expectations of chaplains, there is little reason to imagine that hospital staff do not carry the same concerns and suppositions, particularly if they have not seen chaplaincy support in action. This may be an additional reason why, as other research has shown, nurses are often reluctant to ask about religious or spiritual need.⁵⁸⁰ To counter this, the offering of chaplaincy support should be written into the guidelines and protocols for the care of parents who suffer a pregnancy loss. Alongside this, chaplains should also be proactive in providing teaching about the value that parents find in chaplaincy support. This will hopefully have a secondary effect of allowing staff to get to know the chaplains and counter any myths they hold.

8.2.2 Why chaplains should continue to be employed by the NHS

The National Secular Society, as noted in *section 2.1.3*, counselled that chaplaincy services are an irrelevance for most people and that public funding should be phased out. Instead, they stated that clerics, from a patient's own place of worship, be called in when required. As is clear from the RFQ, parents who valued chaplaincy support were not limited to those who had a religious understanding of life or were well linked to a faith community. Indeed, as noted in *section 5.6.3*, religious care, relating to the eternal destiny of their baby, was appreciated by parents who indicated a non-religious understanding of life, did not identify with a particular religion, nor engage in religious practices. Because these parents are not linked with a place of worship, they simply would not have a 'cleric' who could be called into support them.

⁵⁸⁰ Mark Cobb, 'Assessing Spiritual Needs: An Examination of Practice', in Mark Cobb and Vanessa Robshaw (eds.), *The Spiritual Challenge of Health Care* (Edinburgh: Churchill Livingstone, 1998); Chris Swift, Sara Calcutawalla, and Rosie Elliot, 'Nursing Attitudes Towards Recording of Religious and Spiritual Data', British Journal of Nursing 16, no. 20 (2007).

Moreover, as the comments of Chloe demonstrate below, even if there is a link to a faith community, the 'cleric' may not be immediately available in the same way that chaplains are able to be. Nor, given the sensitive nature of pregnancy loss, may the person actually want people outside the hospital to know of their circumstances:

Initially, I was thinking of ringing my pastors in church but they've got to check their diaries and then I didn't really want the whole church to know... I didn't want to really tell a lot of people. It was... very difficult for me... [When] the midwives... asked me if I wanted the chaplain to come... it sort of just removed the whole logistical nightmare of having to contact church and finding somebody who would be free.⁵⁸¹

The valuing of chaplaincy support by those who were not religious, either in outlook or practice, endorses the view that, rather than religion *per se*, it is religious authority that many people disdain. The findings from my interviews show that, in many cases, good non-dogmatic religious care is good spiritual care. Accordingly, less as a recommendation and more as a reiteration of good practice, chaplaincy support should be offered to parents whether they express a particular faith or none.

8.2.3 Seeing and holding their baby

As discussed in *section* 3.1.4, Hughes *et al.* speculated that parents who saw and held their baby after its death were further traumatised by this action. This research was published in *The Lancet*. The same criticism made of Wu and Sung's 2003 *Lancet* article mentioned in *section* 2.2.3 should also be made of this article; namely, that the human story so necessary in making sense of the situation is strikingly lacking. It seems quite extraordinary that, given the wealth of personal accounts of pregnancy loss, none of this is referenced. Rather than discussing how narrative experience might counter their speculation, they seem to have been blinded by the numbers. I do not know if all the parents in my study held their baby, but they did all see their baby. Noticeably, in this and in Kelly's study, no parent made reference to feeling traumatised by this. Instead, the quotations from parents in earlier chapters portray the direct opposite. We might remember Olivia's comment, 'we just had this quiet moment an' they blessed him, an' they gave him his name an' everything..., it was just really quiet an' peaceful.'⁵⁸² Likewise, Jenny described how 'it made me

⁵⁸¹ Chloe CR12.

