THE UNIVERSITY *of* EDINBURGH

Title	Role of ritual and its co-construction in the spiritual care, provided by chaplains, of parents adjusting to the death of their baby in-utero
Author	Kelly, Ewan R.
Qualification	PhD
Year	2005

Thesis scanned from best copy available: may contain faint or blurred text, and/or cropped or missing pages.

Digitisation notes:

- p.115 missing from numeration in original.

The role of ritual and its co-construction in the
spiritual care, provided by chaplains, of parents
adjusting to the death of their baby *in-utero.*

Ewan R. Kelly

Ph.D.

University of Edinburgh

2005

Contents

Abstract

Aims
- to deepen understanding of parental grief
- to discover parental expectations of chaplaincy support and ritual
- to understand the role of ritual in meeting parents' spiritual needs
- to comprehend the importance of ritual content and the manner of its construction
- to hear the significance for parents of chaplaincy involvement
- to appreciate the impact of the immediate context in which ritual is shared

Methodology:

Semi-structured qualitative interviews were used to obtain in-depth parental reflections.

Results:

Four main spiritual themes were identified from parents' descriptions of their grief – social isolation, loss of meaning and purpose, loss of control and a loss of self worth. Parents' expectations of chaplains and rituals they performed were anxiety inducing. The process of ritualising their baby's life and death enabled parents' spiritual needs to be met by
- aiding deeper communication within families and wider social reintegration
- providing an opportunity to find meaning and purpose through parenting
- helping parents to regain some control, order and sense of reality in their situation
- validating their grief and offering them a safe space in which to express feelings
- helping to create memories which aided establishment of continuing bonds with their baby

Co-authoring their baby's ritual with a chaplain enabled parental affirmation and personalisation of rituals. Whilst relevant words spoken during ritual were appreciated it was being able to act out their relationship with their baby and the chaplain's performance which were of most significance. Parents requested chaplaincy involvement because they perceived them to have ritual authority and enhance ritual efficacy. They perceived chaplains to have both priestly and shamanistic roles during rituals, creating an atmosphere in which families could express or act out their feelings as required.

Contextually, of significance was the reverential attitude and approach of those present which affirmed a baby's uniqueness and enabled creation of a sacred time and space. Chaplains acted as guides during the co-construction of ritual and offered parents an attentive listening presence. A chaplain's way of being and relating was key in meeting parental spiritual needs.

Conclusions:

Baby death *in-utero* causes considerable parental spiritual distress. Ritual and its co-construction helps to meet spiritual needs and facilitates grieving. Chaplains have a distinctive role to play as part of a healthcare team addressing parents' holistic needs. The nurturing of a chaplain's humanity and spirituality is essential in caring for their inner resources utilised in meeting parents' spiritual needs.

Acknowledgements

I am very grateful to several groups of people for their assistance in enabling this research to be completed and my reflection upon the results to form the following thesis.

Secondly, I owe a great deal to former colleagues, from a variety of disciplines, within the Royal Infirmary of Edinburgh. To the midwives, nurses, obstetricians and neonatalogists with whom I worked and learnt so much from, and who helped formulate this study, knowingly or otherwise. I am especially grateful to Dr David Farquharson, Dr Ian Laing and Barbara Herkes for their time and encouragement. The staff of the Research and Development Office, under the directorship of Dr Heather Cubie, were unfailing in their support and patience. Dr George Masterton and Prof Patricia Peattie also gave generously of their time and insight.
My former chaplaincy colleagues could not have been more understanding and committed to this project – giving considerably of their time, energy and themselves. The positive light in which parents talked of chaplains and the support they offered is a tribute to their professionalism and humanity. Therefore, to Sandy Young, Anne Mulligan, Gordon Muchall and Iain Telfer – thanks. Fiona Allan and Grace Dobie gave invaluable secretarial support.

Thirdly, many colleagues within the University of Edinburgh shared their expertise and time with me to help shape and inform my methodology, and kept me going in the insanity of doing a part-time PhD.
Dr Vivian Cree and Prof. Kenneth Boyd were of a great help in the embryonic stages of the study. Dr Scott Murray, Dr Steve Tilley, Dr Kirsty Boyd and Dr Liz Grant shared freely from their experience in doing qualitative research. Dr Hazel McHaffie was ever generous with her hospitality and time. Her willingness, along with that of Dr Marilyn Kendall, to give honest yet encouraging feedback always helped to move my research proposal forwards.
Colleagues and mentors at New College have been of tremendous support – especially Prof. Duncan Forrester and Prof. William Storrar. The supervision I have had from Dr David Lyall has been not only wise and practical but enlivening and affirming. I will miss the creativity and companionship of supervision sessions.

Fourthly, I am very grateful to the bereaved parents who opened their homes and hearts to me, trusting me with their stories. I hope I have done those stories justice. The encouragement and advice of Jenny Rudd and Dorothy MacKenzie at Lothian SANDS was also important.

Lastly, and most significantly, I am grateful to my family - Julie, Stuart, Alasdair and Fraser. Maybe now they can see more of me and use the family's computer more frequently.

List of abbreviations used

HCP – healthcare professional

R.I.E. – Royal Infirmary of Edinburgh

SANDS – Stillbirth and Neonatal Death Society

SMMP – Simpson's Memorial Maternity Hospital

Previously published papers utilised in this thesis

Kelly, E. 2002 Marking Life and Death: co-constructing welcoming and funeral rituals for babies dying *in-utero* or shortly after birth. *Contact Pastoral Monograph* 12. Edinburgh: Contact Pastoral Trust.

Kelly, E. 2002 Preparation for Providing Spiritual Care. *Scottish Journal of Healthcare Chaplaincy* 5(2): 11-15.

Kelly, E. 2002 Three Dimensions of Spiritual Care in an Acute Hospital Setting. *Theology in Scotland* VIII(2): 53-65.

Publishers, where appropriate, have kindly given their permission that copies of the above papers are made available to the reader in a pocket on the inside back cover of this thesis. Details regarding where the material from these papers can be found in the text are given in relevant footnotes.

Part I

Preface

In listening or when reading neither the listener nor the reader comes to a narrative with a neutral perspective. Our culture, upbringing and experience not only inform who we are and the way we interpret our experience of life but also how we understand the stories of others.

My research will involve interviewing bereaved parents regarding the role of ritual in their adjustment to death of their baby *in-utero*. What motivates my involvement in such work? What interpretative framework will I be working with i.e. what influences the prescription and tint of the lenses through which I will view their experience?

This preface, written prior to the beginning of my research, is intended not only to help me unravel what I bring to this thesis and to clarify for the reader something of my worldview but also to invite you to reflect on your experience of, and attitudes towards, baby death and the rituals associated with marking a baby's life and death.

I was brought up in a middle class family in central Scotland in which routine and ritual helped to provide security and shape to life – family meals enabled discussion of the events of the day, church then family outings on a Sunday, Christmas celebrated with extended family and so on. Many families in the 1960's and 1970's to the present day lived, and still live, in a similar way where ritual is part of everyday life as well as marking significant events in the calendar and Christian year. More than that, major life events in our family were always marked in some way with ritual, for example, birthdays, the passing of exams, leaving home and joining the church, by the giving of a gift and the sharing in a special meal.

The Christian narrative and its associated rituals have always been woven into my story - from my baptism onwards. On reflection this has given me a sense of belonging to something other than my family and circle of friends. My questioning and searching for meaning and purpose in life, suffering and death have all been done within a Christian framework.

In growing up death too was part of life. My father is a vet and as a youngster I was conscious of our own animals and those of others dying or being 'put down'. My grandfathers both died before I was born and my first experience of the death of someone close was my grandmother who died when I was about ten. She lived and

died in Aberdeen and I felt perplexed and disappointed when my brother and I weren't given the option of attending her funeral. This experience has informed how I now relate to families whose loved one, young or old, has died.

On leaving school I trained as a medical student and then briefly worked as a junior doctor. Medical training in the 1980s was primarily concerned with disease processes and how to cure them or alleviate the symptoms they caused. There was very little discussion relating to the care of those bereaved due to the death of an adult let alone those grieving the death of a baby. However as a medical student I had the opportunity to accompany several women and their birth partners through labour and to assist in the delivery of their babies. It was then as I listened to their stories that I began to appreciate the depth of emotion that parents invested into their babies during (and before) pregnancy – the longing and hoping, the dreams and fears. I also gained some insight into the intensity and pain, the waiting and worrying involved in a normal labour…and then something wonderfully positive.

Very little was said about perinatal death during my medical training apart from the facts, figures and predisposing factors. I knew it could happen and sometimes expectant parents shared with me some of their anxieties and fears about the outcome of their pregnancy but as a prospective doctor I wasn't aware of any support mechanisms in place if their baby died.

It was only when I became an expectant parent myself that I was able to fully comprehend the potential myriad of feelings that waiting for a wanted baby to be born evoke in a parent. In some ways our baby felt very real from the moment I saw him *in-utero* on an ultrasound screen. This reality was reinforced by a range of experiences and rituals during pregnancy – feeling our baby move, hearing his heartbeat, decorating his bedroom, attending antenatal classes and buying clothes and equipment for him. He became our baby from the moment we knew he was there and was known as the 'bump' as soon as his physical presence was noticeable. However, he only became wholly real when we had to take him home and look after him ourselves. I knew what could go wrong during pregnancy and at different times my wife and I did talk about how we might deal with our baby dying or being disabled. Neither of us knew how we would cope but both recognised that no loss in life so far could be compared to the possible death of our baby.

Shortly before birth our baby showed signs of distress and doctors were called for. After his birth he was removed to another room to 'get a bit of help' as the midwife put it. He was only away for ten to fifteen minutes. It seemed like a lifetime. I felt so helpless and useless, and my wife wasn't aware of much at all at the time. Our baby was fine and we have gone on to have two other healthy, boisterous boys. However, that experience has stayed with me but it is only a mere glimpse into the experience of those parents whose baby has been confirmed as malformed or dead *in-utero*.

As a medical student I realised I had an interest in peoples' stories as well as their medical condition. I began to reflect on what influenced their stories and the way they dealt with their illness, their impending death or indeed the death of their loved one. I was touched deeply by being involved in the care of several young people who died or whose prognosis was very poor on a ward where I worked as a junior doctor. I also was challenged to look at how I dealt with the ill-heath, death and disability around me and was confronted with my own mortality. Not something as a young man I found very easy to do. I began to look inwards as well as outwards to try to find the answers to my questions.

Up until that time my faith and sense of belonging to the Christian community had simply been a part of my life that I took for granted. I had never seriously questioned what I believed. The whole issue of theodicy had passed me by till then.

Three subsequent years at New College enabled me to continue exploring these issues and begin to discover other areas of interest such as medical ethics, spirituality and the relationship of worship and pastoral care. I went to work as an assistant minister in Leith. This was a significant time during which I first began to appreciate the value of reflecting on practice. During my assistantship I began to really learn the importance of listening to people's stories, individual and communal, before responding with ritual in a pastoral relationship (whether that ritual was a prayer on a pastoral visit, the creation of a funeral service or preparing for Sunday worship).

Within three weeks of my ordination I was involved in a pastoral situation which had great bearing on both my ministry and on my developing interest in this particular field of research.

John and Susan were members of the congregation in their late twenties with two young children. They were a couple I was acquainted with but didn't know very well. John was a civil servant and Susan a nurse. Susan was twenty-five weeks

pregnant with their third child when she developed pre-eclampsia and was admitted to hospital for bed rest. I got a call at home from John asking me to visit them urgently. On arriving it was explained that it was possible that their baby would need to be delivered sooner rather than later, as there was an increasing threat to Susan's health. Both of them were understandably very concerned about the baby being delivered so early in pregnancy. They told their story and I listened as best I could. They talked about the importance to them of having their baby baptised, especially with the likelihood of her being so premature, and of their fears that she may not survive or have long-term health problems. Their other children had been baptised and they wanted their new baby to be welcomed into God's family and recognised as a special and unique little person. I assured them that I would come back and see them the next day whatever happened and that their baby could be baptised at what seemed to them the most appropriate time.

Later that day I got another call to say that little Jane had been born and that her prognosis was very poor. Would I come to the neo-natal unit and baptise Jane? I'd never baptised a healthy baby in church before let alone a very sick little one in an incubator. At the time I found the whole scenario surreal – especially the fact I was the one who was supposed to be offering pastoral care. Nothing in my training had prepared me for this.

I remember how important the short ritual was at the time to John and Susan and to the staff who were present. We read from 1 Corinthians 13, Susan's favourite passage from the bible, I baptised Jane and said a short prayer. The staff were not only very supportive of John and Susan but of me too – guiding me through the practicalities. I felt very inadequate and yet deeply moved by being involved at a very special, yet traumatic, time in this family's story.

Sadly, Jane died shortly afterwards and I was asked by the family to help them with the funeral. Susan and John taught me much in the next few days. They wanted the reality of the special place that their baby held in their family, and in God's family, marked in a unique way in the church which they attended. The funeral was a telling of Jane's story set in the context of her family's story as well as that of the local faith community. All of these narratives were informed by the Christian story and this was reflected in what was said, read and sung in the service. Many members of the church and local community as well as John and Susan's family and friends attended. Jane was buried in the adjacent cemetery with only her parents and me present.

At that time there was a dearth of material for baby's funerals within the Church of Scotland tradition though the local hospital chaplain was able to lend me some resources from other denominations and offered me advice. However, it struck me that hard though it was wrestling with what to say or not to say on such an occasion, blueprints were not what were required. It was vital that the funeral I shared in was not just personal but authentic - verbalising the confusion, distress, searching and questioning that people were experiencing. However, the funeral also needed to reflect something of the mystery and hope of the greater narrative which not only informed the life of our community of faith but provided some sort of meaning and comfort for us all.

In the following months I got to know John and Susan well and came to realise not only the significance of their little daughter in their lives, but the way we had marked her life and death. Ritual hadn't taken away their pain or offered any answers to their questions but it had provided a means by which acknowledgement of what had happened could take place and markers for memories laid down. Hard though this experience was I learnt much from it and it sowed seeds of interest for me which began to grow and take root later on.

My feelings that funerals should be personal and authentic were further reinforced when my mother died. It was immensely therapeutic for us a family to tell her story to her minister and then for him to retell it, during the funeral, in his own words. It was comforting too to hear familiar parts of the Christian story retold as part of the ritual and to hear poems read and sing hymns which resonated with both my mother's life and faith.

It also struck me that the whole ritual process which takes place after a death helps the reality of what has happened to sink in. It also helps to provide some sort of order in life at what is a very surreal and confusing time. A funeral is an important part of this process, but nonetheless other less formal rituals have their role to play. For example, for me it was important to see my mother after her death, to join with the rest of my family in writing a death announcement for the paper and to meet with the minister and undertaker and make decisions regarding the funeral. Being involved in this ritual process also helped us as family regain some control in life at a time when everything which had immediately preceded this had been out of our hands.

These were things I had encouraged others to do or had helped facilitate many times before but it was only after going through it as someone bereft that I fully

appreciated how important this process is. It also made me wonder how effectively I offered such support. What did I do well and what could I change to provide more appropriate support?

For over seven years I was a hospital chaplain in two acute hospitals (two years into this thesis I moved from chaplaincy to university teaching), each of which has busy maternity units Supporting parents whose babies have died *in-utero* has been a significant part of my working life during this period. Co-constructing and sharing in ritual marking with parents has proved both challenging and fulfilling. The majority of families have no affiliation with the church and the Christian narrative is not a significant part of their story. Part of the challenge for me has been sharing in rituals which have sought to be relevant to each individual family's needs, beliefs and circumstances, using language, images and gestures which are meaningful and comprehensible to them. Not only does a ritual have to be authentic for parents but I feel as a minister of the Christian church and as a human being with my own frame of reference, beliefs and feelings that I need to act and speak with integrity during rituals also. Working as part of a chaplaincy team and being able to reflect with colleagues on our practice and explore theological questions has been very helpful.

This thesis is an opportunity to hear from parents themselves about their perceptions of ritual in their story following the death of their baby. I hope this study will enable me to reflect on current chaplaincy practice. Moreover, I hope this introduction has provided insight into my interest and motivation for this piece of work and something of what I bring to it. Moreover, it may also have stimulated you into reflecting upon what you bring to this text.

Chapter 1   Introduction

> To remain a recipient – out of humility. And preserve your flexibility.
>   To remain a recipient – and be grateful. Grateful for being *allowed*
> to listen, to observe, to understand.
>
> (Hammarskjold 1960, 107)

1.1. Aims and Objectives

This thesis seeks to explore some of the theoretical and theological reasoning, as well as the spiritual and psychological need, behind the creation of ritual to mark the life and death of babies dying *in-utero*. The research performed sought to aid reflection on the practice of hospital chaplains who seek to create and share welcoming (blessing and naming) and funeral rituals with bereaved parents. In order to facilitate such an exploration bereaved parents were interviewed to hear their lived experience of co-constructing and sharing in ritual for their dead baby, within the context of spiritual care offered by a hospital chaplain. The specific aims of the study, informed by my experience as a chaplain working in a maternity unit, relevant literature and conversations with chaplains and other health care professionals (HCPs), were

- To deepen understanding of the experience of parental grief following baby death.

- To hear parental expectations of chaplaincy support and rituals offered by chaplains.

- To develop an understanding of the significance of the content of ritual and the process by which such rituals are constructed with chaplains, for parents.

- To elicit a fuller understanding of the role of ritual, shared by chaplains, in meeting bereaved parents' spiritual needs.

- To comprehend the significance for parents, of chaplaincy involvement in ritual and providing other aspects of spiritual care.

- To appreciate the importance to parents, of the immediate context in which ritual takes place.

In our postmodern society where there is no longer a single shared meta-narrative which informs our individual and collective sense of identity and worldview, creating appropriate and relevant rituals to mark the life and death of babies has

become increasingly challenging for hospital chaplains and other providers of spiritual care.

This thesis is not an in-depth liturgical study but instead seeks to outline some principles of care, shaped by parental experience and theologically and theoretically (in terms of contemporary understandings of grief) informed, which may aid the future practice of spiritual carers as they seek to construct and share relevant rituals with bereaved parents in a postmodern context.

1.2. Setting the Scene

> Stillbirth is complicated by extraordinary sensations of confusion and unreality, as birth and death are fused. After months of hopes and growing fullness there is a sudden emptiness with nothing to show, an incomprehensible non-event
>
> (Lewis 1987)

The death of a baby *in-utero* for parents and their carers is a complex and distressing experience, where the meeting and leave-taking of a loved one happens concurrently. The grief of parents bereaved in such a way is, thus, like no other and yet may also be a pattern (Kirkley-Best 1982) and intensity (Boyle 1997) of grieving similar to the death of an adult. However, it is only in the last thirty years that HCPs, including chaplains, have begun to appreciate the impact that the death of a baby can have and the importance of sensitive bereavement support. Such heightened understanding has been due to an increase in research interest in the psycho-social effects of pregnancy loss allied to the advocacy work of parental support groups giving voice to their needs. In this period, the significance of appropriate ritual marking of a baby's life and death has also become more apparent. Chaplains have played their part in beginning to explore the implications of such ritual for parents psychologically, socially and spiritually (especially Case 1978, Wretmark 1993, Moe 1997 and Pierce 2003). However, wider society, including the church, is still more piecemeal in its understanding and support of bereaved parents.

1.3. Historical Attitudes to Baby Death *In-Utero*

Since ancient times, as exemplified by the more limited punishment for a man causing a pregnant woman to lose her baby compared to killing the woman herself in the Hebraic world (Exodus 21: 22-25), the death of a baby *in-utero* has been considered a lesser loss than the death of an older child or adult. Historically, the attitude that pregnancy loss was not a significant bereavement pervaded healthcare,

ecclesial and popular cultures - even into the latter half of the twentieth century the death of a very young child was not considered a particularly distressing event for parents (Gorer 1965). The lack of dignity and respect afforded to the disposal of babies dying *in-utero* in the past was a measure of the significance Western cultures held for pregnancy loss. Wretmark (1993), writing from within a Swedish context, notes that prior to the Reformation stillborn and other unbaptised babies were not normally allowed to buried on consecrated ground. Pierce (2003 with reference to Cecil 1996) notes that such practice was commonplace in Northern Ireland till the 1960's. Another frequent method of disposing of stillborn babies was for funeral directors to place them at the foot of an adult coffin to no-one else's knowledge (Walter 1990). In the more recent past, hospitals arranged for stillborn babies to be buried in unmarked common graves – '…a nameless child with a nameless grave'. (Lewis 1976, 619) Therefore, the life and death of such babies occurred often without any ritual marking of their existence and of their parents' loss. Stringham (1982, 322) sums up how communities historically have tended to respond to the death of a baby *in-utero*

> A still-born baby is born into an atmosphere of silence and is mourned by parents who find that the silence continues long after the death itself… because the baby is seen as a "non-person" and is largely unacknowledged by society, families are left unsupported in their grief.

Advances in antenatal care and medical technology, especially in the Western world, have greatly reduced pregnancy loss following the first trimester in the latter half of the twentieth century. The expected outcome of a pregnancy that progresses beyond this at the beginning of this century is that of a healthy and perfectly formed baby. However, as can be see from the figures below experiencing baby death in the latter part of pregnancy is still not an unknown event for parents. The death of a baby *in-utero,* therefore, '…violates our expectations…' (Davis 1996, 1) and, moreover, can confront the way that parents perceive the '…normal established order. Most of us expect to be survived by our children rather than to survive them.' (Ainsworth-Smith and Speck 1999, 50) Thus, experiencing the death of a baby *in-utero* can produce spiritual, as well as emotional, physical and social, distress causing many parents to question their worldview and beliefs.

It is important at this juncture to define some of terms that are being used and to offer some idea of how often different types of pregnancy loss occurs.

1.4. Definitions and some figures

It is important those supporting bereaved parents should listen to the term particular parents use to refer to their pregnancy loss (for example, baby, fetus or end of my pregnancy) and, therefore, not only avoid making assumptions (Case 1978) but also pick up on the meaning of the loss to the parents (Stewart and Dent 1994). In this study all the parents referred to their loss as the death of a baby (the gestation of their losses were between sixteen weeks and term – for full demographic details see appendix 4a). It is also useful to note (below) the medical and legal definitions given to losses at different stages of pregnancy. However, as Thomas (1997, 474) importantly reminds us - 'They are important in so far as they confirm the baby's existence or negate it.' As in this study these legal terms do not necessarily equate with the amount of feeling invested in a pregnancy at any particular stage and that experienced when it ends. Moreover, such definitions vary within different cultural and geographical contexts.

1.4.1. Miscarriage

A miscarriage is either

- a spontaneous abortion – '...expulsion of products of conception before viability (24 weeks)...' (Stewart and Dent 1994, 14)

- or a therapeutic or induced abortion – '...where the pregnancy is terminated by medical means (surgical or pharmacological)...' (Stewart and Dent 1994, 15).

In 1992 the limit of viability was reduced from 28 to 24 weeks to reflect advances in neonatal care, according to the Stillbirth Definition Act. A miscarriage in the first 12 weeks of pregnancy is known as an early or first trimester miscarriage (the vast majority of both spontaneous and induced abortions occur in this period). A miscarriage occurring between 13 and 24 weeks is known as a late or second trimester miscarriage.

It is difficult to give precise figures for the number of miscarriages that occur due to many women miscarrying very early in pregnancy and not realising they have done so (equating the loss with late or irregular menstruation). Two studies (Kline *et al* 1980 and Miller *et al* 1980 cited by MacFarlane and Mugford 2000) suggest that 40% of pregnancies are spontaneously aborted following implantation. Other studies suggest a lower rate of loss before 24 weeks gestation - Regan [(1991) also cited by MacFarlane and Mugford 2000] estimates that 15% of all pregnancies that are

clinically confirmed miscarry, whereas Smith (1988) estimates 20%. To put these figures, and those outlined below, in some sort of context the total number of live births in Scotland in 2002 was 51,270 [Scottish Perinatal and Infant Mortality and Morbidity Report (SPIMMR) 2002].

In Scotland in 2002 there were 124 late fetal deaths (deaths between 20 and 23 weeks of gestation or earlier in pregnancy if the birth weight is greater than 500g). Of these late fetal deaths 77 were spontaneous and 47 were therapeutic (SPIMMR 2002). Specific figures for the number of late miscarriages from 13-20 weeks are not available. However, in 2003 5,631 women between the ages of 15 and 44 required hospital in-patient treatment for spontaneous abortions (Scottish Health Statistics – Abortions 2003) - many of which will have been in the second trimester. It is also worth noting that in Scotland, in 2003, there were 12, 217 therapeutic abortions performed. 208 of these occurred at 18 weeks gestation or over and 172 were carried out on the grounds of fetal abnormality (Scottish Health Statistics – Abortions 2003).

The law does not require babies delivered before 24 weeks, spontaneously or therapeutically, to be registered.

1.4.2. Stillbirth

A stillborn baby is '…any baby born after 24 completed weeks of gestation, who shows no sign of life.' (Stewart and Dent 1994, 52). Prior to 1992 the gestational age was 28 weeks for a stillbirth and was adjusted as mentioned in **1.4.1**. In many parts of America a stillbirth is a baby who is born dead after 20 weeks of gestation or with a birth weight of 350 grams (Pierce 2003). Whereas, in some states in Australia a definition of 22 weeks and 400 grams is used (Boyle 1997).

Stillbirths can be **intrapartum** deaths where a baby dies unexpectedly during labour or an **intrauterine** death where the baby has died prior to labour. In such cases, the mother may not have felt her baby moving and the baby's death is confirmed by a fetal heart monitor failing to detect a heart beat and by ultrasound. Labour may be induced and the baby delivered vaginally. In this study only one loss was intrapartum. The term **baby death *in-utero*** will be used as an all encompassing phrase to refer to all the pregnancy losses (late miscarriages and stillbirths) experienced by parents in this study. The term **perinatal** death is a broader one and is used to include babies who are stillborn or die in the first week of life. **Neonatal** death is used to refer to babies die in the first 28 days of life. Thus, parents whose

baby dies in this period will have memories of a living child, whereas those whose baby is stillborn will not.

A stillbirth is required by law to be registered – certification of the stillbirth being given to the parents by the doctor or midwife attending the delivery to take to the registrar of births, deaths and marriages. A baby dying in the neonatal period must legally have his or her birth and death registered.

In Scotland, in 1972 there were 1,053 stillbirths at a rate of 13.1 per 1,000 total births (MacFarlane and Mugford et al 2000). Thirty years later, there were 278 stillbirths at a rate of 5.4 per 1,000 total births (SPIMMR 2002) – note that the birth rate in the United Kingdom reduced considerably in this period, particularly in Scotland. In England and Wales, the reduction from 1972 to 1998 was from 8,799 to 3,417 stillbirths at a rate of 12.0 to 5.3 per 1,000 total births (MacFarlane, Mugford et al 2000).

During 2001 in the maternity unit of the Royal Infirmary of Edinburgh (RIE), Simpson's Memorial Maternity Pavilion (SMMP), a tertiary referral centre for maternity services in the south-east of Scotland, a total of 6,013 babies were delivered (of these 23 died in the neonatal period and 41 were stillborn). In addition 85 late miscarriages took place in the hospital. In that period the chaplaincy team (consisting of three full-time generic chaplains, a half-time Roman Catholic chaplain and a part-time Episcopalian chaplain), whose practice in working with bereaved parents is being reflected upon in this thesis, performed 63 funerals and 30 welcoming (baptisms, blessings and non-religious namings) rituals.

1.5. Introducing the thesis content

The first half of this thesis (up to and including chapter 5) sets the context within which my research took place. In the second half, my methodological approach and findings are laid out, reflected on and some implications for practice are proposed.

Before setting the broad societal context in which this study was carried out, in the next chapter, the content of the thesis will be briefly mapped out.

1.5.1. Chapter 2 Post-modern context

An overview of the society in which chaplains seek to support parents in the immediacy of baby death will be given. How post-modern parents' worldviews and beliefs may be formed within contemporary culture will be explored. This has

important implications not only for how parents deal with the death of their baby but how chaplains approach meeting their spiritual needs.

1.5.2. Chapter 3 Development of holistic care for bereaved parents

This chapter consists of three parts, sketching

- contemporary perceptions of the human response to death

- developments in the provision of holistic care for bereaved parents within maternity services, and

- attitudinal changes within faith communities to the ritual marking of the life and death of a baby who dies *in-utero*

1.5.3. Chapter 4 Spiritual care in an acute hospital setting

An exploration of what spiritual need may be and how chaplains, in collaboration with other HCPs, family and friends can collaborate to assess and meet such need. This chapter is a reflection on my practice as a chaplain within an acute hospital setting and was written prior to embarking on my research partly to help set the study in context and also to lay out my prior thinking about spiritual care.

1.5.4. Chapter 5 Ritual and its co-construction

My perceptions, from reflection on practice as a chaplain, about the role of ritual and its co-construction in meeting some of bereaved parents' spiritual needs are described. Again, this chapter was written before parents' lived experience in relation to ritual marking was sought out and explored.

1.5.5. Chapter 6 Methodology

This chapter outlines the methodology I employed to hear, record and analyse parental experiences of baby death and the rituals they helped to co-author and participate in. In doing so, I endeavour to clarify the factors that informed my decision making in relation to the method employed.

1.5.6. Chapter 7 Findings in relation to parental expectations, experience and involvement

At the beginning of this chapter an overview of material gathered which had to be excluded from further reflection (and why this is done) is given. What is highlighted

are the following themes which emerged from parental storytelling about their experience

- significant spiritual issues for parents as they grieved

- parental expectations of chaplains and ritual marking

- importance to parents of how rituals were formed and their final content

1.5.7. Chapter 8 Findings in relation to ritual, chaplains and context

In this chapter parental reflections are recorded in relation to

- role of ritual in meeting parents' spiritual needs

- significance of chaplains' involvement in co-constructing and sharing in ritual

- relevance of the context in which ritual was shared

1.5.8. Chapter 9 Co-construction of ritual

The implications of co-constructing and sharing in ritual marking for parents are explored in the light of the study's findings. This is done in dialogue with my reflections on practice and the review of relevant literature contained in the first half of the thesis.

1.5.9. Chapter 10 Theological fragments

Several keys themes which have emerged from the study in relation to the provision of relevant spiritual care are theologically explored in this chapter. These include

- the encounter of human and divine stories in the relationship between chaplain and bereaved parents

- the use of authority and vulnerability in providing spiritual care

- implications of this study's findings on the selection and personal and professional development of chaplains

- what co-constructing ritual offers the church as well as parents

1.5.10. Chapter 11 Concluding thoughts and recommendations

Recommendations based on reflection of this study's findings are suggested for those with a concern for the spiritual care of bereaved parents in the NHS and in the church. Finally, some suggestions are made for further research into allied areas which were out with the remit of this exploratory study.

Chapter 2   Postmodern context

This chapter seeks to set this piece of research in the broad societal context in which it was performed and in which the bereaved parents interviewed dealt with the death of their baby. In particular, the following issues will be briefly explored

- What the term postmodernism means.

- Epistemology and postmodernism.

- Attitudes to faith and death in a postmodern era.

- The rediscovery of the relevance of ritual in postmodern times. ˙

2.1. What is postmodernism

In her novel *Unless,* Carol Shields' (2002, 273) central character Reta Winters, a writer, is struggling to make sense of her teenage daughter's withdrawal from her family and the rest of the world. In the midst of her search for meaning and hope, in a situation which has rendered her both feeling powerless and confused, Reta responds to a newspaper obituary which has caught her eye, that of an elderly man who has died of cancer, by writing a letter to the deceased (a section of which follows).

> You were comforted in your last days, the obituary notice concludes, by that pile of books on your bedside table. You would not be parted from them. Mark Twain, Jack London, Sinclair Lewis, Fitzgerald, Hemingway, Faulkner, Joyce, Beckett, T.S. Elliot, Leonard Cohen – their texts constituted for you an "entire universe." Another "entire universe" reached you through the earphones provided by the hospice and for which your family gives thanks: Bach, Beethoven and Mozart; they sang you off to death.
>
> I am going through some bleak days, Mr Harding …I, too, am hungry for the comfort of the "entire universe," but I don't know how to assemble it and neither does the oldest of my children, a daughter.

According to Lyotard's (1994, 27) now famous definition of the post-modern condition as '…incredulity toward metanarratives…' Reta (like the now-deceased Mr Harding) serves as an archetype for the postmodern person. She cannot refer to a universal objective metanarrative in order to try to make sense of her situation. She is instead seeking to piece or pull together "an entire universe" from a range of sources and provisional perspectives in order to aid her meaning making but this she is

unable (nor she perceives is her daughter) to do so in her distress. This inability furthers her anxiety.

Lartey (2001, 1) helpfully refers to postmodernity as

> ...the situation in which modernity is called to account, questioned and critically appraised. Where the assumptions and assertions of modernity are challenged and critiqued.

In the modern era, driven by a belief that a rational understanding of the world could help to overcome its ills, came the advent of ever increasing sophisticated technology, advanced scientific discovery and deepening medical knowledge. Moreover, the prevalent perception in this cultural milieu, which had its origins in post-Newtonian science and sixteenth and seventeenth century Enlightenment thought, was that such progress was overwhelmingly positive, and indeed, inevitable.

However, in current postmodern times (from the latter decades of the twentieth century onwards), as typified by humanity's powerlessness and confusion in the aftermath of the devastation of the south-east Asian tsunami, there is a recognition of the limitations to human endeavour. The mystery and power of nature may in time be better understood and monitored, and perhaps even harnessed, but not conquered. Furthermore, the post-cold war myth of a stable, secure world (or at least Western world) where the military and political might of America was incontestable has been obliterated with the global impact of the events of September 11 2001(Holdsworth 2003).

Within the realms of healthcare, technological advancements, for example, in the areas of stem cell research and the treatment of infertility, as well antenatal and neonatal care, have led to increasingly complex ethical dilemmas being faced by patients, parents, researchers and clinicians alike. A multitude of narratives inform those wrestling with bioethical issues whether they are helping to shape laws or making particular decisions in a consultant's office or at a cotside. The Christian metanarrative no longer provides the overarching framework in the Western world within which ethical issues are explored and from which statute is formed. Instead, it is now one narrative, amongst many, which have significant things to contribute to such ethical debates and theological and philosophical discussions. Such relativism however, creates, as Gare (1995, 139 cited by Page 2000, 49) suggests, opportunities for

...a second kind of narrative, a polyphonous, dialogical narrative in which a multiplicity of perspectives are represented, where through dialogue the narrative reflects on its own development.

However, in this postmodern era strands of modernism remain. In the assumptive world of the majority of expectant parents is the firm belief that with the development of advanced antenatal and neonatal care that baby death (see **1.3.**) is a thing of the past. Technological advance, increased pharmacological sophistication and heightened medical knowledge has led many in Western society to believe death prior to old age has been overcome (this topic will be returned to in **2.2.**).

Despite such existing threads of modernism there is no doubt a postmodern worldview predominates in twenty-first century society. McCarthy (2000, 194) sums up such a frame of reference.

No longer do we speak of universal principles and laws, valid for all times and places. Instead we look for the particular historical, cultural, social and familial values that may have contributed to this particular set of principles and laws being useful in this particular set of circumstances. The "postmodern" era is one of intellectual, religious, and political pluralism and diversity – an era of "conflict of interpretations" (Ricoeur) and of "texts under negotiation" (Bruggemann). It is an era when the "Sacred Canopy" (Berger), if one can be found at all, seems barely to cover the local ball field.

The era of the metanarrative is dead. Or is it? Sheppy (2003, 102) points out that the central thrust of Lyotard's concept of postmodernism is in itself a metanarrative.

In itself the claim of postmodernism that there are no overarching stories or templates by which we may understand or interpret the world, might be regarded as some kind of overarching story or template.

2.2. Epistemology and post-modernism

The modernist or positivist perspective that reality is something objective and perceived through the senses, and that knowledge is obtained through scientific method utilising empirical observation and quantitative research (Cooper-White 2004) is no longer the only epistemological norm. Reality, from a postmodern perspective, is not something 'out there' but is constructed through our interaction with the world around us and with others. Therefore, our understanding of reality changes with time, context and the nature of our social interaction. The knowledge we acquire '...can only ever be partial, fragmented and incomplete...' (Lartey 2003, 38) Listening to others' perceptions of reality potentially may change our understanding. Therefore, qualitative methods are utilised to hear the narratives of

others which stimulates a process of ongoing dialogue with our personal perceptions, promoting new interpretations of reality (the issue of constructivism is returned to in **6.2.3.2.**)

2.3. Attitudes to faith and death in a postmodern world

In our postmodern society the vast majority of people are not active in a local community of faith. Moreover, the trend in the last century of the reduction in the number of people worshipping in church each Sunday increased in its latter half.

> In Britain …church attendance has declined from 19 per cent in 1903 to 15 percent in 1951, to 12 per cent in 1979, to 10% in 1989 and to an estimated 8% in 2000).

> Wraight and Brierley (1999, 26 cited by Woodhead *et al* 2003, 4)

According to a recent poll carried out by the Scotsman newspaper (Kerevan 2001, 3) only 9% of Scots participate in corporate worship most weeks in the year. Moreover, many of those who do are not Christian and, in our increasingly pluralistic society, belong to a variety of other faiths. Guidelines produced by the Scottish Executive (2002, 6) on chaplaincy and spiritual care put it this way

> Since 1948, patterns of religious belief and practice have undergone a major reformation. Membership of the mainstream churches has declined: Islamic, Hindu, Sikh and Buddhist faith communities are firmly established: 'New Age' religions are in evidence. We have a pluralistic society in which individual beliefs find expression in a multiplicity of forms.

Church membership as well as church attendance has steadily been in decline over the past century. Within my own denomination, the Church of Scotland, membership peaked at 27% of the total population in 1942 and has steadily decreased to 11% in 2003.[1] Reflecting on such trends the Board of National Mission (Report to the General Assembly 2002 20/6) calculated that if the ongoing decline in membership continued at the same rate of 15,000 to 19,000 members per year, as it has since 1966, the Church of Scotland would not longer cease to exist by 2050. However, it is interesting to note that The Herald newspaper (2004, 4) cites that though only approximately 240,000 Scots worship weekly in the Church of Scotland 570,000 are members and about 2 million people '…claim the Church of Scotland as the

---

[1] Based on information from The Herald (April 28 2004, 4) and from the General Registrar's Office for Scotland (www.gro-Scotland.gov.uk) which cite the membership of the Church of Scotland at the beginning of 2004 as 570,000 and the total population of Scotland as 5, 057,000 on June 30 2003.

foundation of their religious beliefs.' As these figures reveal the relationship many Scottish people have with the church is nominal or transitory (through approaching the church at a time of ritual need – this topic will be returned to in **2.3.**), if it exists at all.

In the aforementioned Scotsman poll (Kerevan 2001, 3) it was found that 65% of the Scottish population believe in a god and 45% in an afterlife. Thus, even within a population where nearly two-thirds of people believe in some form of a deity, organised religion seems to have increasingly less relevance. Research performed by Hay and Hunt (2000) in Nottingham revealed in the sample they interviewed that over 75% of people are aware of a spiritual dimension to their lives. Irvine (1997, 57) sums up much about the relationship between personal faith and spirituality and the church in our postmodern world.

> There is no doubt that the statistics on church attendance are not indicative of the number of persons who 'believe' in God, are 'religious' or who are persons of deep spirituality and faith. For many the problem may not be the issue of faith, but rather the institutional church. This, coupled with the rampant rise of individualism in our culture, has led to an increase in the privatisation of the faith. No longer is it considered necessary for 'faith' to be reflected in allegiance to the institution called the church.

There is no doubt in the twenty-first century people are *Believing without belonging* as the subtitle of Davie's (1994) book puts it. Yet Hunt (2003, 164), from the qualitative research she performed with Hay on the beliefs of those who do not attend church, concludes that the faith of those people interviewed was '…not belief in an orthodox Christian God but a belief in "something"'. Many of those interviewed who considered themselves to be believers had very little or no knowledge of the Christian faith

What is clear is that postmodern Western society is no longer as influenced and informed by the Christian metanarrative as it once was. Instead peoples' worldviews are shaped but by what Middleton and Walsh (1995, 43) call 'a veritable smorgasbord of religions and worldviews.' Increasingly, people no longer accept or hold to a defined dogma but are more ready to pull together strands of different religious traditions or philosophies to aid them in their own individual search for meaning. There is, at the start of this new millennium, a more 'pick 'n' mix' approach to belief and spirituality. Moreover, the journey of faith in which meaning and moments of transcendency are sought is made alone and in private, rather than as

previously, primarily corporately and publicly. However, what does remain is a deep desire to find meaning and purpose in life, death and suffering.

In our postmodern world not only are bereaved parents' beliefs and worldviews shaped by a plethora of sources but many young parents whom chaplains meet may never previously have reflected on issues of faith. God, the church and religion in general may not just be peripheral to their lives but may in fact never have been part of their personal or family story. Secularisation is not simply about a decline in church attendance and adherence, or the reduction in the social and moral influence of the church but also a lessening of popular religiosity (Brown 2001).

On the other hand, the Christian religion and the moral values derived from it remain implicitly interwoven into the very fabric of society. Healthcare is no exception to this. Hospitals are places where the central tenants of Jesus' moral manifesto are woven into daily life as McSherry (2000, 1) reminds us

> It could be argued that nursing within modern societies emerged out of the ethos of the Judeo-Christian principle of charity – caring for those who are less fortunate than oneself.

However, there is no doubt that healthcare, as in our society, is overtly less Christian than in former eras and the explicit influence of structured religion on the population general is waning. An example of such former influence hung above the front entrance of the former Royal Infirmary of Edinburgh (built in the late nineteenth century and closed at the beginning of the twenty-first)[2], as the hospital's rasion d'etre.

> I was a stranger and ye took me in…
> I was sick and ye visited me.
>
> (Matthew 25:35-36 - Authorised version)

In sympathy with our increasingly pluralistic and secular society this biblical text does not adorn the entrance to the newly constructed Royal Infirmary of Edinburgh building. Furthermore, chaplaincy departments are being steadily replaced by departments of spiritual and pastoral care and hospital chapels by a sanctuary or quiet room where opportunity arises. The Christian narrative has become one narrative

---

[2] The closure of the building which previously housed the Royal Infirmary of Edinburgh near the centre of the city occurred in two stages. The completion of the move to a site on the south-east outskirts of Edinburgh occurred in 2003.

amongst many in the provision of spiritual and religious care in hospitals – all deserving of equal respect and attention.

Parents may never have contemplated the reality of human mortality until experiencing the death of their baby. Death in the twenty-first century, like the expression of spirituality, has become privatised. Many young parents will never have been bereaved or touched by the death of someone in their local community prior to the death of their baby. It is no longer something we experience or share with those in our immediate vicinity. Death has become something that is thought only to happen to octogenarians in hospitals or that we view at a distance on our television or computer screens or in the photographs of our newspapers. The post-modern development of media technology has led to an almost instantaneous sharing of global information but has contributed to the numbing of our senses. In our fragmented local communities and increasingly fractured and often disparate families we interact via technology with each other and with events across the globe but are ceasing to communicate intimately and share significant moments with those closest to us geographically and genetically. Bauman (1993, 243) describes this postmodern condition as being 'Physically close, spiritually remote.' He uses the metaphor of the tourist to convey the manner in which contemporary men and women drift through life without any real shared purpose with, or commitment to, a particular community. Post-modern sojourners are, thus, anaesthetised from the pain and suffering of fellow humans and relinquished from the burden of any particular moral responsibility for others. Jacques (2004, 21) insightfully develops this theme in relation to death.

> Death – which most of us now only encounter in any intimate way in our 40s, through the death of a parent – has become something that we overwhelmingly learn about and consume through the media. But as such is it is shorn of any pain, any real understanding… the grief of those bereaved utterly inconceivable, the idea that their lives have been destroyed forever not even imaginable in our gratification-society: pain is for the professionals, not something to detain the ordinary mortal.
>
> The decline of settled society and the rise of the media-society has desensitised us as human beings.

Therefore, not only are bereaved parents dealing with the alien landscape of grief, but they are also faced with questions never previously considered. Such disorientation is also shared by those who have been bereaved in the past. Experiencing the death of a baby is not what our post-modern society considers the natural order of life.

"If there is a God how can God let this happen? But if there is no God, is there no afterlife? Then where will my baby be? Who is looking after my baby? Will I ever see or indeed parent my baby again?"

Such is the myriad of questions. Such are the mysteries which confront parents when birth and death come together.

A major part of the challenge for chaplains supporting bereaved parents is that there is no longer a shared language or common metaphors or symbols which can be utilised to articulate these mysteries when facilitating or performing rituals to mark the life and death of their baby. Moreover, bereaved parents may also find themselves devoid of a means by which they may utilise to verbalise their lament and inner wrestling. In addition, they may find themselves bereft of an overarching framework within which to search for meaning and purpose in life and endeavour to make sense of their baby's death. On the other hand, parents may find resources from their own personal experience, family background or culture or from the plethora of contemporary faith perspectives and worldviews which they may have encountered (in person or via various communications media) that have enabled them to express themselves and aided their search for meaning (as Reta sought to do in **2.1.**).

2.4. A postmodern need for ritual

Though the narratives, language and metaphors of the Christian tradition may not be part of the everyday lives of the majority of British people, many still turn to the church (or representatives of the church) in times when ritual is sought to be shared and rites of passage required, informed by familial and cultural influence and personal need.

> People know what they want from the Church – a good funeral, a happy wedding, celebration of a birth but resist when the Church tries to take this further and seems to want to takeover their lives.

(Church of Scotland Panel on Doctrine, Report to the General Assembly 2004, 12/2)

There has been a rediscovery of the importance of ritual in the postmodern world at times of crisis for communities when the familiarity and security of the world, as they perceive it to be, is threatened. We have seen in recent years an upsurge in the informal and formal ritual marking of the lives and deaths of those who have touched and moved people in local, national and global communities. At times when peoples' assumptive worlds have been destroyed by trauma and sudden death through a car

crash, mass shooting or bombing or natural disaster they feel a need to express corporately that which cannot yet, if ever, be verbalised fully. Informal gestures, such as the laying of flowers at a roadside or lighting a candle or signing a book of remembrance, or more formal rituals such as observing a three minute silence, attending a memorial service or mass rally are all ways of acting out feelings, offering respect and showing solidarity with others. In Western society where fellow citizens communicate less in person with one another and no longer share an over-arching metanarrative which may have aided their common search for meaning and expression of lament, ritual brings people together in grief and offers a means of acting out their shared feelings in response to the story of the person or persons who have died.

Having described something of the broad contemporary context in which parents grieve and chaplains seek to meet their spiritual needs, I will now move on to offer an overview of recently developed models of grieving and the heightened awareness of the role of ritual in the holistic care of bereaved parents.

Chapter 3

The development of holistic care for bereaved parents

In the previous chapter the broad postmodern context in which chaplains seek to support bereaved parents has been sketched. The more particular cultures which inform the working practice of chaplains in maternity units will now be outlined. Importantly, the approach to bereavement care within maternity services has become increasingly holistic - one of HCPs, in maternity units and in the community, seeking together to provide appropriate physical, social, emotional and spiritual care for parents whose baby has died *in-utero*. Such a transformation has been informed not only by an increase in research activity in this field, as well as in the broader area of the experience of bereavement in general, but also due to the advocacy work of parental support groups such as the Stillbirth and Neonatal Death Society (SANDS) and the increasing receptivity of HCPs and faith communities to parental needs.

This chapter will, therefore, give an overview of

- developments in the understanding of the human response to the death of a loved one, in general

- changes in the past 30 years in the provision of holistic care for bereaved parents within maternity services

- the gradual shift in attitude to the ritual marking of the life and death of babies who die *in-utero* by faith communities.

3.1. Towards developing an understanding of grief in a postmodern age

3.1.1 Introduction.

Death is part of life, and inevitably not only are each of us going to die but we are also going to experience the death of significant others during our lifetime. Colin Murray Parkes, a psychiatrist whose research on adult bereavement has been his life's work emphasises this

> The pain of grief is just as much a part of life as the joy of love; it is, perhaps, the price we pay for love, the cost of commitment. To ignore this fact, or to pretend that it is not so, is to put on emotional blinkers

which leave us unprepared for the losses that will inevitably occur in our lives and unprepared to help others to cope with the losses in theirs.

(Parkes 1996, 6)

Bereavement challenges our perception of the world (which until then had included the deceased) and confronts us with our own mortality. And yet, as Parkes, and Shuchter and Zisook (1993, 43) suggest, grieving is not all potentially about loss

Although painful and sometimes destructive, grief often promotes growth and development and may bring out hidden resources and strength.

It has already been alluded that grief is something stressful to deal with, but before going any further some attempt is needed to define what bereavement, grief and mourning might be.

Bereavement can be defined as the objective situation of individuals as they deal with the death of someone significant to them. *Grief*, on the other hand, is the subjective experience of bereavement and '…is often recognised as an activity rather than a state of being.' (Katz 2001, 5). However, any definition of what grief may be is limited. Shuchter and Zisook (1993: 23) helpfully warn against any endeavour to succinctly describe what grief is

In our experience, grief is such an individualised process – one that varies from person to person and moment to moment and encompasses simultaneously so many facets of the bereaved person's being – that attempts to limit its scope or demarcate its boundaries by arbitrarily defining normal grief are bound to fail.

Grief, then, involves a range of responses to bereavement – physical, behavioural, psychological (cognitive and affective), social and spiritual (Katz 2001 based on Corr *et al* 1997). *Mourning* is how such grief responses are expressed and acted out in socially and culturally appropriate ways, according to the context in which the survivor is grieving. Such behaviour is learnt from, and shaped by, the beliefs and worldview of the family in which the bereaved grew up in, any association with a faith community and wider cultural influences.

Walter (1999, 205), a sociologist, believes there are two prevalent ways in which the bereaved are currently encouraged to relate to the dead within Western society.

These correlate with two different understandings of what is actively involved in grieving.

> One is that the living must leave the dead behind and move on without them. The other is that the dead are always with us and the bereaved continue to bond with them; indeed the dead must be incorporated in some way if families, other groups and indeed other societies are to have any sense of the past.

These two dissimilar perspectives (outlined below) both involve some form of grief work performed following (and, where expected, before) bereavement but that work in these two contrasting approaches is understood to concentrate on different facets of the human response to loss.

3.1.2. A psychological or modernist perspective of grief

Cobb (2001, 63 based on Walter 1999) feels that the predominant aim of grief work at the beginning of the twenty-first century is

> ...to achieve disengagement and detachment from the dead, resolution of the conflicting emotions surrounding loss and a return to life having adapted and adjusted to this severe change.

Thus, grief work, according to a psychological approach, importantly includes the expression and ownership of, and then the 'working through', of feelings. This primarily individualistic understanding of grief work originated within the work of Freud (Richards 1984) and was integrated by clinicians and theorists, such as Lindemann (1944) and Bowlby (1980), into their influential interpretations of the grief process. Moreover, such a perspective reflects the modernist culture from which it evolved

> The modernist life is one that emphasises goal directedness, efficiency, and rationality...When applied to grief, this view suggests people need to recover from their state of intense emotionality and return to normal functioning and effectiveness as quickly as possible. ...Grieving, a debilitating emotional response, is seen as a troublesome interference with daily routines, and should be "worked through".
>
> (Stroebe, M. *et al* 1996, 32)

Many practitioners, from varied backgrounds, define 'normal' grieving as being time-bound - the bereaved reaching the goal of resolution within an expected period

(for example, two experienced hospital chaplains Ainsworth-Smith and Speck [1999, 11] propose eighteen months to two years as a guide depending on particular circumstances). Woof and Carter (1997, 509 with reference to Kim and Jacobs 1991) say this of grieving in a Western context based on a review of empirical research

> Normal grief is a self limiting process consisting of sadness, longing for the deceased person, somatic complaints and subsequent recovery.

Therefore, failure to recover within a timescale in line with the above is perceived by those adhering to a predominantly psychological perspective as prolonged or abnormal grief.

The phase model of grief proposed by Parkes (1972 and further developed in 1986) and Bowlby (1980) - four phases of numbness, pining and searching, disorganisation and despair and reorganisation – and the stage model by Kubler-Ross (1969) – five stages of denial, anger, bargaining, depression and acceptance - have become established as part of 'clinical lore' (Walter 1999,106). These descriptions of grief have been, and to a large extent still are, absorbed and utilised by the bereaved and bereavement carers alike, as received wisdom. Kubler-Ross's model was originally intended to relate to the anticipatory grief of the dying but was extended to also be applied to the bereaved. The phases or stages which these clinicians outlined were not intended to be perceived as a survivor literally passing through each one in a linear fashion but that movement would occur back and forward between them. Moreover, the length and intensity of feeling in each phase was intended to be understood as varying from person to person.

This extract from Linda Panstan's (2003, 15) poem *The Five Stages of Grief* helpfully underlines the clash between 'clinical lore' and reality

> Acceptance. I finally
> reach it.
> But something is wrong.
> Grief is a circular staircase,
> I have lost you.

Another clinician whose understanding of grief has proved very influential within bereavement care circles is the psychologist William Worden. His original description of the grieving process as working through tasks was

1. To accept the reality of the loss.
2. To experience the pain of grief.
3. To adjust to an environment in which the deceased is missing.
4. To withdraw emotional energy and reinvest in another relationship.

(Worden 1981)

However, Worden refashioned the fourth task to read 'to emotionally relocate the deceased and move on with life' (Worden 1991, 16) when he wrote the second edition of his book *Grief Counselling and Grief Therapy*. In doing so, Worden was reflecting a slowly changing culture - the increased awareness by researchers and some clinicians that bereaved individuals did not simply sever relationships with their deceased loved one but that an altered yet ongoing relationship remained (Pierce 2003).

Psychological models of grief have their limitations – some of which relate more to the manner in which they are utilised rather than primarily the models themselves. They conform to a modernist worldview that nature is something to be controlled and overcome – grief being perceived as a biologically programmed problem to be solved and surmounted within a certain timeframe - rather than as an experience which, though painful to live with, is a part of life. In doing so there may be opportunities for subsequent growth and new meaning making. The lack of recognition of social and cultural influences on grief in the earlier work of proponents of psychological models laid them bare to the accusation of 'psychological reductionism' (Thompson 2002, 5). Such models were greatly influenced by empirical research primarily looking at the grieving of adult widows (Parkes 1972 and 1986) and dying adults (Kubler-Ross 1969) in the West, and were intended as descriptions of experience (which provides an external framework to enable the bereaved to orientate themselves in their grief and feel their particular experience was valid and within the realms of normality) and suggestions as to how grief work may be done. However, they have commonly have been applied by bereavement carers in a prescriptive and, thus, constrictive manner. Practitioners, at times, have been guilty of utilising these models as route-maps to grief (Riches and Dawson 2000) and over-regulating subjective experience, with the bereaved internalising that they ought to feel and behave in a certain way (Walter 1999).

3.1.3. A Dual Process Approach to Grief

This model was developed by Stroebe and Schut (1999) from their own research and reflections on the shortcomings of the perspectives outlined above. It is an approach which

> ...alerts us to the complex web of psychological, cultural and socio-political factors which interact to make loss experiences far more complex than traditional (psychological) approaches would have us believe.

(Thompson 2002: 7)

Stroebe and Schut (1999) describe a process whereby bereaved persons oscillate between two different orientations – loss and restoration – in response to two different kinds of stressor. Loss orientation involves what might be considered traditional grief work - confrontation with and gradual adjustment to the death of a loved one, including the expression of emotions and rumination about the death and life as it was *premortem*. Moreover, it also includes the adjustment a survivor makes over time to find a place, albeit a different place, for the deceased in their life through social discourse. Restoration orientation deals with what Stroebe and Schut (1999, 214) call the 'secondary consequences of loss' and refers not to long term outcome but to the process of dealing with the additional sources of stress associated with bereavement , for example, taking on new tasks which a deceased loved one formerly performed or adjusting to a new identity, such as from anticipating being a parent to becoming a bereaved parent following stillbirth.

Stroebe and Schut's model not only makes room for the social (or interpersonal) and cultural aspects of grief, it also is compatible with Worden's task orientated description of grief. Furthermore, their approach endorses the necessity for the bereaved, at times, to avoid confronting painful feelings and deal with practical matters as they arise. As they put it – '...the benefits of denial are acknowledged.' (Stroebe and Schut 1999, 216)

According to the dual process approach complications in grieving occur when there are disturbances in oscillation between the two orientations and the bereaved dwells in one orientation rather than oscillating between the two.

3.1.3 Continuing Bonds

From the middle of the 1980's onwards several sociologists, anthropologists, and psychologists with an interest in grief and bereavement have developed a 'minor theme' (Walter 1996, 8) observed within the work of Bowlby and Parkes. This is based on the observation that the bereaved continue to have a significant, but altered, internal relationship with the deceased in the months and years following bereavement. Such an understanding of grief takes seriously the influence of the social and cultural context in which grieving takes place and by the late 1990's became a major theme in academic research and writing. Stroebe M. et al (1996) suggest that within western culture prior to the modernist era, grief was not seen as something to get over and the deceased to be 'let go of' whilst doing so. In the romantic period of the eighteenth and nineteenth century sustaining a relationship with the deceased was seen as a commendable act which revealed an ongoing commitment to, and love of, that individual.

Research which has informed the development of the 'continuing bonds' (the title of a book edited by Klass et al 1996) perspective on grief has been done with bereaved parents (Klass 1984, 1988 and 1996, Riches and Dawson 2000) as well as with bereaved widows and widowers (Stroebe, W. et al 1988 and Stroebe, M. and Stroebe, W. 1991) and been qualitative as well as quantitative in nature. Walter (1996), a significant proponent of this model, argues that grieving is a social process by which, through conversation with others who knew the deceased, a rounded 'biography' of the individual can be constructed and internalised. He also acknowledges that personalised funeral rituals can play a part in such a process (see chapter 5 for a fuller account). The cultural context in which this is done informs such a discourse and affects the degree to which the bereaved can do so. Riches and Dawson's (2000) work with self-help groups, such as the Compassionate Friends, revealed that bereaved parents often felt alienated from their families or local communities who did not want to listen to their feelings and share stories of their dead child. However, in such self-groups they found others with common needs and experiences who would listen. Their findings led them to say this about a continuing bonds approach

> ....in this model, **conversation** is seen as much as a vehicle for sharing and creating memories with which the survivors can live comfortably, as it is an outlet for personal feelings of distress.

> (Riches and Dawson 2000, 36)

Anderson and Foley (1998,113), two American pastoral theologians with an interest in narrative and ritual, concur that storytelling is the means by which the bereaved form memories about a deceased loved one which continue to inform their lives long after the death.

> The stories we treasure will both delight us and bring us to tears....Storytelling for the sake of making a memory is the central work of grieving.

Even when the life lost is short; memories of that life are cherished and remain influential for parents in an ongoing way.

> Fleetingly known, yet ever remembered,
> These are our children now and always:
> These whom we see not we will forget not,
> Morning and evening all of our days.

[The first verse of a hymn written by members of the SANDS (Stillbirth and Neonatal Death Society) – Dominica 1997, 113]

In order that a deceased loved one can acquire an appropriate place in the internal life of a survivor and helpfully influence their life in the future, there is first a need for the bereaved to accept the physical loss of the deceased. Grief work according to a continuing bonds model is

> ...a cognitive process of coming to terms with a loss through confronting the loss and restructuring thoughts about the deceased, the events of the loss, and the world as it is without the deceased.'
> (Rosenblatt 1996, 52)

Grieving then, is not just about making memories, it is also about attempting to make sense of a new world – a world in which the deceased does not physically exist and a world which may no longer seemed to be ordered and understood as it previously once was. In the words of Anderson and Foley (1998, 114)

> ...grieving is relearning how to be in the world, to reshape our lives and reinterpret our stories to take into account the loss that has occurred.

Complicated grief, according to a 'continuing bonds' perspective, results from an inability to find an appropriate meaning for the changed relationship with the deceased and also from a lack of insightful others to share stories of the deceased with (Riches and Dawson 2000).

In summary, the major strength of this model is to reflect the significant impact of social and cultural contexts on both individual and communal grieving. Moreover, it recognises the important impact that our ancestors and more recently deceased loved ones continue to have on our individual and familial stories. However, it is limited in that it makes no room for the inarticulate, the reticent story-teller or those '…who might see this way of working as contrived' (Ainsworth-Smith and Speck 1999, 68).

Small (2001, 32) warns of the danger that the 'continuing bonds' approach to dealing with grief becomes the dominant model which may be imposed by practitioners on encounters between themselves and the bereaved they seek to support, replacing the current '…prevailing orthodoxy of "getting over it".'

3.1.4. A post-modern understanding of grief

> The movement seems toward a post-modern sensibility in which the reality of diversity is acknowledged.

(Rosenblatt 1996, 56)

The post-modern perspective of grief is that both emotional expression, as advocated by a psychological model, and/or storytelling in order to form 'continuing bonds' and make meaning from bereavement are appropriate. Moreover, the 'dual process approach' liberates the bereaved from the obligation of continually working at their grief. In short, the bereaved are not constrained by any particular model and are free to create their '…own narrative of grief' (Small 2001, 33). In addition, there is increasing acceptance that grief work is ongoing and not tightly time bound, as illustrated by Douglas Dunn's (1995, 53) response to his wife's death in his poem December

> No, don't stop writing your grievous poetry.
> It will do you good, this work of your grief.
> Keep writing until there is nothing left.
> It will take time, and the years will go by.

It is of further relevance to note that in a recent study by Stroebe, M. *et al* (2002) it was found that in cases of uncomplicated grief the disclosure of emotion or social

interaction, though considered to be helpful, did not shorten or speed up the grieving process. Thus, they conclude, in exemplary postmodern fashion – '…the bereaved have to cope with their loss in their own time and in their own way.' (Stroebe, M. *et al* 2002, 77)

A significant weakness of the postmodern perspective is that of 'under-regulation' of grief (Walter 1999: 124). Walter argues that due to the privatisation of grief in present day society many bereaved persons are not aware of what may be considered a normal way to feel or behave when bereaved and, thus, can be bereft of strategies with which to deal with their grief. Such a lack of shared societal norms, values and expectations may, therefore, add to their confusion and heighten their distress.

3.1.5. Implications for bereavement care

Appropriate bereavement care in postmodern times has to give room for the bereaved to share their stories as well as to express their feelings. An open-ness to, and respect for, how the bereaved themselves perceive their experience and how they have chosen to deal with and express their grief is required. Listening is needed first, the practitioner acting as a companion along the way of personal or familial grief, to '…discover their inner landscape rather than rehearsing our own.' (Riches and Dawson 2000: 185). However, as Walter (1999) suggests there is a need for an external framework of social convention within which the bereaved can orientate themselves and have their feelings and actions validated as normal. The role of the prescribed traditional religious funeral in helping to provide this is no longer relevant for many people. How appropriate, sensitive regulation of grief can be done with bereaved parents is a central issue to be explored in this thesis.

In order to offer bereavement care in a post-modern age it is, thus, important to have a rounded view of what grieving may entail and an awareness of the variety of approaches different researchers and practitioners from a range of backgrounds have shaped. As Stroebe, M. *et al* (1993, 459 cited by Small 2001, 36) remind us

> To limit explanations to those of a single discipline would preclude a
> full understanding of the phenomenon of bereavement.

The breadth of understanding of grief which informs those offering bereavement care in a hospital or community setting has been outlined as the setting within which the development of support in the particular context of parents grieving the death of their

baby *in-utero* can be explored. This is what we now turn our attention to for the remainder of the chapter.

3.2. Development of holistic healthcare care for bereaved parents

There are several issues which have contributed to a significant cultural change in the way parents whose baby dies *in-utero* are cared for in the last thirty years. The stimulus for such a shift has already been alluded to at the beginning of this chapter, including crucially the development of a forum in which parents could express their actual needs and HCPs becoming increasingly receptive to those needs rather than assuming baby death was merely a medical problem requiring only physical treatment. At the end of the 1960's and the beginning of the 1970's a group of like-minded doctors sympathetic to the impact baby death had on parents and HCPs alike, published a series of articles which marked the beginning of subsequent heightening interest in research as to how best to holistically care for bereaved parents. Bourne (1968, 110) recognised that as a 'non-event' with no life existing, or to mourn, outside of the womb, stillbirth was difficult to deal with for parents, as well as for doctors - it could not be treated or cured like an illness. Studies in Australia (Giles 1970), Ohio (Kennell *et al* 1970) and Illinois (Wolff *et al* 1970) concurred that women bereaved by a perinatal death grieved in a similar way to those experiencing the bereavement of an adult loved one. Like Bourne, these practitioners and researchers also found that many HCPs had great difficulty in engaging with the emotional needs of bereaved women. Kennell *et al* (1970, 348) sum up well how the prevalent healthcare culture of their day dealt with perinatal death –

> At present when a newborn infant dies in the hospital, all evidence of his existence is often removed with amazing rapidity, and no special arrangements are made for the parents. The requirements for efficiency and for the mental comfort of the modern hospital society may have crowded out the fundamental requirements for the individual.

From this beginning of consciousness raising within the healthcare community of the potential effects of baby death on parents and HCPs, several factors have enabled a shift in approach towards more appropriate holistic care. These include the following:

3.2.1. Recognition of the significance to parents of the death of a baby in-utero

Subsequent to the aforementioned studies conveying the reality of grief felt by bereaved parents, further research and writing has emphasised the impact of baby death on women and their partners. Boyle (1997) in a longitudinal study compared the psycho-social consequences of baby and infant death on women with the effect of giving birth to, and parenting, a live baby. She found that at two months after their baby's death one in three women were significantly anxious and one in five was depressed – notably higher than would have been the case if their baby had lived. For as long as thirty months after the deaths 14% of mothers were anxious and 7% were depressed. These are comparable with findings by researchers performing similar longitudinal studies looking at psychological morbidity in widows and widowers (for example, Stroebe, W. *et al* 1988 and Zisook and Schuter 1991).

A range of feelings have been found to be experienced by parents following death of a baby, many of which are in common with people living with other types of bereavement. However, there are also dimensions to parental grief which make it a very different experience. For mothers an attachment is formed with her baby *in-utero* and, therefore '...is invested by her (mother) as a part of the self.' (Furman 1978, 214) Thus, experiencing the death of her baby may mean a woman grieves for the loss of part of herself (Davis 1996). Such investment is not just confined to perinatal death. Losses earlier in pregnancy also cause can intense pain. Gardiner (1997, 124) describes the feelings a mother, he had supported in the past, had for her baby who died at 22 weeks gestation

> Because she was premature, Amy's birth could not be registered. Yet she was real. So many hopes and dreams had already gathered around her: so much psychologically had been invested in her. She could not go away without leaving behind her terrible pain. You cannot dismiss miscarriage as a gynaecological accident. This was a real bereavement, as the baby lost was a real child, already an object of love.

Thomas and Striegel (1994-5) found that fathers felt a lower degree of bonding with their babies *in-utero* and that they tended to grieve for their partners rather than their babies. Samuelson et al (2001, 125) discovered, however, fathers felt that they were

the '…forgotten mourners…' and though they felt their partner's grief was deeper they still wanted to be recognised as grieving.

Parents also commonly feel they have lost their anticipated role as a parent, and the sense of loss of a possession when their baby dies (Brown 1993). Mothers, especially, can feel a great sense of guilt and shame in their failure to create new life – with the possible added burden of feeling that they had let down all the other expectant members of their family (Fickling 1993). However, as with any bereavement it cannot be assumed how parents will feel. Brown (1993) suggests depending on circumstances, after perinatal death the myriad of feelings felt may include relief and Moulder (1998) describes similar feelings for some women after miscarriage.

Medical and nursing literature contains conflicting views on whether the intensity of grief felt by parents experiencing pregnancy loss is dependent on the length of gestation. Cuisinier *et al* (1993) and Theut *et al* (1989a) found by that parents grieved with greater intensity following a stillbirth than they did after miscarriage. Nicol (1991) and Peppers and Knapp (1980), however, concluded from their research that this was not necessarily the case. Stewart and Dent (1994, 16) helpfully sum up the latter's findings and their own experience

> …there is no hierarchy of grief that correlates to gestation of pregnancy…We need to remember that grief reflects what the pregnancy, fetus or baby represented to the woman and her family.

Allen and Marks (1993, 248) interviewed 100 American women who had experienced miscarriage between 4 and 20 weeks of pregnancy and found that '71% of the miscarriages were experienced by mothers as **the death of their children**.' (authors' emphasis).