⁵⁸² Olivia CR08.

cope with it better knowing that... she was settled and I knew when the chaplain blessed her..., I just felt like..., she alright she's gone now.'⁵⁸³ Contra to the NICE guidelines, the research presented above supports parents being routinely offered the opportunity to see and hold their baby.

8.2.4 Evidencing the value of chaplaincy

In section 1.1.1 I outlined the increasing drive for evidence-based care within the NHS and stated that one aim of this research was to evidence the benefit of chaplaincy support. Within healthcare, randomised controlled trials are considered the 'gold standard' for assessing efficacy of interventions. At both a practical and ethical level there are several reasons that would make carrying out a trial in this context well nigh impossible: for example, blinding participants to interventions and randomising to receiving support or not. Moreover, as argued in section 2.2.3, there is danger in reducing such complex interventions to numbers. Within this research, for example, the narrative voice gave a much fuller picture of how parents had experienced the support of chaplains than would have been achieved with a quantitative approach.

This does not mean to say that there is no place for quantitative outcome measures in evidencing chaplaincy. Rather than either therapeutic or health economic outcomes, such as reduction in blood pressure or reduction in length of hospital stay, chaplaincy's focus should be on measures relating to adding value to patients. For example, in Scotland, Iain Telfer and Austyn Snowden are involved in developing Patient Reported Outcome Measures (PROMs) for chaplaincy. This looks at patient experience in relation to the effect of chaplaincy support, asking them to grade on a five point scale statements such as 'I found I was able to gain a better perspective on my illness.'⁵⁸⁴ While I commend the taking of a patient perspective and the development approach they have taken, as a research tool it is still missing the narrative voice. It may have an important role in patient assessment and clinical audit, but I do not believe it should be used a stand-alone research tool.

⁵⁸³ Jenny CR02b.

⁵⁸⁴ Jain Telfer and Austyn Snowden, 'Patient Related Outcome Measures (PROMS)' (presentation at the Research Informing Practice Conference, Perth Scotland, June 15 2011), <u>http://www.nes.scot.nhs.uk/media/3716/telfer%20and%20snowden%20proms%20presentation.pdf</u>. [accessed 4 June 2010]

As demonstrated in the published research regarding seeing and holding a baby after death, the lack of a narrative voice may seriously diminish the understanding of a complex situation. Consequently, I believe that, alongside quantitative methodologies, the healthcare community should recognise that evidence consists of more than simply what can be measured. As a result, I advocate continued research into the patient experience and recommend that, where appropriate, the narrative voice is included within study design.

8.3 Conclusions and Recommendations Pertaining to the Church

Over the last decade churches have increasingly made mission and evangelism a focus, with the term 'mission-shaped' becoming a ubiquitous prefix to any number of books. Within the Anglican Diocese of Sheffield, the ministry of chaplains is overseen by the Archdeacon of Doncaster. Preaching on the occasion of his Licensing and Collation as Archdeacon, Steve Wilkinson asked the question:

Do we offer unconditional welcome so that people can work out their faith from within, rather than feel they have to "qualify" first? We need to be people with a vision for those who don't feel they belong, for those who stand apart, for those who perhaps feel "judged." Many of them are closer to the Kingdom than we may think. Don't say other people's "No" for them – at a deep level, they may be saying a kind of "Yes" to Jesus.⁵⁸⁵

The evidence of *section 5.5* is that those outside the church feel that they have to qualify first and that, if they do not meet certain criteria, the church will want nothing to do with them apart from judging them. Writing about the relationship between chaplains and the Church of England, Swift suggests there has been a deliberate policy of intentional remoteness. Among a couple of related reasons, he suggests this is because 'the liberal make-up of most chaplains is unattractive and appears remote from the desire to establish "orthodoxy".'⁵⁸⁶ Certainly I have heard it anecdotally said that chaplaincy is a place for those who are theologically liberal and uninterested in mission or evangelism. The willingness of chaplains to meet parents 'where they are' and to shape liturgy and ritual around their beliefs may well be taken as further

⁵⁸⁵ Steve Wilkinson, Sermon preached at Sheffield Cathedral on the occasion of his licensing, (25 January 2012). [no source available in the public domain]

⁵⁸⁶ Swift, Hospital Chaplaincy, 152.

evidence of this by proponents of this view. Yet, it is clear from the interviews that, in the work of chaplains, parents found exactly the unconditional welcome that Wilkinson describes.