In this era of sophisticated antenatal screening, viewing their baby on ultrasound screens and photographs (Theut 1989b) and investigations such as amniocentesis or chorionic villus sampling (Bartellas 2003), which take place in the second trimester, may further enhance parental attachment during pregnancy and have a bearing on the depth of their grieving.

In short, within the healthcare community there is now widespread recognition that pregnancy loss, at any stage, can be a potentially significant bereavement for both

parents and that their particular circumstances and story will influence not only their grief but how they deal with it.

An indication of wider society's response to the significance of pregnancy loss before the age of viability can be seen in legal changes made, and guidelines proposed, for the disposal of babies who die *in-utero* before viability (parental support groups tend to talk in terms of babies' bodies and remains whereas professional bodies talk of fetal remains). A London-based paediatrician, Hugh Jolly, in the mid 1970s helped to facilitate a change in burial laws to enable parents wishing to hold a funeral service for their baby who died *in-utero* before 28 weeks (at that stage 28 weeks was the gestational age a baby could be legally registered as stillborn) to legally do so (Wretmark 1993). The current law in the United Kingdom requires that stillborn babies and any babies terminated after 24 weeks of gestation are buried or cremated. The responsibility of disposing of a baby's body after viability lies with his or her parents, though they can ask the hospital to arrange the disposal for them if they do not wish to deal with the practicalities or to attend a funeral. In their review of the psychological effects of perinatal loss on parents Hughes and Riches (2003) underline a universal parental wish to show respect for their baby's body.

However, legal requirements and the lack of uniformity in hospital procedures across the United Kingdom for the disposal of babies born dead before 24 weeks do not show the same respect. The remains of a baby dying before 24 weeks gestation

> …are not defined as human remains and are therefore outside of current burial and cremation legislation.

(Institute of Cemetery and Crematorium Management 2004)

Thus, there is no legal requirement for such babies or products of conception that may have been aborted in the first or second trimester, either therapeutically or spontaneously (if any remains can be identified), to be buried or cremated, though parents may wish to chose this option for their baby. Recommendations for good practice to ensure respectful disposal of the bodies and remains of babies dying before 24 weeks of gestation were outlined by SANDS in their publication 'A Dignified Ending' (1992) and were further reiterated in their 'Guidelines for Professionals' (SANDS 1995). These guidelines emphasised the need for sensitive disposal and recommended that parents should be given information about the

options they have and what would happen to their baby's body/remains should they not wish to be involved. In 2000 many hospitals still disposed of remains from early pregnancy losses along with clinical waste (Royal College of Nursing 2002). The Royal College of Nursing recommends that the bodies and remains of any baby dying before the age of viability be either buried or cremated communally or individually, funded and arranged by the hospital, and giving the parents the choice to organise a burial or cremation themselves, if they so wish.

Thus, if the law is taken as a measure of society's attitude towards pregnancy loss before 24 weeks of gestation, it could be argued that prevalent culture does not show the same insight as many within the healthcare community as to the potential significance of such a loss to parents.

3.2.2. Making a non-event a real event

The practice of HCPs in maternity units in the 1960s, 1970s and even some into the 1980s was to attempt to erase from the memory of parents the presence of a stillborn baby from their lives (for example, in Cooper's study in 1980 exploring parental reactions to stillbirth the hospital policy, in the maternity unit where parents were recruited from, was not to encourage parents to see or hold their baby). Babies who died *in-utero* were quickly removed from their parents after birth and disposed of by the hospital, often in common unmarked graves. Such well intentioned protective paternalism says much about how disquieting it can be to care for bereaved parents.

However, by the mid 1970's pioneers with an interest in the psychological adjustment of bereaved parents were proposing that the key to helping parents grieve normally was to enable them to create memories – '…make the most of what is tangible and can be remembered.' (Lewis 1976, 619) Or, in other words, confront the reality (Wretmark 1993) of their baby's existence. Memories can be formed by a process of ritualisation (see **5.2.4.1.**) of the baby's life and death, including talking about the baby and his or her place in the family's story. 'The aim is to fill the emptiness that impedes mourning.' (Lewis and Page 1978, 238) Such ritualisation is made up of a series of ritual moments, formal and informal, which help make the baby real. Formal moments in such a process, welcoming and funeral rituals, help to form a basis of remembrance, facilitate grieving (Wretmark 1993) and help to reduce parental anxiety (Radestad, Steineck *et al* 1996a).

Offering parents to have the opportunity to meet and spend time with their dead baby (a less formal ritual moment) has become a cultural norm within maternity care to aid acknowledgement of their loss. Indeed, recent studies have shown most parents now choose to see and hold their baby [Samuelson *et al* (2001), Rand et al (1998) and Radetsad, Nordin *et al* (1996)]. Radetad, Steineck *et al* (1996b) showed that not seeing their baby for as long as they wished and not having mementoes of their baby, for example, a photograph, increased maternal risk of anxiety and depression. Murray and Callan (1988) discovered parents mourning a perinatal death who were pleased with the time they spent with their baby or who had developed special memories had higher levels of well-being following their loss. They also found parents whose baby had died after birth were better adjusted to the loss than those whose baby had been stillborn. Kuse-Isingschulte *et al* (1996) found that the grieving of mothers bereft by a late miscarriage or stillbirth was positively influenced by seeing or holding their baby.

However, the findings of a recent study by Hughes *et al* (2002) has challenged what they consider to be part of the normal guidelines for the care of bereaved parents within maternity units – HCPs encouraging parents to see and hold their stillborn baby after birth. In a comparative study, they identified that bereaved women who had seen and held their baby were more likely to be depressed and anxious than those who had not, as well as their next born infants being more likely to show disorganised attachment behaviour. They also found that having a funeral and keeping mementoes of the baby did not adversely affect women. This article provoked a strong response from parental support groups who emphasis the importance of bereavement care being parent-centred (as outlined in SANDS 'Guidelines for professionals' 1995) and offering them choice in all matters, rather than being encouraged to do anything which contradicts their natural instincts (Matthews and Kohner 2002). The essence of conflicting opinions here is a subtle difference in the interpretation of prevalent cultural norms in maternity units – creating an atmosphere which encourages parents to see and hold their baby on one hand (perceived by Hughes *et al* as the norm as suggested by the Royal College of Obstetricians and Gynaecologists' guidelines in 1985) and simply giving parents the option to do so whilst also informing them that others have found it beneficial (as per SANDS 'Guidelines for professionals' 1995) on the other. I would suggest in reality,

both norms will be found in maternity units and will vary from staff member to staff member. Clearly, the relationship a HCP has with a woman and her birth partner, the way she communicates with them, her knowledge of research in the field, her experience and her awareness of her own perspectives on death will influence parental decision-making in a situation full of emotional and attitudinal complexity. Some parents may find it very difficult to know what do in such traumatic circumstances and may need time to make the decision whether to see or hold their baby. Kersting *et al* (2002) found that after sensitively being given appropriate information that most parents were capable of making the right decision for them. Furthermore, in their research with women who had undergone a termination of pregnancy due to fetal abnormality between 15 and 33 weeks of gestation, nearly three-quarters of the women saw and held their baby. They did not identify any significant differences in the grieving between those who saw their baby and those who chose not do so.

Though the debate over whether seeing and holding their dead baby is controversial, what is clear is that the philosophy and approach to care currently offered to bereaved parents is very different to that of thirty years ago and giving parents the opportunity to create and maintain memories through a process of ritualization is central to this approach.

3.2.3. From HCPs as experts to parents as teachers

Historically, as has been discussed, baby death *in-utero* was seen as a medical problem and doctors, in particular, dictated how baby death should be dealt with. Babies were seen as the property of the hospital rather than the children of bereaved parents – the hospital disposed of the body and parents were allowed to see their baby only if they were determined enough to go against advice. Out of this paternalistic context developed an increasing desire from parents for attention to their real needs and not the agenda of their caregivers. In 1976 Bel Mooney, a psychiatric social worker, invited bereaved parents in a letter to the Guardian (Mooney 1976 cited by Wretmark 1993) to write about their experiences so HCPs could deepen their understand of parental lived experience. From this catalyst it became apparent that parents had a need to meet together to share experiences and a national body, the Stillbirth Association, was formed in 1978, to enable mutual support and advocacy.

The group widened its scope to eventually becoming the Stillbirth and Neonatal Death Society in 1983. SANDS has been very influential in giving bereaved parents a voice to express their needs to the health service in the U.K. The organisation initiated the development of 'Guidelines for professionals' (which has been re-written three times in 1986, 1991 and 1995, each time becoming more inclusive of different types of loss) to enhance HCPs' understanding of the significance of pregnancy loss and offer guidelines for care in supporting parents. The SANDS guidelines were developed by a collaborative working party of parents and sympathetic senior HCPs. As Moulder (1998, 16) puts it –

> ...the development of the Guidelines is a very good example of how consumers of services have initiated change, but in conjunction with professionals who have been sensitive to their needs.

This example of how the SANDS guidelines were constructed epitomises the shift in power that has taken place in bereavement care in maternity services in the past thirty years. HCPs have become increasingly open to work with, and learn from, parents (Thomas 1990), as opposed to informing or directing parents as to what might be best for them.

3.2.4. Movement towards protocols and principles of care

Through the late 1970s and early 1980s in the U.K., the extent to which bereavement care for parents took into consideration the significance of baby death *in-utero* for parents was piecemeal between hospitals and, indeed, between HCPs. It was clear some sort of uniformity of care was required. In 1978 recommendations for the practical management of stillbirth and neonatal death were produced by the National Stillbirth Study Group – these were circulated in a leaflet which was utilised by parents and HCPs. It highlighted the creation of memories, opportunities for parents to talk to, and ask questions of, medical staff and have access to obstetric and genetic counselling as important. The aforementioned guidelines produced by the Royal College of Obstetricians and Gynaecologists in 1985 and SANDS (1995) have been influential in shaping protocols in maternity units across the country. However, several authors (including Skene 1998-9, Leon 1992 and Bourne and Lewis 1991) warn against the inflexible implementation of checklists used by HCPs to ensure uniformity of care, suggesting they should be utilised as guides and not strait-jackets. Furthermore, such guidelines should be underpinned by principles of good practice

(Pierce 2003 and SANDS 1995, for example, list key principles which should inform sensitive care) and like Skene (1998-99) they also underline the fact that bereavement care should be individualised – centred on the needs of each particular woman or family. Moreover, they emphasise skilled communication (listening to parents as well as giving them as much information, at appropriate times, as they need to enable them to make informed choices) as imperative.

What has not changed in the past 30 years is that – 'Stillbirth is a tragedy for the parents and for those looking after them at the time.' (Speck 1978, 38) Dealing with baby death is hard for HCPs – feelings of helplessness, failure and loss are commonly experienced. Hughes *et al* (2002, 118) make a very pertinent point when they say

> …the protocol might sometimes be rigidly used to reduce staff anxiety, rather than to fulfil the intention of those who devised it of offering more sensitive care of parents.

However, the climate in which staff work may have changed to some extent. Rather than detach themselves from grieving parents HCPs are now encouraged to utilise their own human resources in supporting families (Bartellas 2003). Within relevant literature written by doctors (Bartellas 2003), nurses (Thomas 1997), chaplains (Pierce 2003) and parental support groups (SANDS 1995) there is widespread recognition that HCPs need appropriate emotional support when dealing with baby death. Moulder (1998) in a study of how HCPs deal with baby death in one particular hospital discovered nursing and midwifery staff, in general, found more support in their work place (formal and informal) than doctors (my experience of working in the NHS would resonate with this). Moreover, the same sources suggest appropriate training for HCPs is required in, amongst other things, communication skills and developing their self-awareness. To encourage such support and training, as well as an attempt to provide sensitive care for parents, some hospitals have set up bereavement care teams (Brown 1992) or have employed a bereavement counsellor (Thomas 1997).

3.2.5. *The changing ecclesial response to baby death in-utero*

An in-depth exploration of what spiritual care offered by chaplains, as representatives of the church (though not all chaplains in our multicultural society

are Christian), may be and may involve will be explored in some detail in chapter 4. Furthermore, an exploration of the construction and sharing of formal ritual moments with parents by chaplains will be discussed in chapter 5. However, it is important at this point to look briefly at to what extent the church's response to baby death *in-utero* has evolved in the last thirty years.

In many ways the church's changing approach mirrors that of the wider culture to which it belongs. Its pastoral and ritual response has been influenced, like the healthcare community, by listening to the needs of bereaved parents. Singh *et al* (2004) also suggest that the recent increased attention paid in the church to the issue of pregnancy loss is as a result of women's voices being given more heed. This, they conclude, is due to the fact that women being appointed to leadership roles in some denominations has become increasingly commonplace worldwide. However, the church has been criticised in the past for being sluggish in its pastoral response to bereaved parents. Wretmark (1993), a Swedish hospital chaplain, reports in her extensive study of 79 families who had experienced perinatal death that pastoral support from the local parish churches for parents at home was almost non-existent. In 1993 as part of his doctoral thesis Moe (1997) carried out a survey of 284 clergy, within a localised area of Wisconsin, to inquire of their pastoral response to a death based on the age of a child. Nearly 25% of respondents replied that they would not respond pastorally to a pregnancy loss and one tenth said they would not respond to the death of a baby. Here is confirmation that there are many in the church, as well as wider society, who consider the impact of miscarriage or stillbirth to be inconsequential. Perhaps like Singh *et al*'s (2004) study, whose response rate to a questionnaire about ritualising pregnancy loss from clergy in various faith communities in the Chicago area was 23 from 500 surveys sent out, this reveals an ongoing discomfort with having to deal with baby death amongst clergy. In commenting on this response rate Singh *et al* (2004) sum up the prevalent attitude within faith communities, even at the beginning of the twenty-first century -

> The silence around pregnancy loss is pervasive.

Moreover, denominations have been tardy historically in their liturgical response to the expressed needs of bereaved parents even after the formation of parent advocacy groups and the developing awareness of HCPs of the role of ritual, especially funerals, in creating memories and facilitating grief (Health Education Council *et al*

1979, Lewis and Page 1978 and Lewis 1976). It was not until the 1980s that churches began to create liturgies which could be used to ritually mark the life and death of babies dying *in-utero*. In 1980 the Church of England's *Alternative Service Book* included prayers to be said at a time of perinatal death and then in 1989 a *Funeral Service for a Child dying near the time of birth* was produced by the same denomination. This was the first liturgical text which did justice to the real needs of bereaved parents – namely to have a ritual which recognised the unique personhood of their baby and the depth of their grief at his or her death. However, the wording of the liturgy received some criticism from those in hospital chaplaincy who felt the overuse of theological language in the text meant the rite lacked relevance to those unfamiliar with church vocabulary. The more recently published *Common Worship* (2000) contains a variety of prayers which can be utilised depending on the gestation of the pregnancy loss, including a prayer for parents bereaved by miscarriage which gives opportunity to recognise the uniqueness of the baby by name, where appropriate.

In 1990 the Roman Catholic Church in mainland Britain published the *Order of Christian Funerals* which contains a 'Rite of final commendation for an infant'. This liturgy can be adapted for use in relation to pregnancy loss of different kinds and utilised in a hospital or funeral setting. Though it recognises the grief of parents and the significance of their baby it does not reflect the possible range of parental emotion felt including their lament and search for meaning.

The limitations of these earlier church liturgies is reflected well in the following perceptive observation of Wretmark (1993, 273)

> It seems as if there is a dividing line between rituals which are created by those who have close experience of dealing with loss and grief and those which are products from the writing desk.

The Church of Scotland in its *Common Order* (1994) and the Methodist Church in *The Methodist Worship Book* (1999) both contain liturgies for funeral services for stillborn babies which embrace the key elements outlined above that reflect authentic parental experience of baby death as well as containing a range of appropriate suggestions for scripture readings.

Wretmark (1993), however, is concerned that a funeral is not sufficient opportunity for parents to ritually mark the life and death of a baby who dies *in-utero* and feels

there is need for further ritual which may help to counter the formation of fantasies as to what their baby looks like and confront the parents with the reality of their baby's existence. Smith (1998-9) offers theological and psychological reasons why baptism is not an appropriate welcoming ritual for a dead baby – namely the church does not baptise the dead and that baptism has always been a rite celebrating beginnings rather than helping to make real an ending. Case (1978) suggests the requirement of a range of rituals which can be used to meet the particular pastoral needs of parents following stillbirth.

Pierce (2003), Hamilton (1999), Smith (1998-9) and Wretmark (1993) outline a variety of liturgies which involve blessing, naming and commending a baby into God's care (a fuller exploration of the possible role of such welcoming rituals can be found in chapter 5). Hamilton (1999, 17) feels that such a ritual should

> …avoid becoming a pre-funeral, for a funeral has a different role and other images and messages to convey.

In 1994 The Uniting Church of Australia produced a liturgy entitled *A service to follow the birth of a stillborn child, or the death of a newly-born child* which is intended to be used in a hospital context after delivery. What is especially significant about this liturgy is the preamble to it which encourages those performing the service to personalise the rite by listening to the parents' particular story and incorporating appropriate information into the prayers. Chaplains (Pierce 2003, Wretmark 1993 and Case 1978), midwives (Stewart and Dent 1994) and parents groups (SANDS 1995) also suggest that personalisation of ritual, in this instance funerals, can be very important to parents.

Walter (1990, 278) feels that chaplains, especially, are contributing to a movement away from what he calls a '…production line funeral.' As well as helping parents to personalise ritual, chaplains are empowering many parents (when they want to) to take control of arranging their baby's funeral and having a say in how it is shaped. In practice, chaplains do not tend to use 'given' liturgies but adapt them or develop their own according to the needs of the families they are working with (see chapter 5 for a fuller description of the process of co-construction of ritual).

3.2.6. Role of chaplain and the profile of spiritual care

Historically, chaplains or the representative of the parents' faith community have been considered to have an important role in responding to parents' religious, and in particular, ritual needs. Chaplains (Thomson 1981) and parish based church workers (Radestad 1996b and Kohner and Thomas 1995) are also perceived as trusted persons who will provide a listening and supportive presence. Moreover, chaplains are also seen as resources of information about ritual and those who may perform funerals in a family's locality (SANDS 1995 and Stringham 1982), as well as link, where appropriate, with local faith communities (Pierce 2003). Chaplains in Canada (Brown 1992) and America (Fickling 1993) are involved in leading and participating in perinatal bereavement care teams – supporting and training other HCPs (chaplains in the UK do likewise) as well providing care for bereaved parents.

The term spiritual care historically has not been used to the same extent in healthcare literature relating to baby death in the past years, as it has in nursing (see chapter 4) and, latterly, in medical literature with reference to adult death or ill-health. In the main, the term spiritual need has been synonymous with religious need and issues relating to loss of meaning, purpose or hope have been primarily considered, by non-chaplains, as psychological issues. Authors such as Allen and Marks (1993) and Davies (1996) have recognised that parents' faith can be a source of comfort to them when experiencing baby death or indeed that their beliefs can be shattered which can add to their distress. Others (including Brown 1993 and SANDS 1995) have described the importance of parents' religious and cultural values (and that of their wider family) in the way they deal with their grief and how they ritually mark (or not) their baby's life and death. As has been highlighted in **3.2.5** some HCPs since the mid 1970s have perceived the importance of ritual in the holistic care of parents, especially aiding facilitation of grief and the creation of memories relating to the deceased baby.

3.2.7. Ritual Practice and other faith communities

As with any bereaved family those providing holistic bereavement care have to avoid making assumptions about parents' individual needs, whether they belong to a particular ethic or faith community or not. Those associated with a faith group will have a range of beliefs and ritual practices depending on their upbringing, personal

perspectives and cultural influences. However, common ritual practices amongst the Muslim and Jewish communities will briefly be outlined.

3.2.7.1. A Muslim approach to baby death *in-utero*

A perinatal death is not minimised as is common in secular and Christian communities and it is generally accepted as part of God's will. As much respect and dignity is afforded to a stillborn baby as a deceased adult (Herbert 1998). A baby will be named and, if possible, positioned with his or her head facing Mecca. Prayers and ritualistic washing are performed prior to burial and the baby wrapped in a shroud. Further prayers are said at the graveside and during an official period of mourning in the three days following the death. Within the Muslim community it is believed that the baby will live on in the next world.

3.2.7.1. A Jewish approach to baby death in-utero

Jews believe that a baby dying *in-utero* passes into the hereafter and will be part of the resurrection of the dead. Historically, Judaism has offered bereaved parents little in the way of ritual marking to enable them to acknowledge their baby's life and death. However, with the voice of women within Reformed and Conservative Jewish traditions gaining increasing influence new rituals are being gradually introduced and old ones rediscovered. Rituals such 'A grieving ritual following miscarriage or stillbirth' (in Orenstein 1994) involve readings from the psalms, prayers and the opportunity for ritual action, for example, parents tearing a baby blanket in place of the Keriah (the tearing of one's clothes traditionally done at a burial service). Rabbi's manuals (for example Seth 1997) within the aforementioned Jewish traditions now contain rituals marking pregnancy loss which have been informed by the experience of bereaved parents (Singh *et al* 2004). Burial is the preferred means of disposal for Jews and the naming of a dead baby is important.

The recognition of the importance of formal ritual in making memories is not just confined to faith communities. Non-religious naming ceremonies are performed with the parents of babies who die *in-utero* by some chaplains, as well as non-religious funerals, as part of their role of offering appropriate parent-centred spiritual care (such rituals may also be performed by family members, friends, other HCPs or a representative of the Humanist Society). The Baby Naming Society has prepared

such a naming ceremony to be used in such circumstances which can be personalised.

Having examined the cultural shift within healthcare towards a more holistic approach to the care of bereaved parents and how the ritual response of the church has also, though more slowly, been influenced by increasingly vocal bereaved parents I now wish to explore in more depth what the spiritual element of such holistic care may be.

Chapter 4

Spiritual care – preparation, assessment and provision.[1]

Much has been written in the last twenty years about spiritual care, especially in the nursing literature. It has become recognised as part of the holistic care offered collaboratively within healthcare by HCPs, family and friends in acute hospitals and in the community to patients and their significant others. This chapter seeks to explore, from reflections on practice, what spiritual need may be and how chaplains, collaboratively with other HCPs, may respond to meet such need. This chapter is based on the premise that in offering spiritual care to others we have to develop an ongoing awareness of who we are and what our needs are, as well as the needs of the other. Moreover, it explores different dimensions of spiritual care that may be offered depending on the needs of an individual and surmises that a sensitive approach involves caring not curing, living with and not attempting to fix. It also seeks to reflect on what is unique about the involvement of chaplains in the provision of spiritual care.

4.1. Preparation for providing spiritual care

4.1.1. The spiritual carer's story

Those who offer spiritual care, be they a chaplain, midwife or doctor, potentially will enter into relationships where highly personal information and feelings may be shared. There is potential for much good and much harm to come to both patient and carer. In order that during an encounter with a patient we as carers can separate out what are our own feelings or issues from those of the other, we have to be very aware of our own personal story. Issues arising for the carer, if noted and owned, can be shelved during the encounter and dealt with at another time. Unless we are aware that our own feelings and worldview may be touched or challenged by involvement in

---

[1] This chapter is an amended amalgam of two previously published articles - Kelly E 2002 Three Dimensions of Spiritual Care in an Acute Hospital Setting. *Theology in Scotland*; VIII(2): 53-65 and Kelly, E. 2002 Preparation for providing spiritual care. *Journal of Healthcare Chaplaincy*; 5(20): 11-15. (copies both of can be found in the sleeve on the inside back cover of the thesis). The conclusion of the former article has been omitted from this chapter and woven into chapter 10. Furthermore, material on spiritual care as talking and spiritual care as doing has been added.

spiritual care then an encounter may well end up being more about our issues than the patients.

What are the significant elements - experiences, prejudices, wounds, losses, skills obtained through training and individual needs – in the carer's story? What are the wider narratives which have touched us and have helped to shape our beliefs, values and worldview – our family, circle of friends and our religious and cultural background? What is it a HCP brings to an encounter at any particular moment? How aware are we of our own spirituality? What gives our lives meaning and purpose? What is our theological stance and/or philosophical outlook on life, death, suffering, the existence of God and the possibility of life after death?

What are the buttons in our lives, at the present time, that when pressed may lead to distress and an inability to function as a carer?

How as a HCP am I feeling right at the moment of being with a patient or family? Up all night with a young child at home and desperately needing sleep, had a bad day with administrative work and now developing a throbbing headache – is it appropriate that this chaplain goes to be with a family in labour suite whose baby has been stillborn? Can someone else go?

Spiritual care in the acute hospital setting is about responding to needs in the present moment - the patient's needs and us as carers, acknowledging our needs too. It is often also about disengaging from one moment with one patient, letting go of that moment and then preparing ourselves for the next moment with the next patient. Importantly, it is also about us as HCPs revisiting particular moments later, at a suitable time, to reflect by ourselves, with colleagues or a supervisor to unpack what that moment was about for the patient, for me as a human being (not just as a chaplain) and how I felt we related to each other .

4.1.2. What is spirituality?

The word spirit has its roots in the Latin word *spiritus* and is associated with a force that gives animation or breathe to life. Heyse-Moore (1996, 300) considers the spirit to be the 'essence of life'. As well as something very deep within the human makeup, traditionally the word spiritual has also been associated with the transcendent, the sacred or the 'otherness' in life – different faith groups and cultures having varied perspectives and understandings of its complex nature. However, in more recent

times it has come to have a much broader meaning – life experience out with that which is considered religious is now thought to have the possibility of being spiritual. Grasping the meaning and concept of things spiritual in our pluralistic world is not easy and Bellamy (1998, 185) makes an important point when she says

> The term spiritual, however, needs to remain elusive if it is not to betray its very identity; inherent to it is the concept of searching rather than finding.

To be spiritual is to be human i.e. every human being has a spiritual dimension to his or her life (though individuals may not name it as such). In our postmodern context where the majority of people are not affiliated to any particular religious tradition or faith group, equating things spiritual with things religious is to narrow and constrain the former. The spiritual element in our lives is something, which can be described, in relational terms

> ..a capacity for self-transcendence that is expressed by expanding personal boundaries intrapersonally, interpersonally and transpersonally – inward, outward and upward. Transcendence can be found within or beyond self, depending upon one's religious or philosophical beliefs.
>
> Reed (1998, 43)

Throughout our lives there is an ongoing deep-seated desire to understand ourselves, the world and those around us more fully, as well as that which may be beyond the physical makeup of our environment. This driving force may become more immediate at certain times in our lives. For example, in an acute hospital setting, many individuals become concerned with deep questions about their lives, suffering, death and the possibility of the existence of a greater being.

> Crisis situations, whether they be loss, illness or hospitalisation, bring one face to face with the ultimate issues of life – the limitations of one's humanness, the loss of personal and environmental control, and the meaning of pain and suffering in the overall purpose of life. The questions of why and when events occur raise the issue of a God who does or does not exist and is or is not involved with one's life.
>
> Stoll (1979, 1575)

However our spirituality is not just something, which comes into play as we seek to find meaning and purpose at significant times in our lives – good or bad.

> ...if one reflects upon daily living it is often the mundane rituals such as going to work, doing the washing or walking the dog that bring meaning and purpose to everyday life.
>
> McSherry (2000, 28).

Each of us weaves for ourselves a tapestry in life - made up of many different threads. These threads are the different aspects of our lives, which give meaning, shape and purpose to our existence - everything from enjoying a bath to watching rugby, special relationships we have, our beliefs and values to our membership of the church or a miner's welfare club. Each thread has its place and may seem insignificant or taken for granted in daily life but on admission to an acute hospital and being faced with issues which Stoll describes above may create a tear – large or small - in the person's tapestry, and the patient or relative has to begin to deal with threads that have been severed and may never be able to be repaired again.

A desire to make sense of life and significant events in life is a universal, shared experience and yet our own spirituality, whatever we understand it to be and its role in our lives, is a highly subjective thing. Bailey (1996, 61), an Anglican priest, put it this way

> …spirituality? It is something to do with attempting to explore…taking the risk, setting out. Something to do with the capacity in us to make that beginning – the need the desire, the unrefusable urge….In the words of RS Thomas
>
> "Enough we have been given wings
> and a needle in the mind
> to respond to his bleak north.
> There are times even at the Pole
> When he, too, pauses in his withdrawal
> So that it is light there all night long."
> This need, this desire, this "needle in the mind" is right at the very
> heart of us, deep at my mysterious centre and yet it's a very common,
> shared thing too.

It is a risk to consider wrestling with spiritual issues , to be open to the '…needle in the mind…' and yet in acute hospitals many patients, relatives and staff are forced to do so by circumstance and their involvement with people they are caring for.

Woodward (1997) in his definition of the spiritual underlines the importance of this element in our human makeup. It is

> ..the essentially human, personal and interpersonal dimension which integrates and transcends the cultural, religious, psychological, social and emotional aspects of the person.

The spiritual dimension in all of us holds together and is greater than all the other components of our makeup, including our sexuality (which Woodward omits). It is

that element in us and beyond us that makes each one of us truly unique and gives us, at times, the ability to see beyond what is happening in the present moment.

4.1.3. What are spiritual needs?

Several chaplains – Cobb (1998), Woodward (1997), Stoter (1995) and Speck (1988), and, as well as writers from the nursing profession including – McSherry (2000), Ross (1997), Narayanasamy (1991), Bunard (1987), Highfield and Cason (1983) and Stoll (1979) have described various aspects of spiritual need and distress.

Most succinctly Bunard (1987, 377) describes spiritual distress as

> ..the result of total inability to invest life with meaning. It can be demotivating, painful and cause anguish to the sufferer.

Narayanasamy (1991, 7-8) on the other hand gives a more comprehensive list of spiritual needs

- the need for meaning and purpose

- the need for love and harmonious relationships

- the need for forgiveness

- the need for a source of hope and strength

- the need for trust

- the need for expression of personal beliefs and values

- the need for spiritual practices, expressions of the concept of God or a deity

- the need for creativity

Central to all descriptions of spiritual need is a search to find meaning, reason and purpose in the individual's current circumstances. In the immediacy of acute hospitals – in the accident and emergency department, in intensive care, labour ward or in any acute ward, circumstances can change in a moment. As a working definition for use when considering the spiritual needs of a patient or their significant others I would propose the following

Spiritual need is that aspect of an individual's personhood which seeks to make sense of and find meaning in, the present moment. Any such exploration is done in light of an individual's previous life experience and aspirations for the future and involves, potentially, consideration of any significant element of their unique life story.

Thus, spiritual need is something dynamic – it can change from moment to moment as external circumstances and internal perceptions, thoughts and feelings, change – and is ongoing, especially during or after a crisis. As well as being multi-faceted, involving an individual reflecting on potentially any part of their own story, spiritual need is also multi-layered – the depth of the patient's need and their ability or motivation to explore such need can change very quickly in an acute hospital context. At what level individuals want to explore any spiritual need, at any moment in time, will depend on various factors

- how they interpret their present circumstances

- the privacy of their surroundings

- how they relate to the HCP present with them at that moment – for instance how they interpret the HCP's story as revealed by their profession, their appearance or their manner

- their physical and psychological state

- their personality and ability to articulate thoughts and feelings

Therefore, in responding to these needs HCPs have to be sensitive to the cues that they are given by the individual, at that moment, in order to let that person begin their exploration at a depth they feel safe and comfortable with. The level of the patient's self disclosure may alter during the encounter or at a later time. For example, prior to visiting time a patient may mention to a HCP that they are getting a visit from a member of their family and talk about where the person lives and what they do for a living. However, following the visit the same individual may want to explore some very personal issues relating to family relationships, prompted by the time spent with their visitor.

Spiritual need involves questioning and searching. Hence, often it is difficult for a person to articulate precisely their spiritual needs to another in the present moment of a traumatic event. Their values and beliefs may be called into question or may provide a source of comfort and strength. In a moment of particular spiritual need an individual may well be reflecting on the past or contemplating the future in light of what is happening to them or their loved one in the present.

4.1.4. Assessment of spiritual need

Traditionally a patient's spiritual, or rather religious, needs were assessed on admission to hospital – the patient was asked their religious affiliation, if they wished their minister, priest or religious leader to be notified and if they wanted the hospital chaplain to visit them – and by doing so assumed to be responded to adequately. However, as has been discussed, an individual's spiritual needs can change very quickly in an acute hospital environment, for example, as a patient gains more information about their condition or the bad news they have been given begins to sink in. Therefore, assessment of those needs has to be ongoing. For patients, articulating spiritual needs and asking for support can be difficult as this may mean discussing very intimate issues in an often far from private environment. Moreover, patients may be wrestling for the first time, in stressful circumstances, with issues which are hard, for anyone, to articulate (as discussed in **2.3.**).

Therefore Cobb's point (1998, 110) that spiritual needs are most effectively assessed in '…a relationship of trust, respect and usually out of their (the client's) life story,' is paramount.

Some hospitals and hospices have devised tools to aid assessment of spiritual needs. Whilst this ensures that this aspect of care is not forgotten and may aid some patients to verbalise their needs, there is a danger that a 'tick the box and move on' approach develops. In an already dehumanising environment it is important that assessment of an individual's spiritual needs is done sensitively and at a pace which enables the individual concerned to feel safe enough to share with the HCP involved at least part of their life story.

Assessment may or may not involve the use of an assessment tool but will certainly require good observational and communication skills as the cues given by patients regarding their spiritual needs are both verbal and nonverbal.

As with photography, where the quality, depth and feeling of a photograph depends on the skill and experience of a photographer as well as the quality of the camera, so assessing spiritual need depends on the professional and personal attributes of the HCP as well as the assessment tool used. Assessing an individual's spiritual needs at one moment may give great insight into their needs at that time but it is only a snapshot relevant at that moment and set of circumstances. When assessing spiritual needs we as HCPs need to be aware of the colour of lens we are looking through as

we take the snapshot, as we assess the patient's spiritual needs. Spiritual assessment, as with spiritual care, begins with self-awareness. Our own story – our own worldview, beliefs, values and life experience influence greatly the way we view the world and other people and, thus, any assessment of the spiritual needs of others.

Spiritual needs may be recognised by HCPs but not always by patients themselves. Sensitive exploration of issues elicited may enable help to be offered and 'hidden' needs to be met. However some people may refuse such support and HCPs have to respect the privacy and individuality of all we seek to care for. As Ross (1997, 38) puts it

> We should not assume, therefore, that all patients will have spiritual needs which require constant attention. Some may choose to deal with them in their own way and in their own time. We should respect a patient's right to refuse spiritual care.