Furthermore, and I should be clear here that this is my interpretation rather than parents viewpoints, it may also be that, at that deep level, parents are saying a kind of 'yes' to Jesus. As recounted in section 6.3, a number of parents, either within their interviews or following completion of the RFQ, spoke about finding faith or developing greater spiritual awareness. Noting a consistent theme within Judeo-Christian spirituality that times of testing lead to growth, I suggested that this might not be such a surprising outcome. Continuing by citing Fowler's theory of stages of faith, I proposed that alongside the major upset of losing a baby, both the experience of liturgy and ritual and the sensitive presence of a chaplain could be factors that precipitate movement between stages. As noted within that section, Fowler understands faith not in terms of doctrinal religious belief, but more universally in relation to meaning and identity. Whilst some parents' faith development was Christian orientated, those who spoke in more spiritual and experiential terms were clearly not making dogmatic declarations of belief in Jesus. Yet, understood in terms of the prologue to the Gospel of John,⁵⁸⁷ if Jesus is viewed as both word and wisdom, the one in whom we live and move and have our being, and the embodiment of the God who constantly calls us onward out of ourselves and into our true selves, then at a profound level they could be viewed as saying yes.

In relation to stage change I quoted the comment of Astley *et al.* that, as the shawl of meaning unravels, the job of the pastor is to stand with the wearer in their nakedness and empower them to knit a new one. Several of the more recently bereaved parents in my study described a continuing need for support. Julia, for example, stated, 'it be nice to have a counsellor who deals with baby loss... but there's... nothing like that.'⁵⁸⁸ Similarly, Chloe spoke about how:

I would have loved Jessop to do it as well, bereavement support for the parents, just some counselling... my problem is now and I'm told there is a waiting list of three months and I'm hurting now so there's a gap there, there's a gap.⁵⁸⁹

⁵⁸⁷ Jn 1.1-18.

⁵⁸⁸ Julia CR09.

⁵⁸⁹ Chloe CR12.

Underlining the gap in provision, Thomas described how he and Katy were 'waiting for a bit of counselling... aren't we.'⁵⁹⁰ If churches can provide that unconditional welcome there is an obvious role for them in continuing to support parents beyond the immediate support provided by chaplains.

As Threlfall-Holmes and I have written elsewhere:

Chaplains may be marginal to the churches, but they are often in places where the 90 per cent of the UK population who do not regularly attend church will be found. In marketing terms, chaplains and chaplaincies are gold dust. Like an advertising slot in the middle of a world cup final, they give the Church an opportunity to engage with the unchurched or dechurched majority whom it would otherwise find hard to reach.⁵⁹¹

It is, therefore, inexplicable that 'the experience and insights of chaplains as a group appear to be drawn on both superficially and fitfully.'⁵⁹² Consequently I urge churches to engage more seriously with chaplains with a willingness to listen and learn from our observations and understandings.

8.4 Conclusions and Recommendations Pertaining to Chaplains

8.4.1 Co-creation

At the end of chapter four I stated that one of my aims was to see if Kelly's findings, particularly regarding co-creation, could be replicated or if they needed challenging or nuancing. All the parents who had a funeral service provided by a chaplain spoke about having an input into the service and clearly appreciated this possibility. As with choosing to have a ceremony, the provision of options enabled parents to take back more control. Concerning the ceremonies that took place in the hospital, parents with a spiritual rather than religious understanding of life were grateful that liturgy and ritual was not overly churchy. However, there was little talk about co-creation within these ceremonies. Indeed, mostly in relation to liturgy carried out in the hospital, several parents were grateful that the pressure of decision-making was alleviated by the chaplain taking authoritative action. As such, at one level, my findings

⁵⁹⁰ Thomas CR10a.

⁵⁹¹ Threlfall-Holmes and Newitt, 'Introduction', xv.

⁵⁹² Swift, Hospital Chaplaincy, 155.

substantiate Kelly's claims for the value of co-creation. However, I also caution that it is not always appropriate and chaplains should not presume that it is the default choice.

8.4.2 Paradoxical situations and multiple roles

In section 5.6 during the exploration of why, despite having poor expectations, parents wished for chaplaincy support, I argued that, along with the ability to use liturgy and ritual, parents saw chaplains as representing a combination of religious and spiritual authority. At the same time, parents greatly appreciated the ability of the chaplain to relate to them on a human level. There is a paradox here. Chaplains need the pastoral sensitivity to, in the terminology of Martin Buber, meet and listen to parents as 'I-Thou.'⁵⁹³ At the same time, they must have the ability to step back from that intimate way of relating and carry out ritual with, in Austin's terminology, an appropriate 'force.' In attempting to understand the contradictory ways that a chaplain may have to relate to parents, in *section* 5.7 I suggested that anthropological perspectives on ritual provide greater insight to a chaplain's role and identity than drawing analogies with shamanism. Such complex relating reinforces my statement, in *section* 2.1.5, that rather than requiring 'no expertise', being a chaplain demands distinctive competencies and great skill.

Part of this expertise is the ability to, having only just met them, make rapid decisions in relation to the spiritual needs of parents. As I have made clear, in this complex situation, there is not a one size fits all response. The deftness of the chaplain in reading the situation and responding appositely was key to them forming a therapeutic relationship with parents and providing appropriate care. In deciding how to act, through chapter seven I argued for adopting a virtue-based approach where character acts as the driver for decision-making. Such an approach has merit for a number of reasons, not least because it provides space for the use of emotions within decision-making. Along with 'gut feelings', I suggested that the habituation of chaplaincy virtues was a helpful way to understand how chaplains may make use of intuition.

Within virtue ethics, character is understood as the way in which individual attributes or virtues act out together within a person. In understanding how

⁵⁹³ Martin Buber, *I and Thou*, trans. Ronald G. Smith (London: Continuum, 2000).

character can help guide decision-making, I suggested that the notion of a regulative ideal is particularly helpful. Incorporating but going beyond normative dispositions, I suggested a regulative ideal for chaplains would include, but not be limited to, the code of conduct issued by the UKBHC. While the code establishes the dispositions relating to standards, there is little written on what virtues are essential beyond this. One exception is Martin Kerry's chapter on competencies in chaplaincy. Alongside knowledge and skills, he includes ten behaviours which 'describe the attitudes, personal qualities and "ways of being" which impact upon the way chaplaincy is carried out.'594 Intended as a discussion starter rather than the final word, I proposed attentiveness, openness and probity, along with practical wisdom, as key virtues.

Virtue ethics states that an action is right if and only if it is what an agent with virtuous character would do in the situation. As a result, virtues are acquired by observing the virtuous. As I argued in *section* 7.6.1, there is a need for shadowing and mentoring to be better incorporated into chaplaincy training and development. I recommend, therefore, that all training courses on chaplaincy include placements that involve shadowing and mentoring from an experienced chaplain. Equally, I would encourage even experienced chaplains to both shadow and be shadowed by colleagues. At the same time, I would hope that further discussion will arise out of this work regarding the virtues that chaplains might be expected to exhibit in providing good spiritual and religious care. Part of this conversation should include how virtues may be assessed.