4.2. Dimensions of spiritual care in an acute hospital setting

Spiritual care involves attending to the spiritual needs of an individual or family. Therefore, such care is centred primarily on helping people, in their particular situation, in their search for meaning and purpose in the present moment. HCPs, including chaplains, have different resources available to aid them in the spiritual care they offer. The second half of this chapter seeks to give an overview of these by briefly describing different aspects of such care. Before doing so the relationship between spiritual and pastoral care should be clarified. Pastoral care is offered where the carer and cared for both utilise the Christian metanarrative as an overarching framework within which to aid the patient's search for meaning in life (Gerkin 1997). There is a shared knowledge of language, ritual and metaphor as well as the content of biblical stories, and depending on circumstances the carer may seek to aid the patient to re-interpret his or her story in light of the Christian metanarrative. In contrast, spiritual care may be offered without HCP or patient being informed by this metanarrative. Instead a patient may seek to make sense of their loss with reference to a range of narratives and resources which inform their worldview. In short, pastoral care is part of the over-riding care termed spiritual in nature, but in postmodern times the number of relationships in hospitals between chaplains and patients in which pastoral care is given and received is limited. However, every relationship between HCPs (including chaplains) and patients potentially has a spiritual dimension, whatever the belief system of those involved.

4.2.1. Spiritual care as being present

> For seven days and seven nights they (Job's friends) sat beside him on the ground, and none of them spoke a word to him, for they saw his suffering was very great.
>
> Job 2:13.

When Job's friends were willing in the face of his suffering to be with him and say nothing – not offering him advice, sharing their worldview, not judging him or asking about his feelings - at this time they truly were his comforters.

Being There, the title of Peter Speck's (1988) much read book, which explores the spiritual dimension of people in sickness and in health, hints at what much of spiritual care is about – being present with others in times of distress, if they want someone with them. However, simply to equate spiritual care with 'being there' without unpacking what this may mean to patient or carer is to scratch the surface of something potentially very profound. For the purposes of this discussion I will equate presence with a quality of attentiveness to the present moment.

Janet Stokes (1999, 198) wrote the following after some qualitative research into what she terms as the 'Ministry of Presence' by hospital chaplains in Philadelphia

> Ministry of presence is clearly defined by patients more in the sense of accompanying the patient in distress than passing the time of day.

Being attentive to the present moment with someone who is hurting means having the motivation and desire to get involved, to be exposed to whatever the patient is going through and reflecting on. It is more than making a social call. It is taking a risk. It is taking a step into the unknown and being prepared to deal with that unknown, moment by moment. To be really attentive to the present moment means to cast aside assumptions about the other person – how an individual may be feeling in, or dealing with, their particular situation. It means to begin with a where person is at that particular time on their journey through life. It means being prepared to accept the other as he or she is at that moment – to create a safe place in which the patient can truly be them self and express them self as they need to. Likewise, it means us as carers truly being ourselves too, being authentic, moment by moment during the encounter. For the greatest asset we have as carers is ourselves - our humanity and our willingness to be vulnerable. Henri Nouwen , cited by Salt (1997. 60) puts it this way

> When we honestly ask ourselves which persons in our lives mean the most to us, we often find it is those who instead of giving advice,

solutions or cures, have chosen instead to share our pain. The friend who can be silent with us in an hour of grief, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness is the friend that cures.

When crisis or trauma makes a huge tear in an individual's tapestry or life story there is nothing a carer can do or say to remove the pain or to fix the tear – all we can do is offer ourselves to be with the individual, for a time, as they experience and live through the pain and confusion of loss or bereavement. Cassidy (1988) uses a series of sketches in her book *Sharing the Darkness* to illustrate how the professional tools of a doctor (her diagnostic instruments and competence to use them), a priest (the sacraments) and finally the counselling skills of a HCP become useless in certain situations of great pain and suffering. In the final illustration the patient and the HCP are depicted as both naked – stripped of all their resources. They are both helpless and hurting.

As professional carers and as human beings that is so very hard because our natural inclination is to want to help make things better – to try to fix the situation. It can be very difficult to stay, to be present, in such situations if needed. And yet in such moments where a HCP is present with a patient, sharing for a while their pain and helplessness, in that touching point of one human story with another is affirmation that the patient's pain and feelings are valid and appropriate. There is also the recognition that they as an individual have worth. They are important. They matter. Jean Vanier cited by Stoter (1995. 23) eloquently describes the therapeutic value of spiritual care as being present in the following

> Through a caring committed presence people will discover
> That they are allowed to be themselves:
> That they are loved and so are lovable.
> That they have gifts, and their lives have meaning
> That they can grow and do beautiful things...

In the immediacy of the moment, in a time of distress, very few people find meaning in their suffering but in the following months and years people may be able to pick up the threads of their lives again to weave a new pattern in their tapestry. However part of their story now is the loss that was lived through and the tear experienced becomes incorporated into the tapestry that was, is and will be their life story.

The relationship which we have described between patient and carer is one of mutuality, of sharing something awful, of both feeling helpless and confused and both, at times, desperately wanting to run away from the situation. In such situations

when care and compassion and love are shared as well as distress, paradoxically, moments of transcendence can also be experienced. Moments where something greater than the current trauma is experienced in the personhood, in the very being of the other person (patient or carer), which give hope and strength and courage. Lyall (2001, 140) describes such glimpses of transcendence in this way

> ...from the depths of a pastoral relationship which manifests availability without imposition there often emerges a Word which transcends words. There is a sense in which the pastoral relationship is both parabolic, pointing beyond itself to a deeper grace, and poetic, evoking within the imagination images of transcendence.

4.2.1.1. When a chaplain is the carer present

Spiritual care in an acute hospital context is a collaborative effort, potentially involving relatives, friends as well as HCPs from a variety of disciplines. In the end it is up to the patient, to choose who they want present with them (if anyone). If it is a chaplain who waits with them in their time of distress, as well as hopefully providing a sensitive human presence, the chaplain being there may be important to the individual in other ways (this topic is further explored within the particular context of a maternity unit at **5.2.9.**)

Ontological significance of chaplain

Chaplain as Representative of the Christian Story

For some patients it may be important to have a chaplain present with them in a time of distress because the chaplain may represent something of the Christian narrative to the individual or perhaps, more accurately, something of the patient's interpretation of the Christian narrative. The chaplain may explicitly represent the love, care, forgiveness, compassion and quite literally the presence of Christ in difficult situations for some people. It is not what the chaplain does or says that matters but by being present Christ's love is incarnate. This is not to say doctors, nurses and other HCPs do not embody these characteristics for patients and their families also (whether the HCPs believe they do is another matter). However, for some patients, the very presence of someone who explicitly, by their job title and their training, may represent key elements of their faith and belief system is comforting and strengthening. In this respect the chaplain may 'exercise all the authority of priesthood' (Autton 1968, 28) not just in the saying of prayers and the sharing of the sacraments but also by being present.

Chaplain as Representative of God

For other individuals for whom the Christian story is not part of their own individual narrative, the chaplain may still be seen as someone who represents God, a greater being or a higher power. Consequently, some people in times of stress would choose not to have a chaplain with them as they have no such belief or are wrestling with the issue of if there is a God, how could God let this happen to me or to my loved one? Feelings about God are often projected onto chaplains at such times and this may be a decisive factor regarding whether the patient wishes a chaplain present or not. For some people to express their anger about God and about their helplessness in their current situation to a chaplain, i.e. for the chaplain's presence to enable such expression, may be cathartic.

Chaplain as representative of 'things spiritual or of another world'

Chaplains may be seen as individuals who have reflected on life and death and the meaning of suffering by people with or without a particular system of beliefs. This, paradoxically, can mean the chaplain is both wanted and shunned; a chaplain can be seen as someone who represents hope in the face of or after death but also, as Carr (1985, 107) puts it ' ...he (the clergyman) may also become the purveyor of death, the death-man.'

Chaplains may be viewed as people who are associated with 'other worldly things' or with prayer and meditation. Indeed, for some patients it may be important that they perceive chaplains to have had a theological and philosophical education and spiritual training. Thus, some individuals may more readily explore such issues in the presence of a chaplain rather than another HCP. Willis (2000, 393) puts it this way

> They (patients) want someone willing to explore with them ultimate issues. They expect us to be in awe of and conversant about, the *numinous,* about what Rudolph Otto termed *mysterium tremendum et fascinans,* "the tremendous and fascinating mystery". They assume we believe that what is seen is not all there is.

Chaplain as a 'neutral' presence

Patients may choose a chaplain to be with them simply because they perceive a chaplain to be neutral – someone who has nothing to do with their medical or nursing care or the decision making about the care of their loved one. Chaplains are not part of their family or circle of friends and the chances are that the patient concerned will

never meet the chaplain again.. This may enable the patient to talk to someone about issues which otherwise would remain unspoken.

Chaplain as 'trusted' presence

For many individuals chaplains represent someone who can be trusted, someone who will hold confidences about sensitive issues. As one patient put it 'like talking to a priest in a confession box.'

Chaplain – as 'unhurried' presence

Many patients feel very guilty about taking up the time of nurses, doctors and other HCPs whose jobs involve physical as well as other aspects of care. Chaplains are generally perceived to have more time to offer to individuals as they are not multi-tasking in the same way. Chaplains pop in and out of wards and units. They are not seen moving between patients, doing many practical things, responding to numerous requests- often at the same time – as nurses can be. Having someone present who you feel does not need to incessantly move on or attend to someone else's immediate physical needs can be important. Individual nurses and doctors may not project this message by their persona or approach but their uniform or perceived role may be associated with the immediate physical needs of patients, being busy and overstretched.

4.2.2. Spiritual care as being absent

In an acute hospital, many encounters which a chaplain has with distressed patients, relatives or staff involve a single meeting or a small number of fleeting visits.

After being present, leaving is not just an obvious necessity but it often occurs more quickly than either patient or carer anticipates, for example, X-rays and pre-meds have to be taken and surgery has to be performed. Hospitals are busy, bustling places and patients become weary during visits. Patients go home, are transferred or die. Learning to leave and to let go is as much part of spiritual care in hospitals and as being present is.

Being present with another can be important - it can bring comfort and encouragement, affirmation and hope - but there is always a time when chaplains, as carers, have to leave because of the patient's needs and, at times, because of our needs. Leaving individuals can be difficult – especially if they are distressed, are someone we have got to know well or are someone whose company we enjoy. If as

chaplains, we believe that we embody the love and care of Christ, perhaps Jesus' words to his friends – 'If I do not go, the advocate will not come.' (John 16:7) – may help us to let go or hand over the individual into God's care.

For when we leave the helper, as Nouwen (1977) suggests, fills the space which we have left. We do not leave those we have been with alone; when we withdraw, the Holy Spirit is present.

None of us is the Almighty. Our presence with others may be a reminder of God and God's love and concern for individuals and families but we are not the ever constant presence of the God of Jacob (Psalm 46). For various reasons, patients and their significant others, may want time on their own when they are in hospital. Indeed they may need time on their own or with their loved ones; time in which to think, to reflect, to take stock and to rest and recuperate. However, when we withdraw, we can be assured there is another who is always there, always present.

RS Thomas (1993. 457), who was a priest in a Welsh coastal parish captures beautifully in his poem *The Other*, the constant wakeful presence of God, day and night. He describes lying in bed at night listening to the waves breaking on the shore

> .....And the thought comes
> Of that other being who is awake too,
> Letting our prayers break on him
> Not like this for a few hours,
> But for days, years, for eternity.

When leaving, we can let those we care for go into the care, into the presence of that other being who is always awake and always attentive.

Leaving, letting go is also essential for chaplains so that we can come back - to the same or the next person - refreshed and restored, ready to be present again in the next moment with the whole of our being.

There needs to be a balance for all of us who care for others between being present and being absent; a balance of being with and being away from.

There is a story told about Antony, one of the desert fathers, a wise and insightful monk who lived between two and three hundred years after the death of Christ.

> One day Antony was relaxing with some friends outside his hut when a hunter came by. The hunter was surprised to see Antony relaxing, and rebuffed him for taking it easy. It was not his idea of what a holy man should be doing. Antony replied "Bend your bow and shoot an arrow", and the hunter did so. "Bend it again and shoot another arrow"

said Antony. The hunter did so, again and again. The hunter finally said, "Father Antony, if I keep my bow always stretched, it will break." So it is with the monk," replied Antony, "if we push ourselves beyond measure, we will break. It is right from time to time to relax our efforts."

(Au and Cannon 1995, 111)

4.2.3. *Spiritual care as listening*

Since ancient times there has been evidence that those who were '…troubled and distressed have yearned for an interested and concerned listener.' (Jackson 1992, 1624) Jackson then goes on to give examples from the psalms which '…make it clear that listening has been viewed by many as having the potential to ease a person's distress and suffering.' For example

> Lord, hear my prayer
> and let my cry for help come to you.
> Do not hide your face from me
> when I am in dire straits.
> Listen to my prayer….
> (Psalm 102: 1 and 2)

Such listening in the context of providing spiritual care is not passive but again requires a quality of attention to the present moment. It is active and reflective and involves –'..entering into their (the client's) frame of reference, their view of the world and developing an empathetic relationship with them.' Burnard (1987, 379)

Such profound listening requires much concentration and energy. As Jackson (1992, 1628) indicates – 'The healer truly hearkens to the sufferer – that is to say, the effort is to hear and to know or understand.'

Spiritual care, thus, allows patients or their significant others to tell their story and implies that carers have to respond in such a way as to show that, moment by moment, we not only are hearing what is said but we are reflecting back to the individual the very essence of that story and the feelings associated with it. This not only indicates to the teller that what is being said and felt is understood, but it also allows the patient to hear their story again for themselves.

Oor Wullie is a well known comic strip character who appears in a Scottish Sunday newspaper every week. At the end of each adventure, at the end of each day, Wullie is to be found sitting on his bucket looking back at the day, reflecting on what has happened – the highlights, the sad and happy events, the mistakes he's made, the

trouble he's got into and how he got through it, the experiences that have left him puzzled and so on. In short, Wullie is someone who takes stock of his life at regular intervals, while sitting on his bucket.

Much of what spiritual care is about is listening - enabling people to sit on their buckets and take stock. Enabling them to tell their story and, thus, hear their story, perhaps for the first time; allowing them to remind themselves of the different facets of their life story. Empowering them to talk about their regrets, to express their questions of themselves, of others and of God and to put themselves in touch with the ways they have dealt with difficulty and distress in the past -what helped and what didn't. In this way individuals may discover, or rather rediscover, inner resources or coping mechanisms which may help them through their present circumstances.

Perhaps too, in the telling of their story and in their questioning and wrestling they may find some sense of meaning in life and find hope for the future. However, as Burnard (1987, 381) describes it, one of the main challenges facing a HCP (in this case Burnard is referring to nurses) in providing spiritual care is

> ....to listen, to accept, to explore and finally to offer no ready answers. This is clearly a difficult task but a rewarding one. In the end, persons who discover their own meaning and their own reason for believing in what they do will usually be the most satisfied. The nurse's (or any other healthcare worker offering spiritual care) task is not to get in the way of that process taking place. But equally and almost paradoxically, it is the nurse's task to get involved with the dispirited person. The balance between standing back and being immersed is a difficult one to achieve. It is also, a very human and important one.

Burnard reinforces again the importance of the need for quality of attention to the present moment when offering spiritual care - listening to ourself, as a carer, as well as listening to the patient – enabling us to walk the fine line between 'standing back and being immersed.'

Enabling individuals to tell their stories in times of stress or confusion may be an opportunity for them to re-frame or re-interpret their story in a manner which may help them to deal with their situation. Birch and Miller (2000, 193) suggest

> The invitation to re-tell past experiences can (then) become an opportunity for (re)constructing narratives in different ways, evolving different perspectives on the past, leading to different understandings of the present, with implications for the future.

Attentive listening also involves honesty and integrity on the part of the carer - honesty to say that we don't understand or don't follow the patient's story and honesty to say that we don't know the answers to questions when we too are confused. This may involve questions about God's existence or theodicy or why certain things have happened the way they have. It most cases when patients are verbalising such questions they are not looking for answers but the opportunity to explore them and to vent their thoughts and feelings.

4.2.4. Spiritual care as talking

As has been discussed active listening involves reflecting back to the story-teller what has been heard and observed – the essence of their story and the feelings associated with it. In doing so there may be a place for the use of metaphor.

4.2.4.1. Use of metaphor (see also *5.2.5.*)

Firstly, to show we have understood what has been articulated and a patient's underlying feelings we may use metaphors to respond when it feels appropriate. As with other aspects of spiritual care this involves taking risks. For example, a bus driver who articulated his fear and helplessness while trying to live with incurable metastatic pancreatic cancer felt heard and his feelings of loss of control acknowledged and understood, when this part of his story was described back to him as –'…feeling as though you were a passenger on the top deck of your own bus. The driver is drunk, doesn't know the road, and you have no way of getting downstairs and taking the steering wheel from him…'

Secondly, as a way of helping people articulate, what at the time, feels indescribable. This needs sensitivity and full attention to the present moment but on occasions it can help patients feel those offering support have some perception of their feelings (though of course can never exactly know). For example, one couple who were numb and confused following the death, of their baby son felt added distress by their inability to begin to describe how they felt to their close family. This was causing them added pain and guilt. Their loss was tentatively described as having the best Christmas gift ever given to you as a child, a present which you had desperately wanted and waited for, taken from you even as you opened it. This struck a chord and initiated a tentative beginning in their articulation of their experience to those around them.

4.2.4.2 Speaking with authority

There are times when patients and their significant others wish to hear chaplains speak with authority. Walter (1997) feels what separates the care offered by chaplains from that of therapists or counsellors is the language of '...forgiveness, love and hope.' Certainly Walters has a point. Some people in certain situations after careful exploration of the issues concerning them and assessment of their needs want to hear words relaying God's love and care for them or their loved ones. For example, a young mother whose baby had died *in-utero* was concerned whether her abusive uncle, who had died in the previous year, would have access in the afterlife to her baby girl. Though she quite naturally had ambivalent feelings towards God she quite definitely believed in life after death. After exploring with the mother her feelings, beliefs and fears it became very apparent that she needed to hear from me, as a chaplain (a person whom she felt had authority in such matters), that her baby daughter would be safe, cared for and protected by a loving God.

Patients, and not just Roman Catholics, may want to confess their sins and receive forgiveness as they are taking stock of their regrets and misdemeanours in life whilst in hospital.

Those with religious beliefs may ask for familiar words to be read to them from a sacred text of their tradition. Christians may appreciate hearing the comforting words of a favourite psalm or gospel reading as part of an appropriate ritual, for example, at or near a time of death or during a bedside communion, or simply as requested or indicated during a pastoral visit.

4.2.4.3. Use of prayer

Though the number of people who take an active part in faith communities in the UK is comparatively small at the beginning of the twenty-first century, there remain a significant percentage of people whose life stories have been touched by religious practice in the past or the present. In times of stress in an acute hospital setting many people do find some of their spiritual needs are met in part, through their own private prayers or through a third party, usually a chaplain or their own religious leader, praying at their bedside or their friends, family and own faith community praying for them elsewhere.

When chaplains are with patients, great sensitivity is needed when considering offering prayer. As in all elements of spiritual care it is the patient's needs which are paramount in any encounter. Prayer can be utilised as a way of 'shutting a patient up' or used as a means of escape – a signal for the end of an encounter given by a chaplain – enabling a chaplain to avoid dealing with potentially uncomfortable or time consuming situations. However, when a chaplain appropriately responds to cues given out by an individual, prayer can give great comfort and support. Often a letting go of tears or a deeper level of sharing follows. By asking a patient what they want prayed for and using the content of the preceding encounter (including importantly expressed or suggested emotions) prayers can be created relevant to the individual's story and situation. Moreover, this approach also enables a recognition, and validation of the patient's feelings. Using the first names of the patient, where appropriate, and any significant others also helps to make prayers said more personal. On occasions some patients may wish to pray aloud with the chaplain listening or to recite familiar prayers, such as the Lord's Prayer, together.

4.2.5. Spiritual care as doing

4.2.5.1. Spiritual care as touch

Patients in an acute hospital setting- experience being touched in a variety of circumstances - being touched to have your blood pressure or temperature taken, to be washed or shaved, to be turned in bed or put onto a commode or theatre trolley. Patients are touched all the time, often in very intimate and gentle ways, for specific functional reasons. Touch is also a major part in non-religious rituals that occur regularly in acute hospitals, for example, the last offices performed by nursing staff after a patient has died. This ritual has various practical functions (including washing the body and removing any medical equipment) but at its core this ritual is a mark of respect for the individual and is a very real way in which nursing staff can say their goodbyes; have the opportunity to have some form of closure to their involvement with a patient whom they have cared for.

The type of touch I will briefly explore here is that which is purely offered to bring comfort and support (not that touch with a function, cannot also do this as a secondary effect).

Appropriate loving touch in itself is sacramental in that it is a visible, tangible symbol of God's love. It can be part of a ritual or in itself may be a ritual. Mitchell (1989, 77) writes

> ...the value of touch is very great, particularly in situations involving anything approximating a blessing. Praying with sick or grieving folk and offering them a blessing or benediction ought whenever possible to involve touch. Pruyser writes: " Most pastors ....do (this) almost instinctively, because they know 'in their bones' that tragic situations always call for some kind of touch, some kind of effortless self-giving, some direct primitive, unreflected, spontaneous spilling over of affect into the motor system".

Mitchell and Pruyser are right to say that touch is important when responding to people in crisis and that it may be highly appropriate in the context of meeting particular religious needs as part of a thought out response, as well as an instinctive reflex as we reach out to people in pain.

Margaret Lyall (1997, 37)) insightfully suggests

> ...there are some times when spiritual comfort and hope can be mediated through touch as meaningfully as by a prayer at other times. Is it not generally accepted that quietly holding a bereaved person's hand or putting an arm round their shoulder can express care and support while at the same time acknowledging the inadequacy of any words in the face of their tragedy?

Touch can in a very deep and meaningful way to convey care, support and also understanding. It can eloquently state "I am here for you, right now, in this moment... you matter," without a word being spoken.

However touch is not always appropriate, for various reasons, including

- When patients are not comfortable with it.

- When we as a carer are not comfortable with.

- When a HCP uses touch because of their discomfort with the patient's expression of emotion – touch can be one way of stopping people crying, and preventing further disclosure.

- When patient or carer is seeking to manipulate the other. Here power is an issue which has to be recognised and confronted.

Again the issue of self-awareness as well as seeking to be receptive to what is being felt and expressed by the patient is vital. In this respect our spirituality is very closely linked to our sexuality – how we feel about ourselves and our bodies, how we relate

to people of different genders, of different sexual orientations (if known or assumed) and of different age groups. Moreover, how do we feel about touch in non-erotic, caring, patient to professional relationships? It is important to recognise the potential to misuse power in such relationships. Cotter (190, 18) puts it this way

> You are the needy one.
> You are in my power.
> I can refuse to be with you.
> I can reject you within myself.
> Or I can be with you,
> loving you,
> gently touching you.
> You challenge me to a choice.

Learning who we are spiritually and sexually is a life long process, as is recognising how we use and misuse power in our caring relationships. Discovering who we are is a risky business, as is offering spiritual care. Part of that risk is to dare to touch, to dare to make mistakes and learn form them. Margaret Lyall (1997, 38-9) very helpfully sums this up

> Safety for both ourselves and those to whom we are ministering can lie in travelling along the paths we know and feel comfortable with, and there will be those who over many years have developed their own approach to touching. For the less experienced, and those of us who wish to extend and develop our use of touch in pastoral care, we need to give ourselves permission to respond to God's promptings in ways which may be new to us. To always wait to check out our ideas may be to lose opportunities. And if we regard the inevitable mistakes we will sometimes make as learning opportunities rather than as failures, then our confidence will increase and our pastoral care will become increasingly sensitive and appropriate.

4.2.5.2. Spiritual care as referral

Due to personal or professional limitations, or because of gender issues, it may be appropriate for a chaplain to refer a patient to a more suitable other. As has been said spiritual care is a collaborative exercise potentially involving any HCP, members of the patient's family or their friends and appropriate members of their faith community (if they belong to one). Certain religious needs may be more appropriately dealt with by a representative of the individual's or family's own faith community and on certain occasions a patient may wish to speak to someone of a different gender from the HCP who has perceived a spiritual need. Referral should always be done in consultation with the patient or family. As David Lyall (2001, 151) points out referral is not an exact science but '…a pastoral art.' Thus, a chaplain

may have to trust his or her instinct and sensitivity in responding to cues observed and raise the issue of referral with a patient, where appropriate, recognising that he or she will not always get it right.

4.2.5.3. Spiritual care as ritual

Before moving onto the key aspect of spiritual care to be considered (in the next chapter), namely the role of welcoming and funeral rituals following the death of a baby *in-utero,* mention should be briefly given to other significant rituals which chaplains may share in as part of this overview. Rituals involving words and actions, including touch, are important resources with which to respond to the spiritual needs of patients and their families, according to their circumstances and faith tradition. Blessings given by the chaplain, where appropriate, may be highly valued, as a verbal and physical reminder of God's loving presence and care. Sharing communion with or anointing a patient (the Sacrament of the Sick in the Roman Catholic tradition) also may act out the compassionate involvement of Christ in a person's or family's life at a time of distress and anxiety when words are inadequate and difficult to find, and offer comfort and hope.

Chapter 5   Marking short lives

Having painted a background picture as to the development of holistic care following baby death in recent years and explored what, in general terms, spiritual care in an acute hospital setting may involve, I shall now move on to introduce the central issue of this thesis – the role of ritual in meeting the spiritual needs of bereaved parents. In this chapter I will firstly seek to explore what ritual may be in general terms[1]. Then, by reflecting on my practice as a hospital chaplain, I will outline my assumptions of what I consider the role of ritual, and the process of its construction, has in the spiritual care of bereaved parents (prior to hearing from parents themselves of their lived experience and understanding). Furthermore, the particular role of the chaplain in constructing and sharing in rituals with families will be analysed.

5.1. What is ritual?

> The meaning of ritual is deep indeed.
> He who tries to enter it with the kind of perception that distinguishes hard and white, same and different, will drown there.
> The meaning of ritual is great indeed.
> He who ties to enter it with the uncouth and inane theories of the system-makers will perish there.
> The meaning of ritual is lofty indeed.
> He who tries to enter with the violent arrogant ways of those who despise common customs and consider themselves to be above other men will meet his downfall there.

> Xunzi (third century B.C.E.) cited by Bell 1997, before preface)

---

[1] The majority of this chapter was previously published as - Kelly. E. 2002 Marking Life and Death: Co-constructing welcoming and funeral rituals for babies dying in-utero or shortly after birth. *Contact Pastoral Monograph* 12. Edinburgh: Contact Pastoral Trust. (which can be found within the sleeve on the inside back cover of this thesis). Minor amendments have been made to the original monograph to exclude reference to neonatal death and to enable the language used to be more inclusive. The short sections within the monograph entitled Theological Basis for Co-constructing Ritual and Significance of Co-constructing Ritual for Chaplaincy and the Church are not be found in this chapter but are woven onto chapter 10. Furthermore, much of the section entitled Introduction (to Ritual and baby death). has been incorporated into chapter 2.

5.1.1. Introduction

Ritual fulfils deep human need for individuals, families and communities in relation to self, others and (for many) God, especially during times of transition and uncertainty. Involvement in ritual potentially touches the whole of our human personhood – there may be physical action, stimulation of our imagination and feelings, a stirring of our spirit, senses and sexuality as well as intellectual engagement. Thus, ritual is of great interest to sociologists, psychologists and anthropologists as well as to pastoral theologians. Before proceeding to reflect in some depth about the co-constructing of rituals by chaplains and parents around the time of the death of their baby, I will make some general observations about ritual gleaned from the aforementioned disciplines.

5.1.2. A definition of ritual

Rituals are amongst the most basic of human activities and indeed many birds and animals similarly are involved in creating and using patterns of behaviour to communicate without the use of words (Oswald 1999). Paradoxically, as Xuni's poem suggests rituals are also highly complex phenomena which contain and are associated with a myriad of meanings and any succinct definition or understanding of ritual will be limited. However, the definition outlined by Anderson and Foley (1998, 26) is a helpful starting point

> Ritual for us is certainly ordered, patterned and shared behaviour, but, more than that, it is an imaginative and interpretative act through which we express and create meaning in our lives.

Ritual, therefore, may be a corporate public act which takes place within the context of the worship of a community of faith but ritual is also inherent to the structure of our daily lives and the way we relate to others, for example, the ritual of a family evening meal around a table where the day's events are discussed. Driver (1991) argues that ritual does not evolve out of religion, as often has been traditionally thought, but out of human existence and development. Ritual is a fundamental part of humanity's response to social, political and communal life. Hospitals are places where ritual is part of the daily routine. Strange (1996), for example, examined the ritual of handover in nursing practice (which happens in every ward and unit two or three times a day) in terms of its function and meaning for its participants. Strange

concluded that the handover ritual helped to provide a framework for social contact, psychological support and valuing what is integral to nursing knowledge and practice. During a time of handover nurses are able to share their patients' stories and their care of those patients, and their colleagues are involved in interpreting what has been happening on the ward, to individual patients and the atmosphere on the ward as a whole, before they begin their shift. Handovers importantly involve story-telling, verbally and non-verbally but, moreover, they are also essential concrete tools which enable the collegial and professional nature of nursing to be developed and sustained.

5.1.3. Ritual-like activity, ritualization and ritual

> The most clear cut examples of ritual, those depicting various genres of ritual, tend to be a matter of communal ceremonies closely connected to formally institutionalised religious or clearly invoked divine beings.

As Catherine Bell (1997, 164), a sociologist, points out there are a certain groups of clearly defined patterns of human behaviour which society identifies readily as ritual. These we could think of at one end of a continuum of ritual and ritual-like activity. At the other end might be those repetitive routine tasks which help to give shape and meaning to our daily existence, for example, my routine of washing and shaving before having breakfast in the morning. The question is when does a ritual-like activity actually become a ritual? For Bell (1997, 166) ritualization is '...the simple imperative to do something in such a way that the doing itself gives the acts a special or privileged status.' The style or manner of doing creates a type of framework around the act that communicates the message – 'this has extra significance' (Bell 1997, 166).

Driver (1991) emphasises that ritual is performance and that it is not just what is said and done during ritual that is important but how it is said and done. However, not every performance is ritual – a television actor in a soap opera making a cup of tea is not ritual, but in Japan being made and served tea in a certain manner may be seen and experienced as such. Nerburn (cited by Oswald 1999, 41) helpfully suggests '...ritual is routine infused with mindfulness. It is habit made holy.' Ritualization is the creative process by which humans make their repetitive activity into ritual. Driver (1991, 30-1) puts it this way

> Without its ritualising (new-making) component, ritual would be entirely repetitious and static. Without aiming at the condition of ritual, ritualization would lack purpose and avoid form; it would fall back into that realm of informal, non-communicative behaviour from which it arose…..Ritualization is a way, an experimental way, of going from the inchoate to the expressive, from the purely pragmatic to the communicative.

This has great significance for what I term 'the ritual process' following a baby's death which will be explored later in this chapter. Various tasks may be performed by the baby's parents or hospital staff which in other circumstances may not be considered to be rituals but because they are carried out with love and care and are invested with meaning and significance in this context they only be thought of as such, for example, parents washing and dressing their baby after his or her death.

5.1.4. Role of ritual

The role of ritual is multi-factorial but some central themes emerge in the reflections of those with an interest in ritual from different academic disciplines. Anthropologist and theologian Gerald Arbuckle (1990, 97) importantly suggests that ritual is necessary where there is '…possible or real tension in social relationships…' He then goes on to say

> Not surprisingly, therefore, all cultures have rituals surrounding the dramatic even fear-creating, experiences of birth, marriage and death. On these occasions, not just individuals are involved, but whole social groups are affected, so tension/conflict must be resolved or hidden to avoid disruption of social relationships….Ritual, therefore, aims to express solidarity or oneness despite tensions in relationships. Hence, in ritual, the aim is to express unity while, at the same time, being aware that the tensions of daily life always threaten that unity.

Thus, ritual helps to order our lives, including our worship, and especially brings order and familiarity in times of chaos and uncertainty. As Ramshaw (1987, 23), who has an interest in the relationship between ritual and pastoral care, puts it –'All ritualization…is about the ordering of experience.'

The solidarity or oneness described by Arbuckle also alludes to the heightening of community bonding. The effect of ritual on community relationships is central to the work of the British anthropologist Victor Turner (1969). He coined the term 'communitas' to describe the deepening of relationships which can occur during involvement in rituals. Driver (1991, 164) teases out the meaning of this term

> Rituals are inherently communal, while at the same time being imaginative and playful, even when most serious. They become bearers of communitas, which is a spirit of unity and mutual belonging that is frequently experienced in rituals of high energy....

Ramshaw (1987) in her seminal work *Ritual and Pastoral Care* argues ritual in a pastoral context has several functions including the facilitation of the expression of ambiguous feelings at times of transition and providing a framework for the possibility of encountering the mystery and otherness in life and death.

Ritual, therefore, is not just about reminding people that there is some structure and order in the world at a time when perhaps there seems to be no meaning or reason in an individual's or family's life due to bereavement or trauma. Ritual is also 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. Grainger (1988, 37-8) helpfully compares religious ritual with art

> The nature of art is not to inform but to question ....art asks questions about the meaning of life itself....One could say that art asks questions about the relationship between experience and aspiration, the world as everyday reality and ideal truth. This stands out very clearly in religious ritual, in which men and women reach out to a presence beyond themselves, but do it as themselves, in terms of their own humanity, without pretending. The struggle to give form to chaos, whether subjective or objective, a truthful shape to what was meaningless, is a continual one.

Anderson and Foley (1998) describe the paradoxical nature of ritual activity in terms of the mythical and the parabolic elements that are part of every narrative and ritual. Myth is to do with our aspirations for well-being and the reconciliation of opposites or conflicting thoughts and feelings, whereas the parabolic is related to that which contradicts or confronts our values, beliefs or worldview. Our life stories contain both myth and parable and, thus, for a ritual to be relevant and authentic it must also incorporate both.