8.4.3 Stages of faith and chaplains

In light of the way chaplains shaped liturgy and ritual to fit parents beliefs without imposing their own views, I suggested, in *section* 6.3.2, that chaplains exhibit many of the characteristics of Fowler's faith Stage 5. While work has been done looking at the personality type of chaplains,⁵⁹⁵ research classifying, comparing and contrasting their belief systems, whether using Fowler's stages or some other grouping, would be another valuable insight as to the type of

 ⁵⁹⁴ Martin Kerry, 'Towards Competence: A Narrative and Framework for Spiritual Care Givers', in Helen Orchard (ed.), Spirituality in Health Care Contexts (London: Jessica Kingsley, 2001), 124.
 ⁵⁹⁵ Leslie Francis et al., 'Distinctive Call, Distinctive Profile: The Psychological Type Profile of Church of England Full-Time Hospital Chaplains', Practical Theology 2, no. 2 (2009).

character necessary for chaplaincy. A flexible non-linear understanding of Fowler's faith stages may provide increased awareness of why some people seem to survive and thrive in chaplaincy, while others move on after only a few years. Relating to this, Derek Fraser has carried out, as yet unpublished, research with Baptist chaplains. Speaking at the Spiritual Care and Health conference in Glasgow, he outlined evidence than those who stay in chaplaincy enter it with greater experience of church ministry than those who come and quickly go.⁵⁹⁶ From chaplains' responses, Fraser postulates that this is because they have developed appropriate coping strategies. Given the importance I place in sections 6.2.3 and 7.5.3 on chaplains exercising self-care, I do not disagree with this assessment. However, it does not explain the minority who enter chaplaincy without much church experience and stay. Drawing on his research, Swift states that a theology written out of chaplaincy is unlikely to be tidy and 'may well look somewhat different from that emerging out of academia.'597 Fowler's Stage 5 'involves going beyond the explicit ideological system and clear boundaries of identity' of Stage 4.598 Accordingly, a messy theology is likely to be coped with better by a person demonstrating attributes of Stage 5. Greater experience of church ministry may mean that a person coming into chaplaincy has learnt to be comfortable with paradoxes and a sense that truth is always greater than they can grasp. However, this view does not deny that younger, less experienced, chaplains may also exhibit characteristics associated with Stage 5. As part of understanding the character of chaplains I would encourage research that attempted to group and compare their belief systems. Potentially, such research could inform selection criteria and training if particular attributes are identified as conducive to the work of chaplains.

8.4.4 Transference

As already mentioned in these conclusions, in *section* 5.5 I described the poor expectations parents had of chaplains. As part of my exploration of why, with such views, parents wished for chaplaincy support, I referenced Nolan's depiction of chaplains being an 'evocative presence.' Noticeably, within that quotation, Nolan, who is a trained psychotherapist, mentions 'transferential' responses. The language of transference and enactment stems from

 ⁵⁹⁶ Derek Fraser, 'Understanding How Chaplains Survive in the World of Healthcare' (workshop at the Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing, International Conference, Glasgow, March 13-14 2012). [no source available in the public domain]
 ⁵⁹⁷ Swift, Hospital Chaplaincy, 155.

⁵⁹⁸ Fowler, Stages of Faith, 186.

psychoanalysis and is one way of discussing intersubjectivity and the way our thoughts and feeling may be unconsciously communicated. Conventionally, within the context of counselling and therapy, transference describes 'a process where the client projects a quality, trait or whole person from their past onto the therapist.'599 In turn, countertransference relates to the feelings of the counsellor. This is, though, understood in a number of different ways: '(1) as a reference to all the feelings a therapist has toward a client, (2) as the therapist's reactions to a client's transference, or (3) as the therapist's own transference feeling toward a client.'600 Linked to transference are enactments. These, often subtle actions such as a change in tone of voice or foot tremor, are, 'inevitable, continual, and part of an ongoing dance of mutual influence - an "intersubjective" relationship between both conscious and unconscious between helper and helpee.'601 Currently I have friends training, one as a clinical psychologist and one as a Gestalt counsellor. A significant part of both courses has involved teaching in relation to transference and countertransference. As a chaplain I have had no such training. Given that, in several places, I have explicitly stated that chaplains are not counsellors, it might be asked why this matters. All relationships involve some form of transference and enactment. As Pamela Cooper-White states, 'virtually every action may have meaning, and often some of the most powerful work of the therapy may be carried on at the nonverbal level.'602 In discussing the 'evocative presence' of hospice chaplains, Nolan relates how, despite not using technical language, chaplains described their encounters with patients 'in ways that resonate with being the object of another's transferential projection.⁶⁰³ Being aware of both patients' and their own transferences is likely to help chaplains provide better care. Writing about the use of the self in pastoral care and counselling, Cooper-White observes that the way in which a person uses information gained from transference and enactments will differ depending on the context. She continues, though:

The more we are able to tune in to our own inner perceptions and reflect on these in a thoughtful way, the more sensitively we will also be able to tune in to the nuances of the helpee's own feelings, wishes, and experiences. Then, in turn we can use these insights to choose

(Minneapolis, MN: Fortress Press, 2004), 57.

⁵⁹⁹ David Mann, Gestalt Therapy: 100 Key Points and Techniques (Hove: Routledge, 2010), 98. ⁶⁰⁰ Jeffrey A. Kottler, On Being a Therapist (San Francisco: Jossey-Bass, 4th ed. 2010), 145.

⁶⁰¹ Pamela Cooper-White, Shared Wisdom: Use of the Self in Pastoral Care and Counseling

⁶⁰² Cooper-White, Shared Wisdom, 57.

⁶⁰³ Nolan, 'Chaplain as "Hopeful Presence", 170.

responses and interventions that are most appropriate to our role as helpers and to the helpee's needs.⁶⁰⁴

As I described in section 5.6.3, in responding to parents chaplains have to make rapid decisions in a situation where there may be paradoxical need, and where there are layers of conscious and unconscious communication. I recommend, therefore, that teaching on transferences should be part of all introductory chaplaincy courses and encourage existing chaplains to learn more about it. Within counselling one of the roles of supervision is to help the therapist quickly recognise and control their personal transference toward a client.⁶⁰⁵ I therefore further recommend that those who provide supervision for chaplains should include discussing transferential responses as part of supervision.

8.4.5 Chaplaincy support is the active ingredient

At the end of chapter four I stated that one of my aims was to determine whether particular parts of chaplaincy support were more important than others, i.e. whether there is an 'active ingredient.' This notion was introduced, in section 3.3, with regard to the MRC guidelines for investigating a complex intervention. In that section I raised the question of whether it was the prayers and ritual, the manner and bearing of the chaplain, or a combination of both that lay behind a parent saying that the support of a chaplain had helped 'relieve their sadness.'

Through chapters five and six I consistently argued that the presence of the chaplain in being with parents is as important as the liturgy and ritual carried out. Further evidence that the two cannot be separated comes from the answers parents gave concerning whether there were individual episodes within the support that felt more important to them. Prior to carrying out the interviews my expectation was that parents might pick out a particular moment within the services and ceremonies; for example when they scattered confetti stars into a graveside or lit candles. I was therefore somewhat surprised when universally parents commented that 'the whole process... for me was important',⁶⁰⁶ 'it was just all together I think',607 and that they 'couldn't particularly pull out one

⁶⁰⁴ Cooper-White, Shared Wisdom, 8.