Rituals are vitally important in marking major life transitions. Bridges (1991) helpfully differentiates between change and transition. Change is something that happens to us i.e. is external, and transition describes the internal psychological process which takes place within an individual as he or she tries to deal with change. Traditionally major life transitions have been known as 'rites of passage' – a phrase developed by the French anthropologist Arnold van Gennep (1908). Driver (1991,

93), however, appropriately suggests that 'Rites of passage are performed not simply to *mark* transitions but to *effect* them'.

Hence creating and acting out a ritual is a way of attempting to aid transition during times of significant change, as well as to acknowledge it. This leads Driver (1991) to conclude that rituals are potentially transformative. A funeral for a baby may aid the natural grief process (this topic will dealt will at length later in the chapter) but as Speck (1997, 106) suggests – 'If the funeral is to be effective, as a rite of passage, in facilitating the grief of the bereaved then those present must be actively involved.'

Not only that, they must be involved in all the three phases, which Van Gennep proposed, make up a rite of passage. The three phases of such a ritual are as follows (we will use the example of a baby's death and funeral in order to show what may be involved in each phase)

Preliminal (separating) phase

In this phase symbolic behaviour signifying detachment from cultural and social norms takes place. In this case declaring the death of the baby and marking the death by, for example, seeing the baby and registering his or her death.

Liminal (transition) phase

In this second phase parents are in an ambiguous state. Turner's (1969, 95) description of this period sums up their situation – they '…are neither here nor there; they are betwixt and between …' This phase may last for many months after the funeral, marked by confusion and difficulty in living life with any sense of normality. It is a transition period for the deceased baby also – marked by concern where he or she has gone. This phase is symbolised in the Christian tradition by Holy Saturday [a subject explored thoroughly by Lewis (2001)].

Post-liminal (reaggregating) phase

In this final phase the rite of passage is now seen to have ended and the bereaved are now able to function appropriately in their different roles in life. As Turner (1969, 95) puts it – they are '…expected to behave in accordance with certain customary norms.' Certain activities associated with the funeral may aid '…the re-entry into the community of those who have been branded or stigmatised by death.' (Speck 1997,

107) For example, a small gathering of family and friends after the funeral may offer an opportunity to show support and share stories and experiences.

While ritual can do nothing to alter the circumstances which have enforced painful transition to be lived through, a rite of passage can be a 'gateway' to aid transition.

As Grainger (1988, 7) helpfully states - 'The rite is the entrance to a new kind of life, a transformed kind of person, a new order of being.' Moreover, rituals, as well as aiding social discourse (see also **3.1.3.**) have a role in enabling the deceased to continue to play a role, albeit a different one, in the lives of the bereaved and the wider community. Walter (1999, 22) puts it this way – 'Certainly some mourning rituals can serve to integrate the dead into society and thus integrate society...'

5.1.5. Ritual leader – priest or shaman

Driver (1991) compares the priestly role of a ritual leader with that of someone having a shamanistic function. He feels a priest is associated with maintaining order and ensuring predictability in ritual and as someone who acts as an interpreter and mediator. A shaman, however, takes on a more creative and spontaneous role – allowing ambiguity and facilitating the instinctive expression of feelings in ritual. Driver asserts people try to make connections through a priest but a shaman tries to create an atmosphere in which people can make such connections or glimpse something other. It is arguable, as Driver proposes, that there is a need for a ritual leader to be both priest and shaman in the creation and facilitation of ritual, especially in the co-creation and facilitation of ritual with parents for their dead babies. There needs to be order, someone managing the ritual but also room for creativity, spontaneity, expression of ambivalent feelings and movement.

Much has been written about the role of ritual in pastoral care within the Christian faith community. However, in this post-modern era many pastoral carers find themselves faced with creating and facilitating appropriate rituals with and for people who do not share the same metanarrative as they do. The rest of this chapter seeks to wrestle with this issue, based on my experience working within in the context of healthcare, where chaplains endeavour to provide relevant spiritual care, including the co-creation and sharing of rituals with and for bereaved parents who wish chaplaincy support, whatever their faith perspective or worldview. The role of the

chaplain in co-creating ritual with bereaved parents and performing ritual tasks will thus also be explored.

5.2. Ritual and baby death

5.2.1. Introduction

Parents who request the services of a chaplain to enable them to share in a welcoming or a funeral ritual for their baby, whether they have religious beliefs or not, may be separated into two groups; firstly, there are those who due to the acute nature of events are not able or for their own reasons choose not to enter into any dialogue with a chaplain. Hence, the chaplain does not have the opportunity to develop a relationship with them within which their specific needs may be ascertained. A response is made utilising appropriate resources from the chaplain's tradition, past experience and gut. However, a second group of parents are able, and indeed often find it therapeutic, to enter into a relationship with a chaplain in which an appropriate welcoming or funeral ritual can be co-constructed. This latter group of parents will be represented in the following two case studies. These are people from whom chaplains, and the church, can learn much.

5.2.2. Case study 1: co-construction of ritual with parents who share the same metanarrative as the chaplain

John and Hazel are a couple who regularly attend their local church. They have two young children who were both baptised and go to Sunday School and the church crèche respectively. Hazel was expecting their third child and had been admitted to hospital after learning their baby had died *in-utero* at thirty-six weeks of gestation, to have her labour induced. Hazel and John at this stage asked to see the hospital chaplain as their own minister was on holiday.

John and Hazel were both very distressed when we met. They shared the story of their pregnancy, their shock and utter desolation and their fears about Hazel giving birth to a dead baby. For Hazel it felt so unfair to have come so close to delivering a healthy baby – only the day before she had felt her baby move. She felt cheated and angry. She also felt she had let her baby and her husband down.

In the midst of our conversation Hazel asked me -"What can we do for our baby? What can you do? Can you christen the baby? Our other children are christened. Is that what you do in this sort of circumstance?"

Together we explored what their needs were - for themselves and for their baby.

What became clear as we talked was that Hazel and John wanted to affirm in some way the special significance of their baby. How important their baby was – unique and precious to them and to God – and that she or he had made his or her mark on their family and on the world.

Hazel herself put it this way – "We want to welcome the little one into our family and God's family. That doesn't sound daft does it? Can you do that?"

I replied that was exactly what we would do and began to suggest some sort of order for a short welcoming ritual. Firstly, that together we might name their baby if they wanted, as a person's name was integral to their individuality, their uniqueness. Then, say a blessing, perhaps the blessing that was said in church when their other two children were baptised. At this point Hazel nodded vigorously and said "Yes…the Lord bless you and keep you." I suggested I could read a short passage from the bible and then say a prayer about how they felt about their baby and their family, about the situation they were struggling to make sense of and to ask for strength and help.

I asked how that felt for them. They both agreed with each other that it felt right and Hazel explained that she'd used the word 'Christening' because she couldn't find any other way of describing what she intuitively felt she needed for her baby. We then talked a little more about them choosing a biblical passage and what might be said in the prayer. John, who had been quiet through most of our encounter finished the conversation by indicating that in their helplessness and confusion, it was good to know that, as parents, there was something appropriate that they could do for their baby when he or she was born.

John and Hazel also wanted to know what happened to their baby after he or she was delivered and if having a funeral was the right thing to do. I talked briefly about them having as much time and space with their baby as they needed and that, from experience, parents did find it helpful to have a funeral for their stillborn baby,

especially in retrospect. I mentioned that there were various options available to them regarding funeral arrangements and that hospital and community healthcare staff, including the chaplaincy team and their own minister, would be able to offer support and give them the information they needed to make the right choices for their family. I then suggested that there would be plenty of time to consider these options once the baby was born and reassured them that nobody was going to pressurise or rush them into making decisions.

Next day I got a call from labour ward. Hazel had delivered her baby – a boy named Callum. When I arrived both parents were very tearful and found it hard to express how they felt. As I sat with them for a while, Hazel talked more of how unfair it was to lose such a wanted baby and asked why God allows such things to happen. She felt cheated and that nothing made sense right now. However, she also was keen to "…do what we had talked about yesterday for Callum." I checked out if they wanted other members of their family present during their welcoming ritual for their baby and if they wanted anything in particular read. They didn't.

Hazel and John sat on the bed holding their baby between them. June, their midwife, sat behind them. She had brought a posy of flowers for the family into the room and placed them on the bedside cabinet. June had said to me earlier that she wasn't very religious but asked John and Hazel if she could stay. They were very glad she was there. I started by saying ….

"In your hurt, confusion and grief following the death and birth of your baby, Callum, is a deep need within you to mark his unique presence in your lives, to welcome your little one into your family and into God's family in heaven and on earth."

Together we named little Callum and I laid a hand on his head and blessed him in the name of the Trinity. Then Hazel, John and I said the Aaronic Blesssing together.

I said we were all there at that moment because of love – especially because of their love as parents for Callum, their love for each other and God's love for Callum and his family. I then read from 1Cor 13 verses 7, 8a and 13 which Hazel also spontaneously joined in with. After a short silence, I read

> Listen to our prayer, O God,
> and hear our cry for help.

When we are in trouble and don't understand
Don't turn away from us.

An adapted version of Psalm 102: 1-2 (Good News Bible)

I then finished the short welcoming ritual with a prayer which acknowledged Hazel and John's feelings (their hurt, confusion, anger, shock and sense of failure), their questions of God and their struggle to make sense of their loss. I also stated they had done their best for their baby and that Callum was safe and at peace in God's care, and gave thanks for the wonder and beauty of Callum. I asked for strength and help for Hazel and John to keep listening and supporting each other and for Sarah and Kerr, their other children, and the rest of family. The prayer ended by asking that June and her colleagues would also continue to find the resources they needed to do their jobs with the humanity and compassion that they share.

Before I left I gave them a Blessing Certificate with Callum's name on it for them to keep and to serve as a marker for memories in the years to come. Callum was buried a week later in a part of a local cemetery specifically set aside for babies during a short funeral service, conducted by John and Hazel's parish minister.

5.2.3. Case study 2: co-construction of ritual with parents who do not share the same metanarrative as the chaplain.

In this case study the baby's parents had chosen not to be present at their baby's cremation but had approached our chaplaincy team a month later seeking to mark their baby's life and death in some way.

Janice and Michael are representative of many couples in our postmodern era. Their beliefs and worldviews were not formulated from one particular metanarrative but from an eclectic range of sources. In the course of our discussion they indicated, for example, that neither of them had been brought up in families which had any church connection but through friendship with a Muslim family in their street they expressed admiration for theistic religions where family life was a central component. It was clear that Michael's scientific training had nurtured the empirical tendencies within him. Janice loved working in her small garden which made her feel connected to the earth. She also had a regard for the sacredness and tranquillity of city centre churches and cathedrals in which she sought peace and quiet on occasions, and an active

interest in yoga. Janice described herself as agnostic and Michael didn't assign himself any particular label.

Janice miscarried her baby, in hospital, at eighteen weeks gestation. Lily was a much wanted first baby. After delivery, Janice and Michael had both seen their baby but had chosen at this stage not to have a funeral. During our initial conversation it became apparent that, like John and Hazel, they had a real need to mark, with someone else present, the significance and reality of their baby in their lives. Over the course of the weeks following Lily's birth it had become apparent to both Janice and Michael that Janice's late miscarriage wasn't, for them, the end of a pregnancy but was in fact the death of their baby.

Janice and Michael talked not just about their pain and sadness relating to their loss in the here and now but also about the loss of their hopes and dreams for the future. They wrestled with their feelings of injustice and being cheated as well as trying to fathom why this should have happened to them and to Lily. Out of our conversation developed the concept of a short and simple but dignified ceremony to acknowledge Lily's short life and death. "To underline she really was here, and how much she was loved and still is," as Michael put it.

We talked together about the possible content of the ritual, not just about what could be said but about the use of symbols and gestures (such as lighting a candle and the involvement of specially chosen flowers), music and silence. We also discussed where the short ritual might take place and who might be present. Both Michael and Janice very clearly stated that though they were not religious and didn't want a religious service, they wanted a chaplain to be there and "say something". Michael also wanted to say a few words about his daughter. During our first encounter I tentatively suggested a short order or framework for the shared ritual and suggested that my contribution would reflect something of what they had shared with me that afternoon. It was agreed they would get back in touch with me in a few days to finalise arrangements.

I met with them again later that week, two days before the funeral for Lily, to bring the different elements of the ritual together. Whilst looking for and accepting guidance, Michael and Janice had obviously talked through themselves what felt

right for them and for Lily, since we last met. The hospital chapel was chosen by the couple as a suitable place to hold the funeral.

The service took place with only the three of us present, as follows

A candle (given to the couple from the hospital chaplaincy to keep) was lit and a vase of lilies, some open and some closed, was placed on the communion table.

I spoke briefly – stating that today was a difficult but important day for them as they were here to mark the life and death of their much loved daughter - a daughter who was unique, precious and very special to them both. I acknowledged their grief, their questions and searching for a reason, their dashed hopes and dreams and verbalised some of the thoughts and feelings which they had shared with me. I used a phrase of Janice's – their baby was "...like a Lily which had not yet opened – inherently beautiful but she had not had the chance to open up and bloom," which summed up metaphorically how she felt about Lily. I also talked about the excitement, anticipation and joy that Lily had brought into their lives while they were pregnant as a couple. Moreover, I said that though these feelings were not the same as having Lily alive, they could not be taken from them. Lily's life was short but very significant – she would never be forgotten. Michael and Janice had both said that Lily's death had enabled them to talk a lot as a couple, not just about their present grief but about allsorts of issues, and to bring them closer together. I, therefore, ended by saying that nothing could take their hurt and pain away following Lily's death but that through this experience their love and understanding of each other had deepened. I then read these few words from Paul's first letter to the church at Corinth (mentioning these were words written in ancient times but seemed applicable for today)

> There is nothing that love cannot face; there is no limit to its faith, its hope, its endurance. Love will never come to an end.
>
> 1 Corinthians 13: 7 and 8a.

Silence

Michael then read a poem which he had written for the occasion. It talked of the paradox that was having then losing Lily – pure, untainted by life, much loved, bringing joy yet also it was ironic, but apt, that lilies were associated with funerals, death and pain.

Finally a piece of classical music, chosen by Janice and Michael, was played. I left them to listen to the music alone, as arranged, and to cry together. They then took a lily each from the vase on the communion table and went into the hospital grounds where they threw the petals of the two lilies into the wind. The rest of the lilies, at their request, were left on the communion table.

5.2.4. Principles of co-constructing welcoming and funeral rituals

Several key issues relating to the co-creation of rituals around the time of death of a baby are important to reflect on prior to and following practice.

5.2.4.1. Understanding the role of welcoming and funeral rituals

It is important to consider that welcoming and funeral rituals do not take place in a vacuum. They are part of an ongoing process which confronts a family with the reality of the life and death of a baby which begins with a positive pregnancy test and potentially may be ongoing throughout a bereaved parent's lifetime. This process may include

- seeing baby for first time on ultrasound scan and having copy of scan photograph

- feeling/seeing baby move in mother's womb

- seeing baby at or after birth

- holding and examining baby

- washing and dressing baby

- naming baby – usually informally by family, sometimes more formally by a chaplain or other spiritual carer during baptism, blessing or naming ritual

- mementos taken – photographs, hand and footprints, lock of baby's hair

- registering stillbirth or baby's birth and death (if more than 24 weeks gestation)

- birth/death announcement in newspaper

- funeral - which has associated ritual-like activities which are part of the 'whole' funeral process or ritual - choosing clothes for the baby and things to

put in baby's coffin, visiting cemetery(s) in order to choose an appropriate resting place, relating to a funeral director and choosing flowers

- marking grave

- entry into book or garden of remembrance (especially if baby cremated)

- visiting the baby's grave

- returning to see obstetrician – to get post-mortem and/or test results, (performed in order to try to establish a cause of death)

- memorial services

- family rituals such as lighting candles on significant days or anniversaries

Whilst there is no doubt welcoming and funeral rituals for babies dying before or shortly after birth have different nuances and emphases. There are a number of shared roles inherent to both forms of rite. They both provide a framework, a structure for various important functions. These include

The facilitation of the grieving process and opportunities to fulfil certain tasks of grieving described by Worden (1991), as outlined in **3.1.2.** Namely, starting to accept the reality of the baby's life and then death and beginning to experience and live with the pain of that loss. Welcoming and funeral rites act as milestones or markers in a time of transition and major adjustment for what Arbuckle (1990, 97-8) calls the 'tripartite ritual process'– 'separation, liminality and reaggregation'. Both Worden and Arbuckle make the same point - unless the reality of death is confronted and separation from what actually was, as well as what was hoped for, is acknowledged in the ritual process then the chaos and confusion of liminality is prolonged and the gradual reintegration of the family into ordinary living again within their wider family, social and work circles is potentially more difficult.

Kuller and Katz (1994, 227) highlight the important sociological role of welcoming and funeral rituals in facilitating grief following the death of a baby

> When a pregnancy is lost, grieving ensues. The social acceptance of that grieving through ritual assists in the progression and resolution of the grief.

Similarly, ritual helps to clarify changes in social status for bereaved parents – they have not only become parents, and always will be a parent, but they have also been bereaved. As Ramshaw (1987, 41) puts it

> Society may need rites of passage to realign and clarify the interactions between people in different stages and conditions.

In order to construct formal ritual moments which aid the above process it is essential for the ritual to be authentic and grounded in the reality of the desperate pain and confusion felt. Such expression of lament, the search for meaning and reason and a parent's wrestling with God or their own belief system is central to creating an appropriate welcoming or funeral ritual. A chaplain verbalising or summing up a family's feelings not only indicates compassion and empathy but gives permission for these feelings to be owned , felt and expressed; and for questions to continue to be asked and articulated. As Hazel put it –"Why did God allow us to have Callum for only a few months and then take him away?" Both couples in our case studies were searching for a philosophical or theological reason, not just a medical one, to explain the death of their baby. A families' Good Friday desolation has to be recognised and named before the possibility of Easter Monday (during a funeral) can be introduced. We should never assume what peoples' feelings are but when they have told us or shown us then incorporating them personalises the ritual and validates their emotions.

Whether at the heart of a family's story is the Christian tradition or not, the tradition to which the chaplain belongs provides a great resource, as well as a precedent, for providing expression of corporate and individual lament. Middleton and Walsh (1995) argue that the Christian metanarrative is universal – applicable in all times and places to all people – for several reasons but especially because it embraces pain, recognises it and owns it as part of the human and divine story. The Psalms, for example, provide a rich seam of examples of human wrestling with suffering, loss and God. As I read the first two verses of Psalm 102 with Hazel and John their heads were nodding in agreement. They were in trouble, they didn't understand – where was God? Was God listening? The wrestling of Job with the problem of theodicy parallels many a parent's seeking an answer to the injustice of their suffering and their baby's death when those who mistreat their children or themselves seem to, in the bereaved parents' eyes, give birth to healthy babies. Even when, as in the case of

Michael and Janice, where God is not part of the parents' worldview the Christian story provides examples of human and divine responses to suffering and loss which inform the chaplain as he seeks to create an appropriate ritual. Owning and acknowledging pain and hurt, finding no answer to the question "why?" as well as living with such tensions and longing for reason and purpose in the face of untimely death is part of the chaplain's metanarrative as well the parents' story.

Ritual moments provide a defined and limited amount of time and space in which families can express their feelings which is contained within 'safe' boundaries. It is as if people give themselves permission to release their emotions within the boundaries of these formal rituals and, indeed, expect such an outward display of feelings of themselves and others. Janice described how she anticipated that her baby's funeral would be an emotional and draining experience but for her, at that point in time, an important one. Green (1987, 125) helpfully describes part of the role of such ritual moments – 'We have to discover ways of dealing with the depths of ourselves without destroying ourselves.' Ritual provides 'a container without a lid on it' as David Lyall (taken from a conversation with him) put it, within which parents can explore and express the myriad of ambivalent feelings they may have about themselves, their baby and God (amongst other things), that they discover in their depths [Ramshaw (1987) provides a fuller account of the role of ritual in acknowledging ambivalence during times of transition]. Both couples in the case studies shared copious tears together during the rituals performed for their babies. For Janice and Michael it was the first time they had done so together since the death of their baby and they later commented that this was significant to them.

Both formal rituals and more informal ones, such as registering the baby's death or making funeral arrangements, can create some sense of order at a time of chaos and confusion.

Welcoming and funeral rituals for dead or dying babies may help to reaffirm what gives meaning and purpose to a family's story and to acknowledge the importance of their core beliefs and values. John and Hazel were shocked, almost overwhelmed at times, by what had happened to them and their baby. They were bursting with questions and anger, yet for them having their baby named, blessed and welcomed into God's family was essential. There was a need as a family to be part of a ritual

which acted out the metanarrative to which they and their baby belonged. For both couples, the rituals performed for their babies also were moments when their implicit love and commitment to each other and their babies was made explicit.

Formal ritual moments may, therefore, help to bond relationships. They are a forum for shared and felt experience and become part of the lived story of those who are involved. This is certainly true for both couples in our case studies. It wasn't just their communicating and sharing after Lily's death that helped strengthen Michael and Janice's relationship but their involvement in the process of co-constructing and presence at her funeral. Rituals involving other members of the family and members of the community also act to bring people together united in their feelings for the baby and his or her parents. Attending the ritual gives family and friends the opportunity by their presence to convey their support and affirm the significance of the baby.

The ritual moment itself may give meaning in the face of the mysteries of life and death. As Grainger (1988, 21) puts it - '…it is not a matter of what it signifies but what it is. It signifies itself…the medium really is the message'. Carr (1985) suggests families invest rites such as welcoming and funeral rituals with their own meaning. Therefore, the ritual becomes their ritual, and that of their baby, and is incorporated into their family's story with their own interpretation of what took place and what its role and function was.

Welcoming and funeral rituals for babies also provide a framework for encountering transcendence and foci for reflecting on the mysteries of life and death and what may be beyond, for bereaved parents. During the process of co-constructing Lily's funeral Janice described her lengthy reflections on what life was about, what death meant to her, the possibility of a Creator and whether she would meet her baby again and in what form. She felt having to think about the content of a funeral prompted her into trying to verbalise the thoughts and feelings awoken in her following Lily's death.

The rituals described in the case studies took place in very different environments yet both were tangibly sacred. All of us who were present were not just visibly moved and emotionally touched but were part of something more. These ritual moments were moments of grace. Therefore such ritual moments can also be moments of hope – moments when paradoxically something other is glimpsed and moments when

hope can be discovered or expressed. Hope that there is more to life and death than the sheer physical and emotional pain of bereavement. Hope for Hazel and John was that Callum was safe and at peace and that he belonged not just to their family but to God's family on earth and in heaven. They found hope in the belief of resurrection – that they would be reunited one day with their baby. Janice and Michael found hope in the reaffirmation of their relationship through their mutual need to talk and share their feelings with each other following Lily's death. It was important for them that this was stated at their baby's funeral. Lily in a real way had brought hope and strength for the present and the future and in some way her parents found some reason and purpose for her short life and death.

Thanksgiving for the hope, anticipation, excitement and love that unborn children bring into a family as well as thanksgiving for the beauty and wonder of the baby once he or she is born, can be important elements of ritual in this context. While the former may be suited primarily to funerals, parents (like John and Hazel) often in the immediacy of seeing and holding their baby soon after birth do exclaim how beautiful or handsome their baby is (even when the baby is quite malformed). Pride in his son and amazement at Callum's tiny features was written on John's face as well as a deep sadness as he held his son.

The content of, and the ritual itself, not only express the parent's love for and investment in their baby, but funeral and welcoming rites also affirm the uniqueness and significance of their child in their family circle and in the wider world. Their child's short life and death has not just made his or her mark on their family's story but on the story of humanity itself. The baby's existence and death and the pain of his or her loss matters - the parents' grief is valid. Walter (1990, 123), in this case talking about adult funerals, underlines this point well

> Ultimately the funeral is not just performed for the deceased, who is no longer there to care; nor just for the family...nor just for the community, there may be none; nor just for friends, who may not exist. But the death of a human being must be marked. The funeral belongs to humanity.

The chaplain will also believe, like many parents from a theistic background like Hazel and John, that the baby's life and death is highly significant to God too; God has been touched and moved. This belief not only underpins a chaplain's approach to co-constructing and performing such rituals, religious or non-religious, but also his

or her being and way of being with a bereaved family, their baby and other staff involved. Central to a welcoming ritual or Christian funeral for a baby is that the baby has been loved from the beginning (Psalm 139: 13-16a – being known and formed by God in our mother's womb) and always will be loved and known (Isaiah 49: 15-16 – the baby will never be forgotten) by God.

Formal moments within the process of ritual prior to and after the death of a baby include, as has been discussed, the opportunity to acknowledge the expression of feelings. One feeling, amongst many, which is normal and perhaps inevitable when experiencing the death of a loved one, especially a baby, is guilt. Guilt for things done or left undone, real or perceived to be real, which are associated with the death. Acknowledging this feeling as being part of our human response to such trauma within the context of ritual, when it has been shared with the chaplain as he supports the family, can be normalising and helpful in and of itself. Within a religious funeral service prayers for forgiveness can be used. Forgiveness and acceptance are not just conveyed by words but also by attitude and a way of being with people. The approach of the chaplain and how he relates to the parents is not lost on them, especially if for any reason they have terminated their pregnancy. Hence the chaplain's theology, which informs his personhood and practice, is central to how he responds in such situations. Guilt, real or neurotic, and feelings of inadequacy and failure however cannot be magically dissipated by acknowledging them in ritual and may require further exploration with the aid of pastor or counsellor.

Part of the role of ritual moments is also to confront parents, staff and ourselves … 'with a proper sense of our own limitations' (Green 1987, 41). The vast majority of parents have done and are trying to do their very best for their baby in a situation where the human ability to control life events is shown to be limited. Recognition that the best parenting possible has been done in the circumstances, including having a welcoming and/or funeral service, within ritual is important. What has happened is outwith the parents' control. It is not their fault (even when a termination for medical reasons has taken place the decision made has been with best of intentions and the baby's abnormality itself is not the fault of the parents).

Specific points in this process of ritual may enable families to put down cairns or milestones during their and their baby's traumatic journey which may help them to

create and maintain memories. These memories may, in time, help parents to acknowledge and accept the reality of their loss. In this way rituals, religious and non-religious, act as foci around which memories are constructed and retained. Mementoes of rituals, such as the candle used at Lily's funeral and Callum's blessing certificate can stimulate memories when kept and referred to, which provide comfort and hope in the future as well as an aid to storytelling.

5.2.4.2. Specific role of welcoming rituals

The primary role of welcoming rituals following the death of a baby around the time of his or her birth is to formally acknowledge the life and birth of the baby before letting go in a physical sense at a funeral – saying hello before saying goodbye.

Also of significance is that a welcoming ritual in this context is closely associated with the formal naming of a baby and, thus, with the giving of an identity and recognition of the baby's individuality and uniqueness. In the future, mention of the baby's name in the family circle will be reminder of the reality of the baby and memories of him or her.

A welcoming ritual also literally enables a family to formally welcome their baby into their family and when a blessing is performed the baby is also incorporated into God's family on earth and in heaven. This is a formal way of saying the baby belongs and has a home. The blessing performed for Callum was very important for Hazel and John. They had a need to have a minister from their own tradition formally acknowledge Callum's place in their family and in the church, their family's spiritual home. The short ritual that was co-constructed in consultation with Hazel and John attempted to – '…connect the child's short-lived story with the divine narrative.' (Anderson and Foley 1998, 133)

Parents may find it hard to articulate their desire to have their baby blessed around the time of the baby's death, and indeed it will probably be based on gut feeling and parental instinct rather than intellectual reasoning. Their reasons may be about following family tradition, concern about the eternal destiny of their child or the need to do something for their baby in a time of helplessness and loss of control. Underlying their request may be a plethora of spiritual and pastoral needs. In order to

meet these needs chaplains have to respond with sensitivity, open-ness, creativity and above all a listening ear.

In conclusion, the role of welcoming and funeral rituals for babies dying *in-utero* is both paradoxical and ambiguous. On one hand they offer the possibility of shape and structure, of hope and ultimate meaning but on the other hand they offer a framework for the authentic expression of lament, questioning and exploring life and faith issues.

5.2.5. Process of co-constructing ritual

Central to the concept of co-construction of ritual is the premise that ritual evolves out of story. The story of

- the family and their baby,

- the chaplain,

- and the encounter or dialogue between the chaplain and the family - the meeting and engagement of their stories.

The process of co-construction, thus, involves the chaplain being aware of his or her own story and what informs it prior to encountering the family and for the chaplain to be aware of his or her internal feelings and the dynamics of the interaction as the chaplain's story meets with that which is being heard and experienced. The chaplain also has to be aware that the family's telling of their story and the process of co-construction will become part of the ritual process and will be remembered, as the chaplain will, as part of the baby's and family's story. It is not just the formal ritual moment which may be helpful and potentially healing for parents but also the process of co-constructing the ritual itself. Thus, the approach, theology and ultimately the personhood of the chaplain is central to the spiritual care provided and the ritual constructed.

A multiplicity of experiences and facets of life shape both a family's and a chaplain's story and, thus, their response to the death of a baby, their attitude to ritual and how their stories engage. These include

- Life experience - especially previous losses and bereavements

- Family background and upbringing – family response to death in the past, traditions and family folklore. For example, are babies baptised, are family members cremated or buried and what roles do family members traditionally take on depending on their gender and status when dealing with a death?

- Religious beliefs and worldview – do chaplain and family share the same metanarrative? What stories inform the couple's belief system? What is the chaplain's motivation or raison d'etre for being involved? What do all involved feel about an afterlife? What are the images of heaven individuals hold in their heads, if any, and in whose company do they believe the baby is in? What are their images of God, if any?

- Cultural background

In establishing a relationship in which a chaplain hopes vulnerable parents will share of themselves, a chaplain has not only to act with sensitivity but with integrity. A chaplain has to be open about what he or she considers a chaplain's role to be and what his or her agenda is or is not. Thus, a chaplain has to have worked out what he or she feels a chaplain's role is and the boundaries of it prior to meeting with parents. The chaplain has to gently explore what the parent's expectations are (of him or her as a chaplain and of any ritual which they may want) but also make clear his or her own (this may not be possible or appropriate in the immediacy and distress of a labour ward before a welcoming ritual is performed). A chaplain should make it known from the outset whether he or she is or is not prepared to perform a non-religious ritual.

Families may need gentle encouragement, indeed given permission, to explore for themselves as well as with the chaplain what they might want said and done during ritual. Many families will assume that the chaplain has control of the process not them, and indeed be fearful not only of suggesting that they have a say in what happens but even of meeting the chaplain at all.

Ritual is not something to be done to the parent's baby it is a moment to be shared with them and in order for this to happen, their story must first be heard, understood

and incorporated into the ritual itself. Bohler (1987) suggests there are three ways to listen when engaging with a family's story

Firstly, to listen to the whole story, pull together the fragments and reflect back the essence of the story to ensure that what has been thought to be heard was correct and understood. When listening to Hazel and John's story prior to the stillbirth of Callum the key need for them seemed to be that of marking his uniqueness and special place in their family and God's family. It was important to check that out and have it affirmed by his mum, before emphasising it in our planned blessing and naming ritual. Secondly, for the chaplain to identify key metaphors or images from the story and highlight them, in order to show he or she as listener is hearing the story-teller's interpretation or meaning of their own story. A good example of this is Janice's likening of baby Lily to an unopened flower – she had inherent beauty which was not able to open up and bloom. Thirdly, for the listener to interpret the story with suggested images or metaphors which help to uncover the underlying meaning (see also **4.2.4.1.**). These images or metaphors may help parents to unravel or gain new insight into their story in the confusion of their bereavement and may be incorporated into a ritual through the use of words, said or sung, music, symbol or gesture.

Co-constructing ritual involves not just listening and interpreting but also the sharing of information by the chaplain, in order that parents can make informed choices. Chaplains, therefore, before engaging in creating rituals with parents need to be aware of practical issues including – appropriate physical care of the baby and parents, physical limitations of ritual content in the hospital context (for example, lighting of a candle may be a major fire hazard), what local alternatives there are for making funeral arrangements and what local provision there is for apt disposal of the baby's body. If a chaplain does not know the answer to a parent's question it is imperative that he or she is aware of resource people around him who may. An important part of co-constructing ritual is, thus, handing back control to parents, if they want it, to enable them to do the best they can for their baby in a manner that is appropriate to them. John was very relieved to hear, even before his dead baby was born that there was something he and his wife could do for their baby, which felt right for them as a couple, in circumstances which rendered them feeling useless and helpless as parents. In order to enable this to happen chaplains have to be sure of their facts and share information in a sensitive and timely fashion. It was not

appropriate to go into great detail about alternatives for funeral arrangements with John and Hazel in the immediacy of labour being induced and trying to get their heads round their baby's death as well as how we might ritually welcome their baby. At that stage it was sufficient to say that they could have a funeral if they wished, and that from experience, the majority of bereaved parents (whose baby was stillborn) found this important to do so, and support would be available to help them with that.

During the process of co-construction the chaplain is not merely acting as a listener and sharer of information but also utilises various resources as he or she acts as a guide in such unknown and frightening territory (for a fuller account of guiding as a function of pastoral care see Clebsch and Jaekle 1967). These resources include – a chaplain's reflections on previous experiences of supporting and co-constructing ritual, conversations with other HCPs, written material and research, for example, Wretmark's (1993) study on reality confrontation following perinatal death as well the metanarrative and particular tradition to which he or she belongs to. The chaplain may suggest a possible framework for a particular ritual within which to weave the baby's, the family's and other relevant stories as well as making suggestions as to how those narratives are articulated or expressed. Both couples in our case studies found this essential. Living through a totally alien experience, they had no idea how the ritual which they felt was needed could be structured or held together and were relieved to have guidance regarding form as well as content. To this end, especially while co-constructing funerals with parents, chaplains may suggest or offer certain resources which might provide content for the service or help verbalise parents' thoughts and feelings. Chaplains working within the RIE routinely offer parents the opportunity to take home and consider various resources, including an anthology of material containing an eclectic mix of poetry, prose, prayers and hymns from different worldviews collated by Frances Dominica (1997), the director of a children's hospice, with bereaved parents specifically in mind]. It is important that guiding and making sensitive suggestions is only done after the parent's story and their needs have been heard – the ritual begins with and evolves from their story.

It is essential in the process of co-constructing ritual that parents, where possible, have time and space to think, feel and reflect in the absence of the chaplain. In a time of confusion and turmoil parents need time by themselves to mull over and absorb

what has been shared and discussed. There should be no pressure, again where possible, for parents to make decisions regarding welcoming and funeral rituals in a hurry and reassurances made that it is absolutely normal to find it hard to do so. Indeed, parents should be positively encouraged to take their time in thinking through what has been discussed and suggested – for what is done cannot be undone. It is in this time – in their own time and usually at home in a more familiar space - that the content of a funeral service can be considered and possible resources read and reflected on. The aim of the process of co-construction is for parents to be able to look back in the future and feel that they were able to do their best for their baby and themselves; that they were able to formally say hello and goodbye to their baby in a way that was right for them. John and Hazel were able to take time overnight to ensure what initially felt right at a gut level, was in fact what they wanted for Callum and needed for themselves. Janice and Michael took nearly ten days, after an initial phone call of inquiry, and much time, effort and discussion to make final decisions about the short funeral service for Lily.

5.2.6. Content and form of welcoming and funeral rituals

A basic principle in creating appropriate rituals for babies near to or after death is to personalise the ritual – for the ritual essentially belongs to the baby and his or her family. This can done by using the everyday names of the family involved, especially the baby's, and by weaving details of the baby's and family's story into the ritual. During Lily's funeral, Janice and Michael's hopes and dreams for Lily were mentioned and the feeling her expected arrival evoked in them. Had she been a more mature and well-formed baby I would have talked about her movements in her mother's tummy, her parents' pet names for her, what and who she looked like after birth and how her parents felt about seeing her and holding her (if they had). All of this not only helps to personalise the rite but also grounds it in the reality of the family's story – the baby was and is a real part of their narrative. It would not normally be appropriate to describe these elements of the family's story at length during a welcoming ceremony but certainly commenting on the looks of the baby or the pride of his or her parents may feel right, for example, in the prayer said after Callum's blessing we thanked God for '…the wonder and beauty of this handsome wee boy'.

The language used is – '...not the language of the church, but the language of the everyday.' (Nelson 1999, 81) The language, metaphors and images which are incorporated into such rituals have to be relevant, comprehensible and personal. For John and Hazel it was entirely appropriate to use church vocabulary and the gestures and images of our shared tradition in the short service of blessing. When working with parents who do not share the same metanarrative as the chaplain, as with Michael and Janice, this is not so. By using the above model of co-construction of ritual it means that the chaplain is open to discovering new ways of describing or imagining God, heaven and the mysteries of life, death and suffering. Some parents will have developed their own metaphors, symbols, images and language which capture something of the depth, tragedy and otherness of their experience, for example, Janice's metaphor of Lily's inherent yet unfulfilled beauty and potential pictured in an unopened flower.

Careful and creative attention to the use of symbols and gestures within welcoming and funeral rituals is something chaplains should give careful prior thought to whilst at the same time being prepared to let them occur, if they intuitively happen on the part of the parents or the chaplain, in the present moment. Symbolic actions and gestures may represent and articulate something far beyond the bounds of language. John and Hazel together holding their baby between them as he was blessed spoke volumes about what he meant to them both, his place in their family as well as their approach to parenting and their feelings for each other. I also felt it was very important for me to touch Callum as I blessed him – symbolising the intimacy of God's involvement and care for him. Michael and Janice scattering lily petals taken from the funeral service where there were no physical remains, into the wind represented something of their need to let go of Lily into the mystery which follows death. At the beginning of the ritual a candle was lit – a symbol of stillness and peace and of hope. For other parents carrying their baby's coffin into the crematorium or lowering their baby down into his or her grave can be profoundly symbolic of their need to parent and care for their child to the very last.

The most common way parents, relatives and other people are involved in rituals, especially funerals, is the arranging or bringing of flowers. For parents, like Michael and Janice, the choosing and arranging of flowers is a symbolic act of love and care and in their situation the flowers quite literally represented their daughter. June, by

bringing a small posy of flowers into the delivery room where Callum and his parents were, especially for his blessing, was not only an expression of sympathy but a mark of reverence and respect of what was going to happen. June, though not religious, recognised something of importance, something other than usually happened in that delivery room, was going to take place and she in some way wanted to mark it.

In the face of what is an indescribable loss, not only are symbols and gestures important to enable the acknowledgement, articulation and ownership of feelings and relationships, but silence is too. Silence as the chaplain hears the parent's story but silence also as part of the ritual moment. Silence as a mark of respect but silence also as a realisation of the limitation of words. Silence which can be filled by the memories and dreams, hopes and fears, guilt and regrets, wrestling and reasoning of those present. Silence in which people can be, and express themselves, as they are.

Music too can articulate, in a similar way to silence, that which eludes the spoken word during a funeral service. Music chosen specially for the ritual not only personalises the service but grounds it in the family's story and serves as a very powerful reminder of the reality of the funeral and, thus, the baby. The piece of music chosen by Michael and Janice was not only familiar and liked by them both but had been played a lot in the family home during their pregnancy. They felt it appropriate that this piece became, for them, Lily's music.

The words of songs played at the crematorium or graveside also are of great potential significance to parents, as in a very real way the lyrics articulate for parents how they feel about their baby and his or her death. For many young parents in this postmodern age, pop songs have replaced hymns as a means of communicating their feelings, their questions and their beliefs and worldview.

It is not just in the process of co-construction that parents want to be involved. Many, to a greater or lesser degree, want to be actively involved in the welcoming or funeral ritual itself. This may be planned or purely spontaneous, as happened during Callum's welcoming service when his parents not only named him but joined in the blessing and a biblical reading. As well as being involved in symbolic acts and gestures, some parents or older siblings may wish to write something of their own to be read though few, like Michael, wish to speak during the rite. Staff too, or other

members of the family, may read or be involved in various ways – playing music, singing, bringing drawings or stories specially created for their baby brother or sister - or show their love and respect in gestures outlined above (such as bringing flowers or lowering the coffin into the grave). All who are present at such a ritual moment are actively involved – no-one is a passive observer – and are drawn into the story of the baby and his or her family that has evolved and is evolving.

Often parents find the words and insights of others who have known pain and loss to be comforting and helpful. Pieces of prose and poetry already known to parents or offered by the chaplain may often be read during a funeral.

Resources from the chaplain's own metanarrative can help chaplains and parents, though not necessarily sharing that grand narrative, to articulate relevant thoughts and feelings within ritual moments in the face of the mystery of life and death coming together. From personal experience, many parents who would not consider themselves religious in any way before experiencing the death of their baby do however choose readings from the bible, a prayer or the words of hymns to be read at their baby's funeral when given the opportunity to choose material from a variety of sources in their own time and space (it is given by offering an anthology of resources, described above, with the explanation that it contains religious and non-religious material and that they are free to choose anything that they feel is appropriate for them and their baby).

The significance of biblical lament has already been mentioned as being of considerable help in creating authentic rituals in such situations but the chaplain may feel other areas of scripture may be helpful to use not just during Christian rituals. This has to be sensitively done but the bible provides a rich seam of literary material describing the pain and joy of human life and relationships, which have meaning for the believer and non-believer alike. For example, verses about the nature of love, from Paul's first letter to the church at Corinth were read during both Callum's blessing and Lily's funeral.

Liturgies created from within different denominational traditions will also inform the chaplain's story, approach and choice of content of any ritual performed but as Green (1987, 49) puts it '…they (such liturgies) should be used flexibly and imaginatively'. Even when parents do share the same metanarrative as the chaplain and, thus, share

the same language and understanding of familiar symbols and metaphors, chaplains have to attend to the particularity and peculiarity of the uniqueness of each baby, each family and each ritual moment. No two welcoming or funeral rites are the same in content, context or co-construction.

Whatever the eventual content and form of the welcoming or funeral rite during the process of co-construction parents need to be given appropriate information and options so they truly can, within the limitations of the particular context of the ritual and guided by the chaplain, make informed choices.

In summing up how chaplains should approach co-constructing the content and form welcoming and funeral rituals for babies dying near birth these principles suggested by Anderson and Foley (1998, 130) for creating new rituals should be born in mind

> Let the story of the crisis or loss, change or transition, - the whole story - be heard.
> Allow a significant time for non-verbal symbols in this ritualising.
> Resist the compulsion to explain such action.
> Attend to the peculiarity of the moment.
> More is not always better; sometimes less is more.

Therefore, though a ritual moment has many elements to consider beforehand and to reflect on afterwards invariably something which is short and simple with few words and includes meaningful gestures which attend to the moment, is most appropriate.

5.2.7. Context of the ritual

The chaplain also has to be very aware of the emotional and physical context within which ritual moments will take place as they seek to co-construct them. As has been explored, for the ritual to be relevant and authentic the circumstances in which the ritual takes place have to inform its content.

Welcoming rituals will most commonly occur in the immediacy of labour suite or in a room in a post-natal ward. Whilst these venues are by necessity geared primarily for the physical care of babies and their parents, they can and do become sacred spaces during ritual. It is the attitude and approach of those involved, as well as the ritual moment itself which transforms the functional hospital space. More than this, it is also the willingness of those present to be open and attentive to the moment. In the immediacy of the ritual parents and relatives will be distressed and vulnerable, their focus being primarily on their baby. How the chaplain, and other staff, are during the

ritual and how the ritual is performed I suspect will influence how the physical context is perceived and remembered by families rather than the surroundings. June's bringing of flowers into the delivery room as well as her respect for and awe of the moment is an example of this. For those few minutes during which Callum was blessed that ordinary, functional and rather drab delivery room, for parents, chaplain and midwife, became sacred. It was a time and place in which grace was tangibly shared.

Where funeral rituals take place will be greatly informed by family tradition, the beliefs of the couple and their degree of need to have a place to return to associated with their baby. Thus, the decision whether to cremate or bury their baby, and where, has great importance for the immediate and the long-term future of the family's story. It is important that the place where the funeral is held feels appropriate for the parents precisely because they will remember for the rest of their days the context in which this ritual occurs and may or may not choose to visit it in the future. Therefore, this choice needs to be an informed one and chaplains should encourage parents to think about it carefully and, indeed, to visit the proposed place for the funeral if they have not already done so. Michael and Janice, though not Christian, wanted to have Lily's funeral service in a place which was other, peaceful and had associations for them with their baby (she was born in the hospital).

Many parents choose to have their baby buried in a cemetery, or rather in a part of a cemetery specifically designated for babies, in order that their baby can be laid to rest in the company of other babies. This may be something they wish specifically mentioned during the funeral. Those attending a burial in such a place cannot help but be moved by the context in which the ritual is taking place in. Many parents find immense comfort in having a place to return to which is associated with their baby and some spend a great deal of time and effort tending the grave. Thus, they are still able, in some way, to parent their child.

5.2.8. Ritual integrity

I have explored the importance of the need for welcoming and funeral rituals for babies to have an integrity which enables their content and form to be appropriate and relevant to the context in which they take place and to the family's and chaplain's stories. I have also discussed the need for the chaplain to be open and

honest about the faith tradition to which the chaplain belongs as well as being up front about his or her approach to working with parents whose belief system is different.

However, in addition, rituals that are meaningful and have integrity -what Ramshaw (1987, 56) calls 'ritual honesty'; Anderson and Foley (1998, 30) feel 'the public, private and official meanings (of the ritual) converge.' That is the shared meaning of the act as it is carried out, the meaning of the ritual for any individual involved and the original meaning of the act (when it was first performed or shared) are similar. This does not always happen as individuals have different interpretations and perceptions not only of the ritual but of the narrative out of which the need for a rite to take place arose. Moreover, in acute situations, as has been discussed, it is not always possible, nor indeed pastorally appropriate to begin to explore parents understanding of rituals which they request. However, it is important for the chaplain to have considered the private and official meanings of the particular ritual for him or herself prior to being involved, as well as gently exploring the private meanings of the parents and sharing the official meaning of the ritual with them during this process in situations where co-construction is possible. Furthermore, once the ritual has been performed the chaplain may gain much by reflecting on his or her impression of the shared corporate meaning of the ritual moment, as well as what it meant to individuals involved. This not only informs future practice but potentially deepens theological understanding.

5.2.9. Ontological significance of chaplain

To what extent, is what is said and done during a ritual moment important and meaningful to parents or how it is said and done? The sharing of God's love and compassion in traumatic circumstances will to a greater or lesser degree depend not on the ritual itself but how the chaplain is in such circumstances and how he relates to the baby, his or her parents and the staff he or she is working with. The chaplain's ability to be him or herself and allow others to be themselves during the process of co-construction and the ritual itself I am sure has a great bearing on how the ritual moment is experienced and perceived.

At the heart of Jesus' pastoral ministry was his ability to be himself and express how he felt. We are reminded of his humanity and vulnerability as he wept with Mary over the death of her brother Lazarus (John 11: 35).

Chaplains also have to be aware of what they may represent to families and staff as they seek to offer support around the time of death of a baby and, thus, why parents ask them to perform welcoming and funeral rituals. Chaplains may potentially represent many things to parents and, thus, may fulfil many roles in the process of co-construction and performing rituals (this section builds on the discussion in **4.2.1.1.** and specifically explores the particular nuances of the ontological significance of a chaplain providing spiritual care within the context of a maternity unit, informed by reflection on case material involving the co-construction of, and sharing in, ritual marking). Chaplains are certainly perceived as people who are used to and skilled in, or are simply associated with, handling or wrestling with '…the meaning of life itself and its ultimate significance.' (Carr 1985, 14) He then helpfully goes on to say

> The minister's role is thus assigned to him, and is one which on the whole he does not determine and which cannot be aligned to other "experts".

Within the hospital context other HCPs who work with bereaved parents also help shape the chaplain's role with their own expectations and experience of clergy and church. Some of what chaplains may represent to parents and staff may include

a) *Embodying Christ* or at least being a representative of the church or the particular tradition to which the parents belong. This was certainly the case for John and Hazel.

b) Being a *'Person of God'* with the perceived ability to find the right words at the appropriate moment. This was certainly what Michael and Janice saw me as even though we did not share the same metanarrative. This function of the chaplain is not just about being a wordsmith it is about feeling with and understanding, as far as it is possible, the parent's situation and needs. It is about holding pain, experiencing it and then and only then, articulating the shared lament and our human and the heavenly response. Furthermore, people do associate a chaplain or clergyperson's role with ritual. This is part of our perceived priestly function – not only can chaplain's say the right words but are entrusted with being able to do the right thing, the right way. Ramshaw (1987, 57) puts it well

> At times when people need a sense of order or meaning, a handle on ambivalence or an approach to mystery, it may be the ritual authority of the pastor that draws them, even if they do not consciously define their need as having any ritual dimension.

In addition, she also makes the point that simply the presence of a chaplain or 'holy person' may '…"bless" the event with his symbolic presence.' (Ramshaw 1987, 73)

c) Chaplains may be one of very few people including the midwife who delivers the dead baby, who meets the baby and hears the family's story. In this way the chaplain may *represent humanity or wider society* both during the process of co-construction and during the ritual itself (especially if the parents choose not to have others present). It was highly significant for Michael and Janice that someone else shared in their baby's funeral and had heard, and become part of, their story. This not only was a release for them to share their fears, anxieties and hurt with someone else and have these feelings heard and validated, but my presence symbolised society acknowledging the reality of their baby and the significance of their loss.

d) A *reminder of the possibility of transcendence* in the present situation – that there is hope in a time of pain and bereavement and that there may something more, something else after life rather than just death being the end. Most people whether Christian or not, will have difficulty in verbalising what this might be but a chaplain's presence may represent mystery and otherness in the midst of the harsh reality of death.

e) On the other, hand chaplains working within maternity units are associated paradoxically not just with what may be beyond death but with death itself. Chaplains are not just a reminder to parents of the mortality of their baby but are a *reminder* to parents and staff alike *of the fragility and mortality of human life* itself. Therefore, chaplains can be HCPs who are both needed and wanted, but also avoided and shunned.

f) In our postmodern world the chaplain may be seen to *represent an out-dated and irrelevant institution* which has no real significance to some bereaved parents. In fact for some parents the term chaplain may be totally meaningless. They will not know what a chaplain is and does - or has it something to do with a moustached man with a funny walk who appeared in silent films?

5.2.10. Role of chaplain

I would like to suggest that the role of the chaplain while co-constructing ritual with parents has different nuances from the role of the chaplain while actually performing ritual.

As has been explored, the role of the chaplain while helping parents to construct a ritual appropriate for their baby and their story involves the chaplain listening, interpreting, sharing information, guiding and helping families to bring together the important elements of a ritual. The chaplain is empowering people who by circumstances have lost control of events in their lives and enabling them, with guidance, to shape and mould a ritual that evolves out of the their story and its engagement with the chaplain's. The metanarrative which informs the chaplain's story, may or may not be verbalised to any great extent but nevertheless it implicitly informs his or her personhood and practice. It is those who request welcoming and funeral rituals who control (if they feel able) the process and it is the chaplain's role to manage it [see Carr (1985) for a fuller account of clergy managing but not controlling the bereaved). However during the ritual itself the chaplain also takes on other roles, mainly of a theatrical nature. Walter (1990, 225) makes the following comment about the role of the celebrant during a funeral

> At a time of grief, even if people do not want a priest, they do need someone to orchestrate proceedings, to act as master or mistress of ceremonies who can enable those present to regress safely into their emotions and safely out again.

During the ritual the chaplain has a dual role. He or she takes responsibility for stage-managing the practicalities of the welcoming or funeral rite - ensuring the different parts of the ritual come together as one and the different players involved (HCPs or funeral directors and family members) are sure of their roles, their lines (where applicable) and their timing. Michael and Janice very much looked to me to ensure Lily's funeral flowed and Michael took his cue from me when to speak. However, as well as holding the ritual together and directing its content, most commonly the chaplain is also the main performer – acting and articulating on a formalised stage where the divine and the family's story, explicitly or implicitly, meet.

Having set the context within which my research was done I shall now go on, in the second half of this thesis, to outline my methodological approach, set out the significant findings, reflect on them and their implications for future practice.

Part II

Chapter 6 Methodology

At the beginning of the second half of this thesis I wish to outline how I approached gathering, recording and analysing parents' lived experience and what factors informed the decisions I made regarding methodology. This chapter is the story of my particular approach to qualitative research.

6.1. Why qualitative research?

Every research project begins with a question. In this case– what is the significance in bereaved parents' stories, of ritual(s), facilitated by a hospital chaplain, as they adjust to the death of their baby? How should I set about discovering from parents about such lived experience?

In order to hear parental perceptions and to comprehend their needs, beliefs and struggles for sense of meaning, it became quickly apparent that a **qualitative,** not quantitative, approach to research was the most relevant method to use. I was interested in detail and depth, not an overview or an indication of current trends, and in narrative not numbers.

As Lyall (2000, 314) puts it when referring to qualitative research as a methodology which enables access to such information

> It is when individuals are allowed to tell their stories that deep truth is expressed; it is often in the particularity of a personal story that we find an expression of a reality which resonates most authentically and generally.

Using specific tools to measure the feelings of bereaved parents was considered but decided against. What was sought in this study was not a quantitative measure of how parents were feeling following the death of their baby, but an understanding of the significance of ritual in their grieving.

The premise that underpinned my approach to this piece of research was that the bereaved parents were the experts and I was the learner. As O'Connor (2002, 313) says

> Qualitative research is discovery-orientated, requiring the researcher to be curious and open to surprise.

I did not have a developed theory, which I was hoping to verify but was seeking to build on my insights, gleaned as a hospital chaplain, discover new ones and convey to the wider world the lived experience of bereaved parents.

6.1.1. What kind of qualitative research?

The key questions for me as I sought to find an appropriate methodology for this piece of research were:

What particular approach would enable me to hear the depth and richness of parents' stories? However, at the same time as seeking to hold onto the particularity of parental experience, I also felt such information would give insight into what is a shared phenomenon - grieving for a baby. Therefore I sought a methodology which could enable ideas and concepts to be formulated and used sensitively to create some generalisations that could inform future practice.

Which tools could I utilise and develop to facilitate parental story telling and the recording and analysis of such material? Furthermore, which tools would allow me to explore the gathered stories in a rigorous yet creative manner[1] ?

6.2. What informed the particular approach to qualitative research undertaken?

6.2.1. Grounded Theory

Undoubtedly grounded theory has been influential in shaping the methodological approach to my research. Straus and Corbin (1998, 12) helpfully define grounded theory as

> ...theory that was derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis, and eventual theory stand in close relationship to one another... the researcher begins with an area of study and allows the theory to emerge from the data.

The process of theorising involves identifying concepts or themes in the interview material, interpreting their meaning (in relation to the researcher's understanding of what is described) and trying to tease out the relationships between such emergent categories. For Strauss and Corbin (1998, 22) the term theory

---

[1] See O'Connor et al (2001) for a full exploration of criteria for assessing the rigour of qualitative research in the field of spiritual and pastoral care

> '... *denotes a set of well developed categories (eg., themes, concepts) that are systematically inter-related through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing or other phenomenon. The statements of relationship* explain who, what, when, where, why, how and with what consequences an event occurs.[2]

Such a methodology is not purely descriptive i.e. phenomenological. I brought with me to this research project a certain understanding of the experience of bereaved parents based on my work as a hospital chaplain and was aware that this would influence my interpretation of stories shared in interviews and analysis of this material.

Central to this approach to qualitative research is the idea that the researcher is the key tool in both the gathering and analysis of interview material. Bender and Jordan (1994, 76) emphasis this point well

> The instrument used in qualitative research to gather and interpret material is *you*, the researcher. You are the instrument through which the other's experience is engaged, meaning is discovered...

Mander (1994) whose study on *Loss and Bereavement in Childbearing* involved interviewing bereaved parents and McHaffie and Fowlie (1996) who interviewed neo-natal staff about issues relating to withdrawing treatment from neonates, also concur that the researcher's sensitivity and personality are central tools in gathering material. Self-awareness, therefore, is paramount, during the whole research process. This is an issue that I will return to.

The influence of a grounded theory encouraged a systematic and rigorous engagement with the interview material gathered, as well as offering tools for creative and stimulating exploration of themes that were identified, and how they may be inter-linked. Moreover, this approach ensured I had to ask myself searching questions of the interpretations I made from what I considered important issues in parents' stories. I had been steeped in this area of interest – working with bereaved parents, reading relevant material and reflecting with health care colleagues – and required a methodology which would help me to check out assumptions I brought to the research.

---

[2] The italics are the authors.

However, I did not seek to fully embrace grounded theory in its entirety as a methodological approach to my research. On one hand, I was seeking to convey the lived experience of bereaved parents to a wider audience in a rigorous, comprehensible, yet imaginative way, in well developed themes. On the other hand, I was also seeking to enable particular or differing perspectives to be articulated. I had learnt from working with bereaved parents that though there are common issues in dealing with baby loss, grief has more than a variety of subjective nuances. Living with the death of a baby is a messy, distressing business that is full of paradoxes. Therefore, I did not consider it possible, or indeed desirable; to attempt to create a tidy, tightly formulated theory at the end of my research that definitively represented the significance of ritual and involvement of a chaplain to all grieving parents. To attempt to do so would have reduced the validity of my research.

6.2.2. Theological perspectives

The model by which I am seeking to 'do theology' is integral to the way I have tackled this research project and resonates with qualitative research methodology. Seward Hiltner in his book *Preface to Pastoral Theology* (1958) began to develop an approach to theological reflection, which was correlational in nature and proposed that reflecting on pastoral practice should influence our theological perspectives. Such an approach to doing theology has of course been developed over the years by many pastoral theologians, including Elaine Graham, whose application of feminist and liberationist theological perspectives to pastoral theology has been helpfully summed up by Lyall (2001, 43)

> Drawing upon the insights of liberation theology and that aspect which expresses the emerging feminist consciousness, we are offered a model of pastoral care, which emphasises risk, vulnerability, woundedness, context. It is a model, which is inductive, and correlational, in which the lived experience of women (and men) is brought into living encounter with the Christian tradition in ways, which illuminate both.

Such an approach to theological reflection means the risk of entering into the pain of parents' grief and hearing their understanding of what they have experienced and the significance of ritual for them as they live with the death of their baby. Moreover, it also means taking the risk of having my story, including my theological perspectives, touched and changed in a way that may alter the way I engage with the Christian narrative and the manner in which I perceive pastoral and spiritual care should be offered in the future.

Moreover, theologically underpinning any methodological approach to qualitative research

> ...is Buber's I-Thou relationship of mutual respect between the researcher and the research participant(s) which provides an undergirding context for qualitative research in the process of seeking to listen to the lived experience of persons.

> Bender and Jordan (1994, 72-3)

In qualitative research there is a need for genuine interest in and deference to, the story of the other. What is collected is not data but the unique perceptions, observations and feelings of another's lived experience. For Buber, in the meeting of two persons where there is shared depth of understanding and genuine concern for the other, God is glimpsed - whether recognised or not[3]. To be involved in qualitative research, as being involved in offering pastoral or spiritual care, requires taking risks and being attentive to another. It necessitates an attitude of reverence, expectation, and open-ness to change.

6.2.3. Experience in offering spiritual care

An important factor in shaping my methodological approach was my experience of offering spiritual care. The training and experience I had had in active listening and seeking to be attentive to the present moment (what was happening within the other, within me and between us in a caring relationship) helped to inform my methodology.

6.2.3.1. Active Listening

My experience of working with distressed people and trying to create a warm, accepting context in which they could tell their story to someone who sought to understand their feelings as well as their experience, was important. The manner in which I sought to conduct interviews was, therefore, informed by the Rogerian therapeutic triad of unconditional positive regard, empathy and congruence (Rogers 1961). Basic active listening skills were also of importance to the way in which interviews were conducted, as was the key pastoral principle, of seeking to begin where people actually were, and not assuming I knew where they were on their journey of grief.

---

[3] For a fuller account of the work of Buber and its implications for pastoral theology see Pembroke (2002).

The interviews did not primarily set out to be pastoral encounters but an approach to qualitative research which utilised basic counselling skills, has helped to fulfil the study's aim of not just hearing factual information but more importantly parents' feelings and perceptions. I also anticipated, as other qualitative researchers have found, that utilising such a methodological approach may enable some parents to find the telling, or re-telling, of their stories within such a context, therapeutic. Previous research shows that some bereaved parents often do find talking about their experiences helpful (McHaffie, 2001). Birch and Miller (2000, 200) emphasise this point and an associated important ethical issue when they state

> …the qualitative researcher must continually consider the potential implications of inviting individuals to engage in a reflexive project, which may lead to the revisiting of unhappy experiences. Whilst this may result in new understandings being achieved and perceived as positive outcomes for the interviewee, it may also result in the respondent placing the interviewer in a role she/he does not feel fully able to fulfil….

> Social science researchers who set out to explore the intimate sphere must be prepared for encounters being perceived as opportunities for therapeutic engagement. Acknowledging this may occur during an interview and deciding on a plan of action if the need arises is a necessary step for the researcher to take.

Ethical considerations, including that of making appropriate support available to parents who have found re-visiting unhappy memories distressing, will be returned to (see **6.3.8.4.**).

6.2.3.2. Reflexivity

I have suggested the researcher who embarks on a qualitative research project is the principle tool whereby material for the study is both gathered and analysed. This, therefore, requires the researcher to be reflexive

> …to have an ongoing conversation about experience while simultaneously living in the moment.

> (Hertz, 1997, viii)

A qualitative researcher does not just report facts or information but conveys his or her interpretation of the significance of stories shared. Furthermore, the content and depth of the material shared by a participant depends very much on the relationship established with the researcher. Prior to beginning each interview I considered it important to give time to establishing a rapport with bereaved parents. This occurred

not just whilst I sought to obtain informed consent, but invariably parents were keen to discover more about me and did so as we chatted informally over a cup of tea.

Hertz (1997, xi) puts it this way

> Respondents learn who we are in the field as we participate in their lives or as we actively interact with them in shaping their telling of stories about their lives…Respondents react to us as individuals, with ideas of their own, not simply in a role of researcher. In plain talk, they "size us up" in order to situate us. The interaction between their locating us and our own subjective positionality produces a unique account that can only be more fully evaluated by the audience when social scientists acknowledge this relationship and depict it more fully as part of how we know what we know about the social world.

In recognition of this, I sought to find ways to aid reflexivity and make this available to a wider audience (many of these tools also enabled a heightened degree of rigour to be attained). These included

- Writing an account of my motivation to be involved in research in this area and my previous professional experience of childbirth and baby death, as well my experience of ritual and death in my personal life, before beginning the study (see preface).

- The writing of a checklist of issues related to ritual, which I assumed parents might consider important (developed from my experience as a chaplain, conversations with other HCPs and relevant literature) – see appendix 1.

- The keeping of a fieldwork diary to record my thoughts, feelings and insights during interviews.

- Tape recording the interviews and transcribing them as an accurate record.

- Tapes of two pilot interviews were listened to by two separate individuals – one a former hospital chaplain, and the other an experienced qualitative researcher in the field of healthcare. This was done in order to monitor my interviewing technique and to check the themes I felt were emerging. Subsequently, these two pilot interviews and their analysis were included in the main study after consultation with the aforementioned independent reviewers – the richness of the material and the validity of categories identified were deemed appropriate.

What is important to note at this point is that the stories I gathered were not the same stories that any other researcher would have gathered. Collins (1998, 15) helpfully states

> Lives do not consist of data; they consist of stories and stories are negotiated during social interaction.

Such an epistemological approach challenges the positivistic worldview that truth and reality are objective and can be known directly through the perception of our senses. How we understand our experiences and try to make sense of them is in fact a social activity; it is something we do with others.

> Meaning, and, therefore, reality itself in the form of one's worldview, is continually being co-constructed in relationships.

> Cooper-White (2004, 47)

What parents shared with me, the stories we constructed together, depended, in part, on what they knew of me or associated with me as we began the interview - my 'brought' selves [4] - and what roles they perceived me to play during the interview - my 'created' selves (Reinharz, 1997, 4). An awareness of these 'brought' and 'created' selves emerged during the interview process as I made fieldwork notes and continually re-read and reflected on them.

'Brought' selves into interview situation

- Researcher

- Academic – associated with university

- HCP associated with hospital where baby died

- Chaplain

- Representative of God

- Representative of the church

- Colleague of chaplain who worked with parents

- Stranger

- Male

---

[4] These were primarily gleaned by parents from the study information sheets (see appendix 2) sent to parents when inviting them to take part in the study

I experienced a degree of anxiety and discomfort whilst knocking on the door of parents' homes prior to an interview - anticipating how an interaction, which would involve encouraging them to talk about distressing events with a complete stranger, would go. Perhaps, this did give me some insight into how parents felt waiting for me to ring their doorbell.

6.2.4. Feminist Research Methods

Feminist research has also influenced my methodological approach. Firstly, it has heightened my awareness of issues of power and control that invariably will be present in any relationship between interviewer and interviewee. Attempting to note the selves I brought to, and were created in, the interview context also facilitated increased sensitivity. The perception of an interviewer, by an interviewee, as having power and authority within the interview context may be lessened by the development of a rapport and 'mutual trust' (Oakley, 1981, 56) between researcher and participant.

Secondly, the feminist social science perspective that no interviewer is neutral and can be detached from those being interviewed, underlines the point already argued that an interviewer participating in qualitative research becomes a collaborator in facilitating, in the case of this study, bereaved parents to share and interpret their stories. Far from being a disadvantage, as was traditionally thought in objective scientific research, personal involvement is '….the condition under which people come to know each other and admit others into their lives.'(Oakley, 1981, 58)

I will now, in the next section of this chapter, seek to outline how this research project moved from reflection on methodological concepts and philosophies to becoming a practical reality – firstly, by describing how I gathered my interview material and then how I approached analysing it.

6.3. Hearing parents' stories – gathering interview material

It immediately became apparent that this exploratory study should be **retrospective** in nature, as it sought to give voice to the lived experience of bereaved parents. A **prospective** study was disregarded for ethical and practical reasons. Firstly, in the immediacy and confusion of their baby's death, parents would have found it impossible to unravel and articulate their feelings and perceptions. Secondly, a chaplain concurrently acting as a researcher would potentially have interfered with a relationship based on therapeutic intentions.

6.3.1. Who should perform the interviews - chaplain as researcher and research tool?

There were two main reasons why I felt strongly at the outset that I, as someone with chaplaincy experience working in a maternity unit, should interview parents and not assign the task to an independent researcher

1) Other qualitative researchers have discovered interviewees '… are more willing to talk in depth if they conclude you are familiar with and sympathetic to their world.' (Rubin and Rubin 1995, 76). As a hospital chaplain, I was an 'insider' to the world of supporting families dealing with the death of their baby. However I was also an 'outsider' (Bender and Jordan, 1994, 91) because I have never experienced the death of a baby my own family.

2) Due to my professional and personal life experience and training, I felt I would carry with me into each interview, associations and attributes which may enhance the establishment of a rapport with parents and empower them to tell their story. These included active listening skills and as a chaplain I felt that I may be perceived as someone who was used to keeping confidences and relating to people wrestling with issues of suffering, bereavement and death. I was also aware, as a chaplain, former medical student and junior doctor, and as a father and husband, of many issues around childbirth and baby death for parents. I hoped the insights that I brought to the interviews would enable me to connect with what parents shared and be sensitive to nuances and issues which were hinted at rather than fully explained. Thus, encouraging further exploration of what may be initially tentatively flagged up.

I also considered asking a chaplaincy colleague to interview parents – someone else who was an 'insider'. However, due to the nature of my methodology I felt I was the only person who would be wholly in tune with what I was seeking to explore and the tools I was attempting to utilise. If someone else had performed the interviews, even a fellow chaplain, different stories would have been gathered and the research, even if I had performed the analysis, would have belonged to someone else. Furthermore, the aspect of the research process I was looking forward to most, and subsequently have found most fulfilling, was participating in the interviews.

6.3.2. Who should I interview –participants to be included in the study?

At the time of working through these methodological questions I was working as part of a team of chaplains within a large acute teaching hospital, which included a

regional maternity unit. I ruled out interviewing parents with whom I had worked for the following reasons

1) Prior to interviewing parents I would have fulfilled the role of chaplain, not researcher, in my relationship with parents. This would have been confusing to both parents and myself – to attempt to change our relationship from being one in which responding to parental spiritual needs was my aim, to being primarily research orientated. Whilst I realised the interviews may have a therapeutic effect for some parents, the goal of the interviews was to gather stories for research purposes, not to provide spiritual care.

2) Parents may have told me only what they thought I wanted to hear and been less than honest with their feelings about chaplaincy support because of my direct involvement. Britten (1996, 31) underlines this point with respect to doctors intending to interview their patients for research purposes

> An interviewee who is already a patient or is likely to become one may wish to please the doctor by giving the responses he or she thinks the doctor wants.