⁶⁰⁵ Anthony Ryle, 'Transferences and Countertransferences: The Cognitive Analytic Therapy Perspective', British Journal of Psychotherapy 14, no. 3 (1998), 306. 606 Lewis CR01.

part.'608 Even when parents did single out particular items it was normally related to episodes of care rather than individual constituent parts:

It was a sense of everything but..., for me, I think it was the... naming an' blessing... ceremony 'cos [sighs] it's very important that it was just me and Alfie there an', you know, [the] person doing the ceremony.⁶⁰⁹

The whole package I can say the whole package was... quite excellent, but I can just sort of single out, if I may, the baptism... it was sort of like an awakening moment for me because when the... baptismal rites... were being done actually Stuart was still alive with us and that one sort of gave me some bit of hope.⁶¹⁰

In arguing that the elements of chaplaincy support cannot be separated out, I am not denying that parents may have found certain parts particularly moving. Diane, for example, spoke about how hearing how the chaplain had 'put together our words' was 'very poignant.'611 Likewise, Thomas described when 'carrying my little boy into [the] crematorium... I just felt right proud for them few minutes.^{'612} Yet, in each of these instances, it was clear that they mattered in relation to the support in its entirety. In reflecting on the co-creation of liturgy and ritual, Kelly describes how parents in his research 'experienced the co-construction of ritual as a process which they and the chaplain were engaged in, not as a one off event.'613 Developing this, as discussed in section 6.1.2, parents experienced the support of a chaplain as a constant presence despite them not being present at all times. Linked to this, it is clear that parents understood all the support a chaplain provided on separate occasions as part of one single process; whether listening, planning or carrying out liturgy and ritual. Accordingly, rather than there being an 'active ingredient', although it is not a perfect analogy, alluding to palaeontologists Niles Eldredge and Stephen Jay Gould's theory of punctuated equilibria,614 the support of a chaplain might best be thought of as a punctuated process. Such a view recognises that the journey of chaplaincy support is ongoing, though punctuated by moments of face to face care.

⁶⁰⁸ Alistair CR06a.

⁶⁰⁹ Sarah CR11.

⁶¹⁰ Martin CR03.

⁶¹¹ Diane CR06b.

⁶¹² Thomas CR10a.

⁶¹³ Kelly, Marking Short Lives, 169.

⁶¹⁴ Stephen Jay Gould and Niles Eldredge, 'Punctuated Equilibria: The Tempo and Mode of Evolution Reconsidered', *Paleobiology 3*, no. 2 (1977).

As noted in *section* 6.1.2, several parents appreciated 'seeing the same face.' Consequently I recommend that, whenever possible, the same chaplain provides support to parents throughout. When this is not possible, explanations should be given and, where appropriate, introductions made. Several parents commented on how frustrating it was having to repeat things to staff. To avoid this, when another chaplain has to take over providing care, it should be ensured that they are given a comprehensive handover.

8.4.6 Researching the chaplain

As part of my discussion of virtue ethics in section 7.4, I proposed that in supporting parents a regulative ideal for Christian chaplains is engendering an encounter with hope. In choosing hope, rather than a medically focused ideal, I appear to have much in common with hospice chaplains. From his research with them, Nolan writes that 'unlike other healthcare professionals, chaplains seem not to conceptualize their clinical work in terms of therapeutic aims.'615 The statements in the DIPEx research, which my study supports, of how chaplains did not try to 'fix everything', suggest that it is not just in the hospice that chaplains do not conceive of their work in this way. The lack of a therapeutic aim adds further credence to my notion, discussed at several points in this thesis, that chaplains are able to listen differently to other healthcare professionals. It is important to state here that the lack of a therapeutic aim should not be confused with a lack of purpose or goal. In section 7.6.2 I recounted Flitchet's aspiration for chaplains to publish case studies of their work. I endorse such a desire. However, in addition, I recommend that there should be further research exploring how chaplains conceptualise their interventions.

I started this thesis by stating that, at its heart, it was the attempt of myself as a chaplain to better understand how I can support parents. Linking together several of the themes in this thesis, Sidney Dekker describes the notion of 'the uniquely gifted shaman, witch doctor, healer, medicine man—who is able to interlocute between mortals and the metaphysical, ruling over life and death.' He continues by writing, in relation to this description, that 'real medicine

⁶¹⁵ Nolan, 'Chaplain as "Hopeful Presence", 172.

men perform dancing art. They don't use a checklist to map out the steps.' ⁶¹⁶ Dekker portrays this as a negative approach to the practice of medicine. It is, however, perhaps a good description of what bereaved parents look for in a chaplain.