3) Due to previous involvement with a family, prior to interview, I inevitably would have developed particular assumptions about them and how they understood or experienced ritual. This would have made it very difficult to actually begin where they were during an interview and listen to their story, rather than referring internally to what I thought I had observed whilst sharing ritual.

Therefore, after deciding I was going to perform the interviews and that I was not going to interview parents I had previously worked with, I had to decide on a group of chaplains to approach who might agree to me inviting parents, whom they had supported, to critically reflect on their experience of rituals. I had three options

I.   To interview parents cared for by my chaplaincy colleagues in SMMP.

II. To interview parents cared for by chaplains based in another, or other, maternity units in Scotland.

III. A combination of I and II.

Realistically limitations of time, resources and energy made alternatives II and III difficult. Therefore, I discussed the first proposal with my colleagues in SMMP. As a team we had similar theological outlooks and had shared ownership of our chaplaincy team's mission statement (see appendix 3), and had always endeavoured

to be open and honest in our sharing and support of one another. We considered together the dynamic of me, their colleague, being involved in potentially critiquing their support of bereaved parents - what that might feel like and the effects that may have on our working relationships. After an opportunity for individual reflection and further discussion my colleagues were in firm agreement with the proposal (a similar discussion took place with my replacement after I left the team and he was like-minded to permit me to interview parents he had worked with).

6.3.3. Sample size

I initially proposed to interview the parent(s) of twenty babies who died (twins or triplets counted as one subject for the purposes of the study) *in-utero*, from the beginning of the second trimester of pregnancy, or in the first month of life. The number of subject families chosen for this study was based on the premise that the quality of the material gathered would depend on 'depth of involvement' (Bender and Jordan 1994, 77). Hence, a small number of parents were to be interviewed and given ample time to share their experiences, but a large enough sample to be representative of a range of demographic variables.[5] Parents were sought -

- from a range of socio-economic backgrounds

- from a range of belief systems and worldviews

- in different forms of relationships

- who experienced baby death at various stages of pregnancy

- who for medical reasons had terminated their pregnancy as well as parents whose baby had died of natural causes.

However, during the study the sample size was reduced to fifteen interviews. This was for two reasons

1) Data saturation

Strauss and Corbin (1998, 136) describe saturation as

> ...a matter of reaching the point in the research where collecting additional data seems counterproductive; the "new" that is uncovered does not add that much more to the explanation at this time.

---

[5] The full demographic details of parents participating in the study can be found in appendix 4a.

It became apparent that I had reached the point where no new significant themes were emerging during interview.

2) Reduction in number of potential recruits

The number of potential recruits gradually reduced during the period of the study. This was not due to a significantly reduced number of baby deaths *in-utero* but due to fewer parents receiving chaplaincy support. The chaplaincy team attributed this, in the main, to a change in the method of provision of midwifery support during the research project. Community midwives, based in the mother's home area, had become the primary care-providers for mothers whilst delivering in labour ward, not midwifery staff permanently based in labour suite. Mothers, therefore, got continuity of care but this meant that many midwives did not have an existing relationship with chaplaincy staff or first-hand knowledge of the support they offered.

Furthermore, the study took place during a time of transition when the RIE was moving in two stages (over a year between the stages) to a new site. The chaplaincy service continued to be based on the old site, three miles from the recently moved maternity unit. This inevitably meant less routine presence of chaplains in the unit, whilst the team had to cover two sites. In addition, there were changes in chaplaincy personnel during the course of the study. In short, the study took place at a time of adjustment to new ways of working for both chaplains and midwives and when many midwives had not previously worked with a hospital chaplain. This would have appeared to influence the number of families requesting or agreeing to chaplaincy support.

These fifteen interviews were carried out within a period of thirteen months between July 2002 and August 2003.

6.3.4. Criteria of study sample

I initially interviewed bereaved parents with whom my two full-time non-denominational colleagues and part-time Roman Catholic colleague worked. Subsequently, parents were also interviewed who had shared in ritual marking of their baby's death with my replacement in the chaplaincy team. All parents, including single mothers as well as those in ongoing relationships, who requested chaplaincy support to help perform a welcoming ritual and/or a funeral, whether religious or non-religious, for their baby from up to four months before the start date

of the study onwards were invited to participate in the study. The only exceptions were the following

- Parents of twins, triplets and quadruplets, where one or more of the babies survived.

- Those parents who were non-English speakers or required an interpreter for any other reason, for example, a profoundly deaf mother who needed to communicate with the aid of a sign language interpreter. The sensitive and potentially emotional nature of the interviews did not lend themselves to an interpreter being easily utilised.

6.3.5. Timing of Interviews

It was initially proposed that parents would be invited to be interviewed between two and four months after their baby's death. This was in order to allow the immediacy of the baby's death to have passed and yet still enable accurate recall of experiences and feelings (McHaffie, 2001). However, this timescale was altered midway through the study to interviewing parents between three and six months after their baby's death. This was because some parents were not replying initially when invited to take part six to eight weeks after their baby's death but did reply positively to a follow-up letter four weeks later (even in the early stages of the study no-one was interviewed before three months after their baby's death). Some parents made it clear that, two months after their baby's death, they were still too emotionally fragile to be interviewed. One couple waited till after baby's due date – four months after her death - to be interviewed.

6.3.6. Mode of interview

Semi-structured interviews were utilised to facilitate parental story telling. Previous research using semi-structured interviews had shown bereaved parents to be very willing to share their experiences (for example, McHaffie, 2001 and Skene, 1998). An interview guide (see appendix 5 for the initial version) was drawn up, informed by my chaplaincy experience, conversations with fellow HCPs and relevant literature. It was designed in order to encourage parents to share their experience of ritual in depth. The guide evolved slightly as the research process developed, being informed by themes emerging from the initial interviews and to improve clarity of wording (see appendix 6 for the final version). After asking an initial question, I then

sought to respond to cues, probing for details and seeking clarification where appropriate.

6.3.7. Recruitment

It was envisaged that several interviews would take place during four months study leave from chaplaincy work at the beginning of the project (the remainder took place after a subsequent change in job). Therefore, several recruitment options were identified. Consultant neonatologists and obstetricians agreed to hand over a letter of invitation (appendix 7) as well as a study information sheet (appendix 2), to bereaved parents at a postnatal follow-up clinic approximately six weeks following their baby's death. Lothian SANDS and the bereavement counsellor working within SMMP also agreed to do likewise when parents attend for group support or individual counselling. Parents whose postnatal meeting with their consultant had already taken place and had no had contact with SANDS or the bereavement counsellor were sent a letter of invitation. The letter of invitation had an attached reply slip (appendix 8) to enable individuals to indicate whether or not they wish to participate in the study. A follow-up letter (appendix 9) was sent out to non-respondents four weeks after the initial invitation. A detailed list of those sent or given letters, and their response, was kept to avoid duplication.

As the research project got underway it was not always possible to recruit parents through their consultant. This was due to the chaplain supporting the parents, in the immediacy of caring for them, not always noting the mother's consultant (the form devised for recording the details of parents that chaplains worked with - see appendix 10). Gaining this information retrospectively before the post-natal meeting took place was not always possible due to the workload demands on administrative staff. Therefore, a significant number of bereaved parents were approached by postal invitation (for details of recruitment by different modes – see appendix 11).

Only two sets of parents were recruited via SANDS and none via the bereavement counsellor owing to the fact that most parents utilising these services during the period of this study did not tend to do so in the first eight weeks after bereavement.

6.3.8. Ethical Considerations

6.3.8.1. Ethical Approval

Ethical approval had to be obtained from the Lothian Research Ethics Committee before the study could commence. Approval was granted subject to acceptance of an opt-in approach to recruitment (as outlined above). I had initially proposed an opt-out method whereby I would telephone parents a week after they received an invitation to participate, to arrange a suitable time for interview (based on the methodology of Smith [1998] who interviewed parents coping with a childhood cancer and McHaffie [2001] who interviewed bereaved parents about their experiences of treatment withdrawal from their infant).

6.3.8.2. Informed consent

Informed consent (see appendix 12) was obtained prior to each interview and included obtaining permission to inform the parents' general practitioner (see appendix 13) of their involvement in the study.

6.3.8.3. Anonymity

The anonymity of parents has been preserved both in the transcription of tapes and in the writing up of the study findings (parents were happy to agree to anonymised verbatim quotes to be utilised).

6.3.8.4. Support for parents

It was recognised that sensitivity to the well-being of parents during this study was paramount. Prior to starting the interview parents were reminded that they could stop the interview and, indeed, withdraw from the study, at any time, for any reason. If a parent became distressed whilst being interviewed, the tape recorder was switched off and she or he was given as much time as was needed. If necessary, the interview could have been postponed or the parent(s) could have withdrawn from the study – neither of these options was ever taken. Within the study information sheet given to each parent was information about support available (the contact names and telephone numbers for the bereavement counsellor at SMMP and Lothian SANDS) should they wish it, following interview. The availability of such bereavement support was reiterated at the end of each interview.

6.3.8.5. Support for researcher

I was also aware of the potential emotional drain on me while interviewing bereaved parents and arranged for counselling supervision during the period of the study. These confidential sessions as well as being cathartic, also aided reflexivity and reflection on the construction and interpretation of parental stories.

6.3.9. Interviews – practical issues

All interviews took place in the comfort and secure environment of parents' own homes. Parents were given a choice of time and venue (a room in the chaplaincy in the RIE was available). Parents also had the opportunity to be interviewed together or individually. Though I anticipated there may be individual differences between partners about their perceptions and feelings, I felt it was important while investigating such a sensitive topic to enable parents to have the choice of the supportive presence of their partner (or another supportive individual) with them or not. During the study only one parent was interviewed on her own, as her husband did not wish to be present. One interview was planned per couple, or individual parent, who agreed to take part.

6.3.10. Length of time of interviews

Interviews lasted between forty-five minutes and two hours ten minutes, with the average being one hour twenty-five minutes. Significantly up to an hour was spent in parents' homes out with the actual interview. Much of this time was spent building up a rapport with parents prior to interview.

6.4 Observations about the methodology adopted

6.4.1. Possible factors influencing parental story telling.

As has already been discussed, stories are socially constructed, and those that parents shared would be different if another researcher was involved. Furthermore, '… "one off" interviews with individuals provide single-snapshot pictures and may not reflect their feelings on different occasions.' McHaffie (2001, 23) Interviewing parents more than once to note any change in perspective about, or understanding of, ritual would have lessened the 'snapshot' effect but was not possible with limitations of time and resources.

I was also aware of factors, which may have specifically inhibited parents speaking freely to me during interviews. Firstly, parents may have felt inhibited about saying anything negative about my colleagues and they may, to a certain extent, have told me only what they felt I wanted to hear. Secondly, there may have been cultural or personal issues for parents that limited how negative they could be about a chaplain or to a minister. Collins (1998, 2) cites Bourdieu (1997) who feels that during qualitative research

> ...the interviewer is likely to provide the interviewer with the "official account" (what reifies norms, values, ideals)...

In order to counter this to some degree, it was important to state in the information sheet given to parents, and at the start of each interview, that honest and open sharing about chaplaincy support – including its strengths and weaknesses –was sought, in order to improve practice. This emphasised the importance of taking time to establish a rapport with parents at the beginning of each interview in order to convey to parents that I was genuinely interested in their actual experience and not what they might think I wanted to hear.

6.4.2. Parents who had a positive experience of chaplaincy were more likely to participate.

Some parents who participated in the study did have some negative comments about chaplaincy support or suggestions as to how the provision of the service might be improved or made more accessible. However, on the whole parents were very positive about chaplaincy care. It is interesting to note that the most negative comments made were done so not during interview but in writing. However, the mother who offered such feedback in this manner did so because she and husband did '...not feel able to participate in [your] study at this time.' A limitation of the study was that due to a chaplain performing the interviews parents who had had a negative experience of chaplaincy were probably less likely to participate (see also **6.4.1.**).

6.4.3. Motivation of parents to take part in the study?

The methodological approach I adopted was strongly influenced by a desire to reflect on the current practice of hospital chaplains and, thus, to aim to inform future practice. Thus, it is of value to note why parents agreed to participate. Four different motivating factors were identified as follows

- A desire to help other bereaved parents in any way they can (as also noted by Boyle [1997] in her study involving mothers bereaved by stillbirth, neonatal death and Sudden Infant Death Syndrome).

- Chaplaincy has been supportive of them and they wanted, in turn, to help chaplaincy service in a tangible way.

- A need to talk through the experience again with an independent, yet interested individual.

- Significantly a few parents, or someone in their family, had a doctoral degree, or a research job, and wanted to help.

6.4.4. Participation of mature parents in study

The majority of parents agreeing to be interviewed were in their thirties and forties. Indeed, the youngest parent to participate was twenty-five (see appendix 4a). Within the sample invited to participate were a number of parents under this age (though no detailed record of age was kept).

Sammuelsson *et al* (2001) noted that the bereaved fathers who participated in their qualitative study following the stillbirth of their baby were aged between thirty-one and forty-six. This raises several questions

- Does it require a degree of life experience to agree to participate in qualitative research, especially in relation to such a sensitive subject, and to recognise that verbally reviewing a distressing experience may be potentially therapeutic?

- To what extent did issues of perceived power and authority associated with me (as outlined in **6.2.3.**) prevent younger parents from agreeing to participate?

- To what extent is maturity linked with altruism (given that many parents' motivation for participation was to improve support for other parents and as a gesture of appreciation for chaplaincy support)?

- To what extent may younger parents have been influenced by the baby's grandparents to request ritual marking and, thus, be less motivated to participate in the study?

6.4.5. Recruitment

6.4.5.1. Response rate

In total the parents of forty-five babies who died *in-utero* (during or after the second trimester) or in the first month of life were invited to participate in the study. Fourteen couples and one mother, whose babies had died *in-utero*, agreed to be interviewed. In addition, one mother declined to be interviewed but responded to the interview guide by written correspondence. Her reflections have also been analysed and included in the study. Therefore, the response rate to involvement in the study by bereaved parents was 36%.

Stroebe and Stroebe (1987) point out that the response rate for participation in grief research is usually lower than in other areas of investigation. Much depends on the particular methodological approach of each study. Some qualitative studies exploring parental grief following perinatal death, involving semi-structured interviews, do not include their exact response rates in their final report (Skene, 1998 and Wretmark 1993). Wretmark (1993, 91) using an opt-out approach for recruitment, made her first contact with parents via the telephone and found – 'Most parents accepted the call immediately.' Smith (1998) had a response rate of 90% and McHaffie (2001) 73% (see **6.3.8.1**. for details of their studies) – both had utilised an opt-out method. I suspect that my low response rate had much do with the opt-in approach I was asked to take. Other possible contributing factors are reflected upon elsewhere in **6.4.**

6.4.5.2. Lack of recruitment of parents not in stable relationships

All parents recruited were in a secure long-term relationship. Several sets of parents who had different addresses from each other were approached but none were recruited (some parents living at different addresses were known to be young couples staying with their respective parents). Letters of invitation were addressed to both parents in each case but I had no means of knowing whether their relationship was ongoing or not. This may have been a contributory factor to the lack of participation from this group, if the parental relationship was under stress or over. This group of parents may have also have less inclined to speak to a researcher associated with the church and God, for fear of judgement (however, they had agreed to or requested chaplaincy support).

6.4.5.3. Lack of recruitment of parents of babies who died in the first month of life?

Why did the parents of babies who died in the neonatal unit not agree to take part? The majority of letters of invitation for the parents of babies who died in the first month of life were handed over by a neonatologist at a meeting with them, four to six weeks after their baby's death (one family did not attend this follow-up meeting and were sent an invitation through the post).

Was it too distressing to be asked so soon after their baby's death to participate? Yet, several parents whose babies had died *in-utero* were recruited by being given an initial letter of invitation at a post-natal clinic appointment with their obstetrician six to eight weeks later. It is worth noting, however, that some parents who only agreed to take part after receiving a follow-up letter at around three months after their baby's death commented they would have been too upset to respond positively any earlier. Was it more distressing experiencing the death of a baby who had lived, with whom parents had formed different types of relationships than with a baby who died *in-utero*? One set of parents whose baby died at nineteen weeks of gestation felt it was preferable for them that their loss occurred at this point in time rather than at term or early in the neonatal period. However, there were also replies from parents who had experienced early second trimester losses indicating it would be too upsetting for them to participate. Perhaps, this infers that the death of a baby at whatever gestation or age will mean different things to different parents and have different implications for them depending on their unique life story. This is an area where further research is required.

However, a consequence of lack of recruitment from this group of bereaved parents meant that the study became more focused and my research question which was initially -

What is the significance of **welcoming (baptism, blessing or non-religious naming)** and **funeral (religious and non-religious) rituals,** facilitated by hospital chaplains, to parents who are adjusting to the death of their baby *in-utero* (from the second trimester onwards) or in the first month of life?

- was amended to omit the original final clause as well as the word baptism.

6.5. Analysis of interview material

In the last section of this chapter I will seek to outline my approach to the analysis of material gathered from interviewing bereaved parents.

6.5.1. Preparation for analysis

My analysis began before my fieldwork commenced with attempts to deepen my self-awareness (see **6.2.3.**), as I was aware what I brought to the interview material informed my engagement with it, and continued throughout the research process. Dey (1993, 63) helpfully underpins the potential creative use of a researcher's prior experience and knowledge in analysis of interview material

> ... there is a difference between an open mind and an empty head. To analyse data, we need to use accumulated knowledge, not dispense with it. The issue is not whether to use existing knowledge, but how.

My identification of key themes within the interview material and my interpretation of their meaning were indeed informed by such 'accumulated knowledge'.

In order to aid rigorous analysis of parental stories, the interviews performed were tape recorded and then transcribed by a secretary. Prior to listening to the tapes and reading the transcripts, field notes were made following each interview, noting

- any observations about parents' homes (mementoes of their baby on show, for example), the depth of expression of parental feelings, significant non-verbal communication and any relevant material shared when the tape recorder was switched off,

- counterintuitive and key issues raised during each interview, and

- my feelings about the interview and the roles which I felt I performed.

6.5.2. Coding – identifying, gathering and interpreting themes from interview material

My field notes were used as an aid to reflexive analysis (see **6.2.3.**) - to develop an awareness of the 'lens' through which I was interpreting the world of bereaved parents. Moreover, they also helped to shape the themes that I found to be emerging from parental stories as I engaged in an ongoing active engagement and re-engagement (Smith 1998) with the tapes. The transcriptions were also read through several times as a means of both checking the accuracy of transcription and to immerse me in the parental stories. During such reading I began to code the

interview material using the aid of a qualitative computer package QSR NUDIST*Vivo (NVivo).

Coding not only involves selecting or 'noticing relevant phenomena' but also involves 'collecting instances of these phenomena,' and 'analysing the relevant phenomena…by comparing the different pieces of data in order to find commonalities, differences or linkages between them.' (Seidel and Kelle 1995, 56-7).

Out of such a process of reflection and making comparisons (asking if a piece of text is similar or different to other segments and does it warrant inclusion or exclusion from a variety of existing categories), phenomena are labelled in order to categorise them. This is a creative, interpretative process – an art not an exact science (Strauss and Corbin, 1998). As well as utilising my field notes to help inform my categorizing of themes, they were also informed by my background knowledge and life experience. Thus, the set of assumptions I drew up relating to ritual and baby death (appendix 1) were an aid to labelling some phenomena – where my hunches and expectations were confirmed. However, significantly sometimes they were not. Categories also arose from the parental stories themselves. As Boulton and Hammersley (1996, 291) put it

> …the people studied may use concepts that seem particularly significant for understanding their behaviour…look out for 'insider' terms: words and abbreviations that are distinctive to the world that the informant inhabits, and which may appear strange to outsiders.

Such 'insider' terms were used as categories and well as insights I developed when reading and reflecting on the interview material.

Coding, within the context of an interpretative research paradigm is primarily a learning tool, which enables a researcher to reflect on and explore gathered interview material more deeply (Seidel and Kelle, 1995). Coffey and Atkinson (1996, p44) helpfully talk of coding involving '…a series of readings and re-readings of the data, in which the details of the interview and our own emergent concerns interact.'

Initially, in light of the creative and exploratory nature of the analytic process I sought to generate as many categories as possible from three of the first few interviews I performed. This was in order to avoid an over focussed approach early in the process, to be open to unexpected issues and allow my assumptions to be challenged. A framework to aid analysis of the remaining interviews was formed

from the multiplicity of the original categories identified – some categories were grouped together into broader themes, others made into sub-categories, others collapsed or were dropped altogether (Simmonds, 1997). I found it very helpful as I teased out the relationships between categories, and between categories and sub-categories (see also **6.2.1.**), to draw diagrams using pencil and paper to visualise such inter-relating (Barry, 1998).

Sandelowski (1995, p375) makes an important point regarding the hazards of the formation of such a framework

> There is always the danger here that the researcher will let an initial organizing framework prematurely close off recognition of other ways of organizing the data that are truer to them and more illuminating.

Therefore, during the rest of my analysis I was not only open to the formation of new categories and the possibilities of merging these with existing ones, but also to the way I perceived the identified categories to be related. In order to develop such a framework I did not just code with great detail the first three interviews but deliberately selected three interviews early in the research process which contained a spread of demographic variables (see 6.3.3.)

6.5.2. NVivo (a qualitative computer software package) – a tool to aid analysis

NVivo enhanced the rigour of the process of analysing parents' stories in several ways. It enabled

1) Systematic coding of the interview transcripts, storage of multiple categories after initial coding and quick and accurate retrieval of these when further reflection, exploration and re-coding was required.

2) Organisation of categories into a pattern that was representative of the way I felt they were interlinked. Moreover, categories that were counterintuitive, particular or different and did not fit into the initial 'conceptual framework' of categories and related subcategories, could easily be retained separately (Coffey and Atkinson, 1996, 178). Creative reorganisation of this framework at different stages of the research process, utilising NVivo, was straightforward.

3) Linking the coding of part of a parent's story to a memo, in which I described the meaning I perceived to be found in such a piece of text. I also noted the

comparisons I made, and the relationships I was making with other categories or subcategories, in the memo. In short, NVivo enabled me to 'tell the story (often referred to as an audit trail) of how a category "emerged", was developed and explored.' (Bazeley and Richards, 2000, 96) and how it became part of my overall interpretation of what parents felt was significant. Thus, NVivo enables the actual research process to become more transparent – allowing others to follow the researcher's exploratory journey. Corporately, elements of many of these memos formed the basis of the exposition of my research findings.

4) Reduction in both fragmentation of the original text and decontextualistion of coded pieces of a parent's story (Dey, 1995). Fragmentation is reduced by attaching memos to the categorised text explaining a researcher's thinking and also by linking the piece of narrative to its original context. Thus, after reflecting on an identified phenomenon, trying to interpret that part of parental experience and making comparisons, the particular segment of text can be put back into its original context to see if its meaning perceived by the researcher makes sense within the context to which it belongs (a further attempt to reduce decontextualisation of categorised segments of narrative during the research process was an ongoing engagement with my field notes during coding, to ensure I kept in mind observations that I had made immediately after each interview).

Having described how I gathered the narratives of bereaved parents and how I approached analysing what significant perceptions those narratives contained. I will now outline what these emergent themes were in the next chapter.

Chapter 7

Parental reflections on expectations, experience and involvement

7.1. Criteria of inclusion of particular parental issues

In this, and the subsequent chapter, significant findings emerging from the interviews with bereaved parents will be outlined. In this particular chapter parental descriptions of the following elements of their lived experience will be mapped out

- Spiritual issues affecting parental well-being as they grieved.

- Parental expectations of chaplains and the rituals they may perform.

- Significance to parents of how rituals were constructed and the content of the ritual performed.

During the interviews a plethora of rich and fascinating issues were described and it became apparent that not all of this material could be utilised within the bounds of this thesis. Therefore, criteria had to be developed in order to inform which themes would be highlighted and explored in this and subsequent chapters and which would be excluded.

My criteria for including, and then exploring, particular themes which arose from parental story-telling and excluding others are largely formulated from the aims and objectives which were laid down at the outset of this research project (see **1.1.**). These were informed by my experience as a chaplain working in a maternity unit, relevant literature and conversations with colleagues (as were in turn the research questions which were constructed to help me reach these goals). At this point it may be useful to recap on the study's original aims

- To deepen understanding of the experience of parental grief following baby death.

- To hear parental expectations of chaplaincy support and rituals offered by chaplains.

- To develop an understanding of the significance of the content of ritual and the process by which such rituals are constructed with chaplains for parents.

- To elicit a fuller understanding of the role of ritual, shared by chaplains, in meeting bereaved parents' spiritual needs.

- To comprehend the significance for parents of chaplaincy involvement in ritual and providing other aspects of spiritual care.

- To appreciate the importance to parents of the immediate context in which ritual takes place.

Material excluded from this thesis does not relate directly to these aims and will not be further explored. However, in order to give some indication of the breadth of topics raised by parents relating to their experience of baby death a brief resume of the issues will be given here.

7.1.1. Issues relating to parents' experience of their baby's death in-utero which were identified in this study and will not be explored further are

7.1.1.1. Sources of bereavement support (other than chaplains) utilised by parents following the death of their baby

Family members, friends, SANDS (one-to-one and group support), a Christian counselling service, on-line networks for bereaved parents and other HCPs (including the bereavement counsellor working within SMMP, GPs, midwives and obstetricians) were the variety of sources of support which the parents accessed.

7.1.1.2. How parents met their spiritual needs in ways other than co-constructing and participating in rituals for their babies.

Parents found some sense of meaning and purpose in life and hope in their situation through the following –

- **Meaningful relationships** – most often their relationship with their partner or other children.

- **Getting with on with life** – getting through each day as best they could by trying to concentrate on everyday tasks and occurrences.

- **Parental personal development** – many parents found their baby's death stimulated self-reflection, a heightened self-awareness and a reprioritisation of what was important in life. For some, the realisation that they could cope with

personal tragedy was affirming of their personal resources and their relationship with their partner.

- **Personal beliefs and worldviews** – some parents found prayer and church attendance sustaining and others their belief in an afterlife comforting.

- **Comparisons with other situations of grief** - the feeling that others had to live with what they considered more traumatic losses than theirs gave some hope and comfort to a few parents.

7.1.1.3. Issues relating to bereavement support which parents did not find helpful other than issues specifically relating to ritual and chaplaincy support.

Parental expectations of the place of their baby's disposal

Parents' expectations of the cemeteries and crematoria where their baby would be buried or cremated varied. Some of these expectations contributed to parental anxiety prior to their baby's funeral.

Concerns regarding the place of disposal of their baby

Many parents had particular concerns about the appearance of the area in which babies are buried within in the local council cemetery. Many graves have been elaborately marked contrary to council policy.

7.1.2. Key counterintuitive themes emerging from the study and recent literature relevant to the research question and to be included in the thesis.

7.1.2.1. Lack of cultural norms and lack of language to articulate experience.

It became clear from analysing the interview material that to fully convey the lived experience of bereaved parents and the significance of rituals shared by a chaplain for their babies, I had to include within the thesis two significant aspects of the postmodern cultural context in which they were dealing with their loss. These features were

- The lack of cultural norms available to parents to aid their decision making relating to ritual and disposal of their baby's body, and to help gauge the cultural acceptability of choices made whilst dealing with baby death.

- The lack of language with which parents could utilise to articulate their feelings, needs and experience had a significant impact on the how they dealt with their baby's death.

7.1.2.2. Factors influencing parental grieving and approach to ritual

It will also be important to make evident the more particular social and cultural contexts which parents inhabited as they experienced baby death and shared in ritual moments. This will enable a deeper understanding both of parents' perceptions in the immediacy of their baby's death and of the influential attitudes that they absorbed from their family of origin which informed their approach to baby death and ritual.

7.1.2.3. Comparison between parental expectations and the actuality of chaplaincy support.

Parents talked at great length during the interviews of the very marked contrast between their expectations of chaplains and the rituals they may perform and the actuality of the support given, the ritual shared and the approach of the chaplain who worked with them. Whilst an original aim of this research was to hear parental expectations of chaplains, it was not anticipated that such a comparison would feature so vividly in parental story telling and, thus, justify such a significant place in the description and exploration of its findings.

7.1.2.4. Importance for parents of seeing and holding their baby.

In recent research by Hughes *et al* (2002) women who had seen and held their stillborn baby were found to have an increased risk of developing depression and anxiety compared to bereaved women who had not, as well as their next born infant being more likely to show disorganised attachment behaviour. These findings of Hughes and colleagues challenge the prevalent perspective that enabling parents to see and hold their baby aids grieving through reality confrontation and the establishment of concrete memories (see **3.2.2.** for a more detailed discussion). Whilst this study is not specifically centred on the effects of parents seeing and holding their babies, it is about the significance of welcoming rituals for parents which do create opportunities for parents of seeing and holding their baby. Therefore, some exploration of this theme will be made

7.2. Findings

7.2.1. Parental grief - significant spiritual issues affecting parental well-being.

Whilst every parent's experience of their baby's death was unique, each lived through *"...a roller coaster of emotion."* (Father 5)

In parental stories of such turmoil the following common spiritual themes were identified

7.2.1.1. Social isolation

Bereaved parents often felt other family members, friends and acquaintances did not understand what they were experiencing and as a result they felt lonely and isolated.

"It is just us and basically no one has had the experience either. I mean they are grieving for us but not with us in the same sense so you are kind of isolated."

(Mother 1)

Leaving hospital after delivering their baby was a particularly difficult time in this regard for mothers.

"...when you actually leave it is horrible because you feel like you have left everybody behind that knows and understands what you went through." (Mother 7)

The same mother left her work because she felt her grief wasn't acknowledged appropriately when she returned after the death of her baby of 22 weeks gestation.

"I went back to work four weeks later and it was to be brushed under the carpet."

Other parents not only felt their baby's life and death wasn't acknowledged by others but felt ostracised by some members of their local community.

"Some people do not know how to handle it, some people ignore us basically."
(Mother 6)

Parents recognised that the discomfort of others and their difficulty in finding appropriate words to say contributed to their isolation.

"But the hard bit is that people probably do care but they just cannot show it and we just don't know any different." (Father 6)

Fathers too found dealing with the death of their baby a lonely time as their emotional and spiritual needs were seldom addressed by others, in comparison to their partners.

"Everybody asks how the wife is but forgets to ask how the husband is." (Father 9)

7.2.1.2. Loss of meaning and purpose

For many parents the death of their baby meant the loss of their main reason for living in the present.

"I just wanted to give up. It was like there's nothing to go on for...There was nothing, everything we have ever worked for it was just gone... like that. I mean I felt really, really empty..." (Mother 4)

Parents had invested emotionally, spiritually and materially in their baby. Many had moved house, decorated rooms and made a variety of plans especially for his or her arrival. Their dreams about future parenting had been shattered and their plans and sense of purpose for the future had been lost

"What might have been? The loss of that..." (Mother 8)

"We just felt all our hopes for the future had been taken away." (Mother 11)

All parents interviewed struggled to make sense of their loss and attempted to find meaning in it, within the framework of their belief system.

"Why us, why can we no' just have this baby that we so much loved? I was thinking why Lord... why? Is it because we couldn't love a baby enough? That's wrong. Is it because we couldn't support it because that's definitely wrong?" (Father 12)

"Why did you give us gifts and take them away again?" (Father 6)

Parents' particular worldviews which had previously given meaning and purpose to life were challenged. For one father, the death of his baby *in-utero* challenged his sense of his family's immortality.

"I just thought we were indestructible. We had confidence that everything is okay, everything is meant to be and then when it is taken away from you. You just expect it all and it's like this can't be right."

(Father 6)

Parents talked eloquently of the pain and bewilderment that such a confrontation to their way of understanding the world and belief systems caused them.

"We didn't do anything to hurt anybody or anything! We just go about our own wee business." (Father 5)

7.2.1.3. Loss of control

Parents experienced a sense of powerlessness that events happened out of their control - both parents whose babies died spontaneously and those whose babies were diagnosed with severe abnormalities *in-utero* (leading to a decision to terminate the pregnancy). Parents desperately wanted to intervene and actively do something to alter what they were experiencing. Fathers, who felt their paternal role was to protect and care for other family members, especially felt impotent.

"I know he felt useless." (Mother 4 referring to her partner after the stillbirth of her baby).

Such feelings of loss of control were heightened by

A lack of cultural norms

Parents struggled with the absence of prevalent cultural norms regarding how they might deal with baby death resulting in a lack of comparative markers to aid their decision making (for example, relating to ritual marking).

"It is quite a surreal situation because you don't know, you have never been in that situation, you don't know what to do and you don't know what is right and what is not right and if there is actually anything you're meant to be doing or not meant to be doing then....and so there's that sort of black hole of not knowing at all what to do." (Mother 14)

"I had horrible images of her just there (in the mortuary)...and nothing happening to her. I didn't know what the hospital did with very young babies. I had no idea." (Mother 9)

Parental confusion and disorientation

Parents found they lost all their usual sense of order and routine in their daily lives, in the immediacy of their baby's death.

"You do lose your parameters, you do lose your kind of structure and your, you know, I suppose you are kind of floating." (Father 1)

Parents' perception of the bigger picture of life – their understanding of the way the world was ordered and operated was also shattered. Death of a baby from mid second trimester onwards was not expected.

"We were in this sort of positive world that you get past 12 weeks and unless the baby has got spina bifida or something, you are there – you're okay. Every experience that we have had, everyone that we knew confirmed that and to suddenly fall into this other world..." (Mother 1)

Parental disbelief

Parents, at different moments in the days and weeks following the death of their baby, experienced feelings of disbelief at what had happened. It did not seem real.

"Because sometimes you just feel as if it is a bad dream." (Father 14)

Parents felt at times in their grieving that they did not want to face up to the reality of their baby's death and the pain and the hurt that involved.

"You just wanted to pull the covers up over your head and say look... but you can't do that." (Father 14)

Parents, therefore, found themselves in an alien and distressing situation compounded for some, by the fact that this was their first experience of close bereavement.

"We have never really dealt with death before." (Mother 13 – age 31)

In such unknown territory parents struggled to regain some control and make informed decisions.