⁶¹⁶ Sidney W. A. Dekker, 'We Have Newton on a Retainer: Reductionism When We Need Systems Thinking', *Joint Commission Journal on Quality and Patient Safety* 36, no. 4 (2010), 147.

9 <u>Appendices</u>

9.1 Appendix I: Interview Schedule

- I realise that it is not an easy topic but could we begin with you telling me a little bit about the circumstances of your loss? (For example, at what gestation was delivery, was it sudden or had there been some warning signals, was it a stillbirth, miscarriage or neonatal death.)
- Could you now tell me about the support provided by the chaplain(s). (For example, what service/ceremony/ritual(s) did the chaplain carry out, did they spend time talking/listening with you?)
- 3. Thinking about the service/ceremony/ritual(s) in a little more detail, what input, if any, did you have into the service/ceremony e.g. did you chose readings or music?
- 4. Was there are part of one of the ceremonies/services that felt particularly important to you?
 - a. If so, can you attempt to explain why?
- 5. Do you think that any of the service/ceremony(s) helped you in any way?
 - a. If so, can you attempt to explain how?
- 6. Returning to the support provided as a whole, what were your thoughts when a nurse/member of staff asked you if you would like to see a Chaplain?
 - a. what expectations did you have of the chaplain and the support they could offer/provide?
 - i. Do you feel that your expectations were met?
- 7. Was there anything that you did not like about the involvement of the chaplaincy service?
- 8. Was there anything else that the chaplain could have done that you might have found helpful? (E.g. read something from scripture/holy texts, said a prayers, spent more time listening to you?)
- 9. Have you talked to anybody else about these experiences/feelings?
- 10. Is there anything else that you would like to tell me about your experience?

Name and ID number	Gestation and type of loss	Baby's date of death	Age of participant at loss	Time since loss at interview	Indices of deprivation Decile*	Chaplaincy involvement
Lewis CR01	41 weeks stillbirth	May 2007	35	4 years	6	Naming and Blessing
Adam CR02a Jenny CR02b	35 weeks stillbirth	August 2009	29 29	9 months	2	Naming and Blessing, Funeral
Martin CR03	24 weeks neonatal death	November 2009	44	7 months	1	Baptism, Prayers of Commendation, Funeral
Craig CR04a Claire CR04b	42 weeks stillbirth	May 2004	35 36	6 years and 2 months	4	Naming and Blessing, Funeral
Liz CR05	22 weeks neonatal death	April 2007	35	3 years and 3 months	1	Baptism, Funeral
Alistair CR06a Diane CR06b	27 weeks neonatal death	April 2008	35 38	2 years and 3 months	6	Naming and Blessing, Funeral
Wendy CR07	24 weeks & 4 month neonatal deaths	August & December 2006	42	4 years	5	Baptism
Olivia CR08	41 weeks stillbirth	May 2003	35	7 years and 2 months	9	Naming and Blessing, Funeral
Julia CR09	16 weeks miscarriage	July 2010	25	10 months	1	Naming and Blessing, Funeral
Thomas CR10a Katy CR10b	29 weeks stillbirth	February 2011	25 22	3 months	1	Naming and Blessing, Funeral
Sarah CR11	21 weeks miscarriage	March 2011	34	3 months	2	Naming and Blessing, Funeral
Chloe CR12	20 weeks termination for fetal abnormality	2010	37	1 years and 2 months	1	Naming and Blessing, Funeral
				*	Scalad from	1 the most deprived

9.2 Appendix II: Demographic Details

* Scaled from 1 the most deprived.

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