7.2.1.4. Loss of self worth

Mothers in particular, expressed a sense of failure as a parent when their baby died *in-utero.*

"You are trying to bring a child into the world and you have not been able to do it." (Mother 1)

A sense of guilt and letting their baby down was described by several mothers and fathers. For example, on reflecting on her discharge from hospital one mother (13) said

"I just found it very difficult walking away and knowing that I was leaving him there...I had a baby, to me he was still my baby. Still the same as anyone else's baby but you knew that he was dead but you were leaving him."

Low self esteem was especially felt by mothers who had terminated their pregnancy due to fetal abnormality.

"I did not expect a funeral service that was so personal. It might have been how I was feeling at that time when I didn't think I deserved anything – so I didn't expect anything." (Mother 2)

In addition to the above spiritual themes which emerged from parents' description of their grief, the following issues were identified which also significantly contributed to how they experienced and dealt with their baby's death.

7.2.1.5. Lack of language to articulate feelings and experience

Parents' spiritual and emotional distress was often compounded by their struggle to find words, in their grief, to express how they felt and what they had and were enduring. One Mum described her difficulty in expressing how she felt about her baby prior to the baby's funeral.

"I had just gone in and ordered flowers (for the funeral) and for some reason I had chosen not to write a card....I did not know what to say." (Mother 2)

Some parents, in particular those for whom religious language was unfamiliar, struggled to articulate their beliefs and worldview. There was a paucity of language readily available to them to describe their inner wrestling and hopes and aspirations for their baby.

"I didn't believe ...I don't know ...How would I put this? How do I put this? I don't know. I have been brought up as protestant but never ever went to church, chapel ...anything so although I have my family, I've never had to go to somewhere, had to believe in something. I just take it like He is there and if He's going to help me He will help me and if He's ...that's it ...I don't know how to put it ... I believe He is there now and He's looking after our baby. See, I'm not one for words I don't how to put words into what I feel. They get all muddled up." (Father 4)

Moreover, parents found it difficult to describe their actual lived experience in relation to baby death and ritual.

"I couldn't start to put it into words." (Father 9 trying to describe the experience waiting with his wife in during labour and the delivery of his dead baby)

"It was never really as bad as, not that I was expecting it to be bad, it was how I was going to cope was what was concerning me. It was all very nice, or as nice as nice could be sort of thing." (Mother 12 trying to describe her baby's funeral)

This further contributed to social isolation as sharing with others how they felt and what they had experienced was not easy (See **7.2.1.1.**).

7.2.1.6. Particular factors influencing parental grieving and approach to ritual

Influence of the culture of their family of origin

Parents described various strong messages that they had absorbed during their formative years relating to death, ritual and belief which informed their approach to grieving and decision making with regards to ritual, following their baby's death. One father described how his family dealt with his father's death when he was a child by not talking about it. As a reaction against this he made a conscious decision to talk openly about his baby's death with his family but he found his brother reticent to do so.

A few parents who had been brought up in Roman Catholic families but were now no longer practising Catholics talked of their motivation to involve a chaplain in ritual marking as being influenced by their upbringing.

"And I suppose if I am really honest in some ways it was guilt because the fact that I was brought up a Catholic and was very religious and I went to seminary, junior seminary for 5 years so maybe part of it was kind of guilt. I don't know (refers to his wife), or do you think my parents would want obviously a priest to be present and some religious ceremony? Maybe it's partly driven by that. I think if I'm honest." (Father 8)

Previous experience of baby death and ritual

Two couples who were interviewed had previous experience of a baby, or more than one baby, dying *in-utero*. This certainly informed their decision making and approach to dealing with their baby's death this time around. One set of parents had not previously seen or held their baby or had their baby blessed. They regretted not doing so and with their second baby chose to do all three.

"Well, last year I lost a little boy. It was around about the same time and I didn't actually spend time with him at all. I think it was just a big shock and we've got photographs. I didn't spend time with him but I definitely found spending time with our second baby helped as opposed to what I did the year before...But it was a shame that we had to learn from experience beforehand to compare it you know." (Mother 7)

Concurrent or past major life issues for parents

Grieving for a baby who had died *in-utero* did not take place in a vacuum. There were significant concurrent or previous life issues which undoubtedly affected parental grieving. These included

- **Parental Illness**

One mother was diagnosed with breast cancer during pregnancy. She refused surgery because of her baby but began some chemotherapy. Subsequently, her baby died *in-utero* at 26 weeks. Another father was already struggling with depression when his baby died.

"Since we moved here everything has literally went wrong – one problem after another. I was off with depression and contracts had cancelled at work, and house moves, problems and then you thought our baby is coming along and it is going to turn round and then wallop. Well how much can you take, how much more can you take in this?" (Father 6)

- **Recollection of previous significant bereavements**

Parents talked of their baby's death bringing to the surface thoughts and feelings of major bereavements in the distant past. One mother talked of unresolved issues regarding a previous stillbirth 13 years prior to her current bereavement (she hadn't seen her baby or ritually marked the baby's life and death). Another parent spoke of the effects of his father's death which happened 26 years previously (see also **7.2.1.6.**). Many parents talked of more recent significant bereavements that were vividly recalled to mind by their baby's death, especially if their recent bereavement had occurred close to the anniversary of a previous death. This further contributed to their distress.

"...that was a real big stress going back there (the cemetery). I mean it was practically a year to the day." (Mother 7)

- **Infertility**

Some parents had been struggling with infertility problems prior to conceiving their baby who subsequently died *in-utero*. Much had been invested in these particular pregnancies – these babies were especially precious - and their loss was experienced as very difficult to bear. One couple felt it was their last chance of being parents. Their grieving was not just for their baby but for their opportunity ever to parent a live child of their own.

"We felt at a bit of a loss because we are pushing on a bit in terms of parenting years and we are probably not the most fertile of couples so it was a big loss because we felt that that was probably our only chance I suppose...although we haven't given up. So in that way I think that added to the whole grief of the situation." (Father 11)

- **Parenting baby's siblings in their grief**

Parents with children old enough to have some perception of the death of a baby sibling found that trying to support them in their grief, whilst grieving themselves, was an added strain.

"To me telling the boys she wasn't there, that was the hardest thing." (Father 6)
"He's (oldest child) coming through it. He was very upset during the holidays and more emotional because he is quite emotional, but really emotional over silly little things. The smallest one he got worse, he got wilder." (Mother 6)

Relationship with baby

Several parents talked of the development of a close relationship with their baby (in one case twins) from early in the second trimester onwards through regular ultrasound scanning.

"Because unfortunately the situation that we were in, with the problem that the twins had, my wife and I had been going in every week, sometimes twice a week, and been seeing them on scans. We had seen them from virtually week 14 or something, every week, twice a week, so we felt like we knew what they were" (Father 14)

Whether the baby's death was anticipated or unexpected and sudden

Several couples knew that their baby's prognosis was very poor or indeed that their baby would not survive outside the womb for some days, even weeks, prior to their baby's death and had begun to grieve then.

"We knew, I don't think we ever had a time where we thought about names and thought nothing was going to happen, you know we were choosing names because we knew what was going to happen." (Mother 14)

"I can't imagine what other people must go through who didn't know there was anything wrong, you know we had an expectation of what was likely to happen and what the likely outcome was." (Father 14)

Other parents had no such prior warning of what was to happen.

"It was just a shock...it hits you." (Father 15)

Gestation of baby

Some parents whose baby died in the second trimester or even early in the third, clearly felt that if their baby had died later in pregnancy, for example, at term, they would have felt even more distressed. Moreover, some felt they would have wanted to more publicly mark their baby's life and death by inviting friends and family to rituals performed. However, other parents, due to their circumstances and family story, were deeply distraught following their baby's death at similar gestations and made no such comparisons.

7.2.2. Parental expectations of chaplains and the rituals they may perform

Parents' expectations varied according to their previous experience of church, clergy and funerals, but in general were low and rather negative (the majority of parents interviewed considered themselves non-religious or had some religious belief but were not active members of a community of faith – see appendix 4a).

Midwives played a key role in acting as gatekeepers to parents accessing chaplaincy support.

7.2.2.1. Parental expectations of chaplains

Parents expected chaplains to be inappropriately formal, detached and paternalistic.

"A minister type in black robes." (Mother 9)

"...more austere, more looking down on you, treating you as a child." (Mother 1)

Chaplains were foreseen as inflexible and directive.

"Telling us what to do or what is the right thing to do and all we were looking for was guidance." (Father 14)

Some parents felt a chaplain would be task orientated and not offer the time or the commitment to respond to their particular needs. Chaplains were not expected to actually engage with a family's story and be open to their pain and grief.

"Somebody who didn't really have the time.....that would just come along, do their job." (Mother 7)

"Go through the motions." (Father 7)

"I was just expecting him to come in and say what he had to say and go." (Mother 4)

Most parents anticipated chaplains would only offer religious support and only to religious people.

"A preconceived idea that it is a strictly religious or very religious, over the top religious offering." (Father 13)

It was thought that support given would be insensitive and dogmatic in nature. One mum expected a chaplain to give her a theological explanation for their baby's death, rather than listen to her interpretation of her experience.

**"I thought it would very religious, trying to give you an explanation from a religious point of view of what happened and why it happened...it's God's will and you must be grateful...trying to put their slant on it."* (Mother 1)

Chaplains were expected to preach and proselytise.

"A religious bible basher." (Father 12)

Many parents were unsure what to expect from a chaplain and one dad was honest enough to admit he didn't know what a chaplain was or did, prior to meeting one.

Contemplating meeting a chaplain was therefore anxiety inducing for parents.

"I expected a lot more awkwardness." (Father 7)

"I think if I didn't go to church or I wasn't religious in any way but I still wanted to have something and do the best for my baby I think I would have been scared and apprehensive about what a hospital chaplain could have offered me and my family." (Mother 14)

7.2.2.2. Parental expectations of ritual

Some parents whose baby had died *in-utero* during the second trimester did not expect to be offered ritual marking. These parents thought they would have no choice about their baby's disposal.

"I just thought he was going to be taken away and incinerated." (Mother 9)

Many parents foresaw a set, given, impersonal ritual which did not reflect their beliefs or experience nor gave any opportunity for parental involvement in its planning or performance.

"I did not expect a funeral service that was so personal. I expected something that was just done." (Mother 2)

Other parents were unsure what to expect as they had never attended a baby's funeral before nor ever given such an event any previous thought.

Contemplating their baby's funeral was also anxiety-inducing for parents. It was anticipated as a traumatic ordeal, *"...a nightmare."* (Mother 12) which would be *"...all absolute doom and gloom."* (Mother 16)

7.2.2.3. Midwives as gatekeepers to chaplaincy support

Some parents with religious belief spontaneously asked a midwife to contact a chaplain for them. Parents who were non-religious or had little contact with a faith community often agreed to see a chaplain to explore possibilities of ritual marking, **despite** their expectations. In these cases, it was the midwife working with them who advocated the benefits of chaplaincy support.

"It was on the high recommendation of the midwife...if that hadn't been the case we probably wouldn't have had the chaplaincy service." (Father 13)

Parents perceived that it was experienced midwives who had previously worked with chaplains, who took time to explain something of the role of ritual and chaplaincy in meeting their spiritual needs. In doing so midwives dispelled some myths about chaplains and ritual marking, enabling chaplaincy support to be accessed.

"The midwife said no it's not what you think it is." (Father 13)

"It was useful when we did show some uncertainty that the nurse said it's a really nice person ...just have a word with her and discuss things." (Mother 1)

As well as the midwives' persistence and sensitivity being appreciated so was the manner in which they introduced the topic.

"I remember the midwife coming and sitting on the bed and talking through the whole thing. I am very thankful that she did suggest it quite positively." (Mother 1)

However, several parents identified issues relating to communication of information by midwives regarding ritual marking, chaplaincy support and options for disposal of their baby's body as problematic. This related to the timing of when such information was shared, the manner in which it was done and the lack of emphasis placed upon it.

7.2.3. Significance of how ritual is constructed and its content

7.2.3.1. Construction of ritual

The majority of welcoming and funeral rituals (see appendix 4a) were formed by parents and chaplain working together in a process of co-construction. Such a process began with the chaplain listening to parents' particular stories and being attentive to where they actually were in their journey of grief, enabling any ritual performed to have evolved from that story - respecting their experience, beliefs and feelings.

"There are obviously set things to say but it wasn't like that. It was very personal. She did listen very carefully to what we said to her." (Mother 11 describing her baby's blessing)

Such an opportunity to be involved in co-authoring ritual marking was of great significance to parents and helped to address many of their spiritual and emotional needs.

Co-construction enabled:

Development of a rapport with the chaplain

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. Thus, there was the opportunity for some development of trust and the dispelling of some myths about chaplaincy. Parents invested much into ritual moments and they appreciated the chance to find out something about the person

who was going to share such a significant experience with them; this was not only to do with the chaplain's competence and capabilities but also their humanity.

"...you could trust him and everything was getting done as it should be done." (Father 12)

"He showed us that he was a person. He is not the religious; put him on a pedestal type." (Father 6)

"She gave us a little background knowledge into herself, to which we could relate to. None of us had met each other before. Obviously what she was going to be doing for us was very intimate and I found her very easy to talk to." (Mother 11)

Co-construction, thus, enabled parents to feel more relaxed about relating to a chaplain and less anxious as they anticipated the ritual itself. Parents, therefore, felt more able to be themselves and be more honest and open in their sharing of their ideas and concerns about rituals.

"If you didn't feel right about something you didn't sort of feel well I can't say." (Mother 7)

Subsequently, the parental development of a rapport with a chaplain during co-construction enabled parents to feel supported and less isolated and anxious during the ritual itself.

"When she came back to actually carry out the blessing it was, it felt like a familiar face." (Mother 11)

"Even though we had only met her briefly it was almost like an old friend and we needed her." (Father 11)

For some parents, it was very important that the chaplain with whom they had established a rapport with during co-construction of a welcoming ritual and who had performed the blessing then shared in their baby's funeral. The chaplain had become an integral part of the baby's and family's story – one of few people who had known and met, and where appropriate, held their baby.

"There was no danger of a stranger burying my baby, no way." (Father 6)

Parental Affirmation

Co-construction of ritual helped parents to re-establish their self worth in two different ways

- **Affirmation through chaplain's attentive listening**

Chaplains affirmed parents, and their needs as being important and worthwhile responding to, by engaging with their particular story, beginning where they were and listening attentively and empathetically as part of the process of co-construction.

"He was a very good listener and he gave us time to say what we wanted to say…and it was actually really good." (Mother 16)

- **Affirmation of parents' creative ability**

Some parents appreciated the chaplains' affirmation of their ability to help shape a unique and personal funeral for their baby (welcoming rituals- though in the main had some degree of co-construction involving parents in this study - due to their timing, usually in the immediacy following delivery, did not lend themselves to the same degree of parental creativity). Co-construction allowed parents to be creative, at a time when they perceived themselves as failing – both as parents and in their ability to create. Thus, parents' creative and parenting abilities were affirmed in a period when their self-esteem was low.

"I felt very valued after that. Given everything that happened, to be able to look back and say that was absolutely right. It is quite special I think." (Mother 2)

"It did reassure us, in the sense, that you can create something because you have lost something that you should be able to create and I suppose it goes some way to giving you some self belief back." (Mother 1)

Parental catharsis

In the process of co-construction some parents found telling their story to the chaplain cathartic.

"All we did was spill our hearts out that first day." (Mother 9)

Other parents who chose to write something themselves for their baby's funeral had a similar experience.

"It was a way of hanging out our emotional washing." (Mother 3)

An opportunity for parental review

Co-construction allowed parents to talk through or write out their experience and feelings, take stock, and for some, to re-frame or this part of their story. This helped

them in their struggle to make sense of what had happened and attempt put it into some sort of perspective.

"You think back all the feelings that we had and try to put them into some sort of context and put them into a stage where that's what had happened and this is where we have got to. And it is really now when you look back that you appreciate how that really helped." (Father 14)

Sharing of cultural norms which related to ritual and baby death

The majority of parents interviewed found themselves in a situation which they had never contemplated let alone had any, even second-hand, experience of. Co-construction played an important role in informing parents what, in terms of ritual marking (and content) and options for disposal, were available to them. This reinforced, clarified or supplemented written or oral information given by midwives (often parents in the immediacy of baby death did not absorb such information).

"We got quite a lot of information sheets which the midwife had given us and there were a couple of things from that we just clarified with the chaplain and it was most helpful." (Father 12)

Sharing cultural norms with parents during co-construction enabled

- **Parents to have markers to aid decision making**

Chaplains not only explained the practicalities of ritual to parents, including the given parameters within which parents had to conform, but also shared the previous practices of other parents to act as markers by which to gauge their own decision making about possible options relating to ritual content. Moreover, the chaplain commonly suggested an outline for each service, which other parents had found helpful, as a starting point to prompt discussion about ritual content.

"It was almost like planning your wedding. There will be this sort of set of things you kind of have to do but you have variations between them, like music and stuff and I'd never thought." (Mother 1)

"He gave some ideas for a framework to build on… He gave us a lot to think about and spoke about what other parents found helpful" (Mother 3)

"He gave us a book and other things that people wanted obviously to hand on and let them be used at other babies' funerals." (Mother 15)

- **Parents to regain some control in their situation**

Parents greatly appreciated the fact that they could make informed choices about rituals performed for their baby and, thus, regain some control over their circumstances. Co-construction enabled parents to have ritual ownership – to feel the ritual performed was their ritual for their baby.

"It was the importance of just having all the information, so you could take ownership... It was our opportunity to do something for our children rather than just letting somebody else do it...He gave us our place as parents" (Father - of twins - 14)

"We could almost design our own funeral which is what we did, and everything we asked to be there was there, which was very pleasant." (Mother 16)

Parents were thus able to feel that they had invested something of themselves into rituals, especially funerals.

"We feel as if we put some contribution into the funeral as well." (Father 6)

"I think we did make it special." (Mother 1)

Parents were able to choose their level of involvement in co-construction – from writing their own funeral service to telling their story and then wanting the chaplain to create an appropriate ritual – and in participation in ritual itself– from reading a poem or prayer to bringing and laying down flowers. The content of ritual was teased out, negotiated and mutually agreed upon.

"We felt we wanted to say a few words but we never got pushed into doing anything we didn't want to do or, which was nice. He discussed our options as well. We all came to an agreement." (Mother 7)

- **Clarity regarding practicalities of ritual**

Co-construction allowed the chaplain and parents to talk through the practicalities involved in ritual and ensure parents were aware what each ritual entailed. This greatly reduced parental anxiety.

"We were really well prepared for when we were going up there (the cemetery) and it was nice because it took a lot of the stress out of it." (Mother 7)

Parents felt uncomfortable when something unexpected was included within ritual which had not been adequately clarified.

"The sheet thing, prayer sheet that he had passed round was just something that I didn't personally like...just for the simple sake that we hadn't spoke about it." (Father 5)

- **Normalisation of Baby Death**

Hearing from a chaplain about cultural norms regarding baby death and ritual marking enabled some parents to feel comforted that they were not alone in their experience. This reduced their feelings of isolation as they discovered many others had also lived with baby death

"A book of readings from people who've been in the same, a similar situation to yours, actually does make you think it is normal, not nice but its normal and I'm part of something within a level of normality, rather than being this complete freak." (Mother 1)

7.2.3.2. Significance of co-construction of funerals as a process

The co-construction of baby funerals did not just occur during a one off meeting between chaplain and parents. It was a process which happened over a number of days, beginning with an initial meeting with the chaplain and then involving parents mulling issues over and reading various resources offered by the chaplain, if they felt able. Contact was then made again, usually over the phone, to finalise arrangements and ritual content. Parents appreciated time and space on their own to discuss and reflect on what they felt was best for them and their baby. Having the opportunity to change their minds if needs be or seek clarification from the chaplain, at such a stressful and confusing time was also found to be helpful.

"And even if at the time we were unable to answer a question of what we wanted it was never a problem, he would just phone back or and we would decide then." (Mother 12)

"We got to put in (the baby's coffin) a little outfit and you know a teddy bear and things like that. That was nice. We got time to do things like that and make decisions about what you wanted done." (Mother 7)

7.2.3.3. Significance of parents meeting in person with chaplain as part of co-construction

One set of parents interviewed did not have the opportunity to meet in person with the chaplain as part of the process of co-construction of the funeral of their baby. Conversations were had on the phone with the chaplain (when their previous baby had died the same chaplain had been involved in the funeral and had met with them in person as part of the process of co-construction then) which was not experienced as being as helpful as meeting face to face.

"I think he actually just phoned us and it's when you felt all over the place, and it wasn't right. I felt it wasn't right, rather than sitting and saying right this is what is going to happen and everything like that." (Mother 5)

7.3.3.4. Significance of the place where the chaplain met with parents to initiate co-construction

Some parents felt strongly, in retrospect, that they would have felt more relaxed meeting with the chaplain at the beginning of the process of co-construction in the comfort and security of their own home rather than having to meet in a hospital environment, albeit in the chaplain's office.

"It was a bit daunting what with going to the hospital and into the chaplaincy and crying your eyes out and trying to hold yourself together to walk back out again." (Mother 9)

In conclusion, co-construction allowed parents to find a sense of meaning and purpose at a time when life felt devoid of such, by enabling them to parent their baby as well as they could in the given circumstances. Therefore, retrospectively they could look back without regrets and unfinished business at how they had dealt with marking of their baby's life and death, and disposal.

"I think between leaving the hospital and the funeral ...the contact we had with the chaplain in between that time and then the actual funeral itself...if we had wanted to add anything into that a few days later then that would have been fine. We really just did it the best we could have done. And that was nice because we know there is nothing else that we could have done under the circumstances to make it any better than we had." (Mother 7)

7.2.3.5. Ritual Content

Ritual involved the acting out and the expression of a family's story – an articulation of their feelings, beliefs and experience.

"It just seemed to encapsulate the moment for us." (Father 14)

Significance of words spoken

Some parents could not recall much of what was said during ritual due to the emotional nature of the experience.

"Although our bodies were there, parts just didn't sink in." (Father 15 relating his experience of his baby's funeral)

Other parents recalled not so much the words spoken but the feelings that the words evoked.

"I can't remember the words he said but I can remember the feeling that I was going through...some of the words...I just wanted to break down and cry. It was lovely." (Mother 4 relating her experience of her baby's blessing)

The overall sense of parents was of the great significance that the ritual performed for their baby was personalised and authentic – grounded in the reality of their story. What was said during rituals reflected what had been shared with the chaplain during co-construction – either through the poems, readings and prayers parents or chaplains had chosen or had written, and /or by the chaplains' weaving of the family's story into the ritual. Moreover, parents appreciated that what had been said was not an imposed set or given liturgy but that time and trouble had been taken to create something unique and special for a unique and important little person – their baby.

"It was all true and to the point." (Father 7)

"It very clearly reflected how we felt. I mean I have huge feelings of guilt which don't go away and he talked about that and was absolutely right to do that."

(Mother 2)

"Today was about celebrating what we had. I think acknowledging that was very important and I guess that contributed to a feeling of uplift." (Mother 1)

"It was personalised. It did not follow a schedule." (Father 6)

Parents expressed their surprise and appreciation that the chaplain used ordinary, everyday language during rituals.

"There was nothing I didn't understand, the whole service I understood." (Father 7)

Parents also stressed how important it was that their baby and other family members were referred to by their preferred names.

"I think the nice thing about it was he always referred to him by his name."

(Mother 4).

Moreover, parents appreciated that rituals were proportionate in duration to the length of their life and not over-complicated - *"...short and simple."* (Father 8)

Significance of chaplains' performance

For many parents, the manner in which rituals were performed and how words were spoken was as important as the choice of words used. Chaplains were observed to be touched and moved by their involvement and felt to speak with genuine feeling. Parents felt that chaplains believed what they said. Chaplains were perceived to give of themselves when sharing in ritual – they were committed to, and caught up in the ritual moment, and performed the ritual to the best of their ability.

"He was touched. He must go to a lot of funerals and you can become desensitised but he wasn't." (Father 6)

"I think the whole experience was, with the chaplain, it was true. It was real. It wasn't, you did not feel it was stage managed, or it was something that had to be done." (Father 7)

"A feeling she had, a feeling that this is not an end." (Mother 9)

Chaplains were also felt to perform ritual with real gentleness and compassion – being mindful of the physical fragility and beauty of the dead babies being blessed and sensitive to the emotional fragility of families within the context of welcoming and funeral rituals.

"He made the sign of the cross on her head. He was so gentle." (Mother 6)

"He performed the funeral in a very gentle way." (Mother 2)

Chaplains were thought of as performing rituals with an appropriate degree of intimacy and informality. The chaplain was perceived by parents to be sharing in a ritual with them as an integral part of, and not apart from, their family's (including the baby's) story. Furthermore, chaplains were seen by parents as being warm, supportive and caring within the ritual context.

"It went as if she had almost known us for 10 years and like she had known our baby as if he was running about in the back green kind of thing. There was that sort of bond and that really, and when other people came up and say that was a beautiful service, that says a lot." (Mother 13)

Yet, paradoxically it was also important to parents that the chaplain's approach was professional and dignified, and not so personally involved as to be unable to conduct the ritual.

"...empathetic and also being detached and professional in being able to direct things." (Mother 1)

Furthermore, it was significant for parents that chaplains did not rush or hurry through rituals. Chaplains were perceived to allow parents to have time during and after rituals to attend to and express their feelings when they needed to. Chaplains conveyed the significance of the baby and the parents' experience of loss partially by the unhurried nature of their performance.

"We did not get the feeling of sort of being rushed. You know sometimes you get that at crematoriums. It is a case of you're in and you're out. He sort of let you move out at your own pace, so you were not pushed...well, you got the feeling you were not pushed for time." (Father 3)

Significance of gestures and actions in ritual

Ritual enabled the enactment of what was so difficult to put into words, at a time when language seemed lacking and limited. Rituals gave families a means of expressing some of their deep feelings, needs, hopes and beliefs in gestures and actions.

- **Importance of parental gestures**

Parental actions and gestures associated with and carried out during ritual enabled parents to act out their relationship with their baby. This had profound meaning and significance for them. Fathers carrying their baby into the crematorium, parents reading a prayer or poem during the ritual, lowering their baby into his or her grave, mothers specially choosing and laying down posies of flowers were all acts of parenting. They were gestures of love and care which expressed the depth of feeling that they had for their babies and their need to parent their child as best they could. One father talked of his need to carry his baby's coffin into the crematorium not just

as an expression of his pride in his son but also to enable his baby son to feel proud of him, as a father, doing the best he could for him.

"He was my boy. He was my son and I was proud to carry his wee coffin into the crematorium because I was his father and he was my son. I wanted him to be proud of me for doing that." (Father 9)

"He carried her in and I carried the flowers in. We did it together." (Mother 3)

"We brought her into the world and we let her go." (Father 6 talking of the importance to him and his wife of lowering their baby into her grave).)

Much time, thought and emotional energy was invested in such gestures. Specific colours and types of flowers were chosen for specific reasons. One mother made up a posy of roses containing a rose for every member of the immediate family circle. Parents chose to wear smart or special clothes as a mark of respect for the occasion of their baby's funeral.

"....we had made an effort to get dressed up and I always feel good, feel comfortable with my kilt on." (Father 12)

All parents interviewed had been given the option by the chaplain to carry their baby's coffin from the funeral director's car to the graveside or into the crematorium. If their baby was being buried they also had the option of lowering their baby into his or her grave. Some parents decided very definitely they did not want to carry the coffin or lower it and others did, but were unsure how they would feel on the day. All were reassured that there was no right or wrong way of doing things and that it was culturally normal to do either. It was what they felt was right for them as parents. For some parents, especially fathers, a great deal of inner wrestling and deliberating took place prior to the funeral until they invariably they followed their gut feeling on the day.

"I think it was the day before, I can't remember if the chaplain phoned or if I phoned her, I said I am really having problems with this. I don't think I can carry our baby's coffin, I want to, I want to be able to take my own son on his last journey but I feel if I take 2 steps and break down in tears I have let myself down and I have let our baby down. The chaplain said listen up until the very last minute you will have the choice and option. If you still want to carry your baby, even at the last minute you don't feel you have to take the 2 steps; if you feel you don't want to do it the undertaker will do it." (Father 13)

Families' involvement enabled them to share in ritual marking as active participants and not just as passive observers. This allowed people to do something at a time when they felt helpless and useless.

"I feel as if we put some contribution into the funeral as well and not just turned up and it happened, we played a part." (Mother 6)

"I feel they (wider family) got an opportunity to do something (bring flowers to funeral) because everybody is sitting there not knowing what to do." (Father 14)

Significance of chaplains' actions

The myriad of feelings and questions in the face of the mystery of birth coming together with death rendered chaplains, not just parents, devoid of adequate words. Chaplains' actions also had significant meaning for parents, including

- **Aiding acknowledgement of the uniqueness of their baby**

For one mother in particular, it was very important that the chaplain who blessed her baby, held her baby and by doing so contributed to her feeling that the individuality and worth of her baby was being recognised.

"The time that touched me most was when the chaplain held our baby and called him by his name. He is a real person even though he is not here." (Mother 4)

- **Communicating care and support for parents through touch**

Some parents talked of experiencing a chaplain's touch as an important means of feeling supported and cared for. Touch was interpreted as the chaplain appropriately communicating concern, understanding and solidarity in the intimacy and emotional intensity of the ritual context. The chaplain conveyed her willingness to be with parents in their grief and distress by risking her touch.

"She held our hands." (Mother 11)

"I just remember just being cuddled by her. I just sat there. That meant a lot to me. The fact that she wasn't distant ...she was ...someone to hold onto." (Mother 9)

- **Affirming parents' beliefs.**

Parents whose baby was blessed recalled the chaplain making the sign of the cross on their baby's head. Words of faith and belief were not often remembered in any great detail but such a familiar gesture, representing the baby's belonging to the church in

heaven and on earth, had a deep impression on the parents concerned. Chaplains involved in ritual not only, therefore, affirmed parents' beliefs but acted them out.

Chapter 8

Parental reflections on role of ritual, chaplains and ritual context.

In the previous chapter parents' lived experience of baby death and ritual shared with a hospital chaplain was outlined relating to

- Spiritual issues affecting parental well-being as they grieved.

- Parental expectations of chaplains and the rituals they may perform.

- Significance to parents of how rituals were constructed and the content of the ritual performed.

In this chapter parental reflections on their experience relating to the following themes will be explored

- Role of ritual in meeting parents' spiritual needs.

- Significance of chaplaincy involvement in providing spiritual care.

- Significance of the context in which ritual is shared.

8.1. Role of ritual in meeting parents' spiritual needs

Parents found ritual marking of their baby's life and death an emotional experience and some found it very difficult at the time.

"Emotionally it was just draining. There was an awful lot of emotion." (Father 5)

A few parents described particular coping mechanisms they utilised during their baby's funeral. One mother physically distanced herself from other members of her family in an attempt to avoid having to deal with anyone else's feelings apart from her own. One father talked of focussing on his chosen role during the funeral, lowering his baby into her grave, in order to get him through what he felt he ought to do for his daughter.

"I chose to have my back to people. I suppose I kind of took myself away from people probably because I wasn't able to say anything to anyone, so I just wanted to put a bit of distance between me and...I just needed to be there on my own." (Mother 2)

"It's funny being confronted with this wee white coffin... if that was somebody else's funeral I'd be greeting my eyes out and yet you stay strong to do this, to lower the wee one." (Father 5)

However, all parents interviewed found the rituals they shared in paradoxically comforting and many felt a sense of peace, calm and hope during the ritual and afterwards.

"I found it upsetting I suppose and comforting at the same time." (Mother 3)

"It's almost like a calm came over the room during and after the chaplain had done the naming service." (Father 13)

"Within this turmoil there was this kind of oasis of light." (Mother 1)

"I thought the service had taken the anger away from me and made me be at peace." (Father 9)

None regretted sharing ritual marking with a chaplain and all recognised its significance in their grieving.

"It was really important to me. I hadn't appreciated how meaningful a funeral would be to me." (Mother 2)

The majority of issues raised by parents regarding the role of ritual in meeting their spiritual needs related to both welcoming and funeral rituals. However, there were some themes that emerged which were only applicable to one or the other. Firstly, the common issues identified relating to both types of ritual will be outlined.

8.1.1. Role of welcoming and funeral rituals in meeting parents' spiritual needs

Both rituals enabled parental spiritual needs to be met in a variety of ways.

8.1.1.1. Aiding Communication and social reintegration

Within families

During ritual, parents' stories were told and, thus, there was the opportunity for them to be heard, enabling their wider family (if they were present) to more fully understand their experience.

"I think it helped my mum and my dad understand how I was feeling as well. We were all probably feeling different things and not wanting to say too much to each other." (Mother 2)

Moreover, ritual enabled parents to become more aware of the grief felt by members of the wider family.

"Mum wanted a copy of the words the minister had said which surprised me. But I suppose in many ways they have lost a grandchild as well so obviously it does impact on them which people tend to forget. You are tied up in your own grief." (Mother 3)

With friends and within the wider community

The significance of parents' loss and how they felt about their baby was communicated to others by the fact they had marked their baby's life and death with ritual.

"I suppose they were surprised that I had to have those things in place but they have realized how significant my baby was." (Mother 2)

"You find that a lot of people just think a miscarriage is a miscarriage and you have lost a baby but you know your baby has been blessed he has been recognised as a person and I find myself saying that to people sometimes." (Mother 7)

"It (ritual) is acknowledgement for yourselves but it is saying to everyone else - we do acknowledge this baby." (Father 13)

Some parents used the topic of ritual in conversation with others as a reference point of common experience- a strategy to help their social reintegration.

"People won't mention it (baby's death) and then we feel we cannot mention it and it just becomes this awful thing. If you can actually engage them by describing the day because it is quite a positive thing. It is a funeral and most people would have attended one...it is perhaps relatively mutual and it is not talking about your feelings but it is something that you can actually engage about ...the connection is very difficult to make." (Mother 1)

"It all helps with isolation." (Father 1)

8.1.1.2. Finding meaning and purpose

Parents found meaning and purpose in ritual through

Parenting

Ritual enabled the best possible parenting of their baby in the circumstances. For some parents it felt as if it was their only opportunity to parent. Thus, ritual marking reduced parental feelings of regret and unfinished business, as well as offering some sense of meaning and purpose.

"We grieve because he is not here, not because we did not do all we could for him." (Mother 11)

"We just wanted to give him the best we could." (Mother 13)

"If we hadn't had one I would probably feel really bad for the rest of my life, but having one does help a bit." (Mother 15)

"It (a blessing) was the only thing we were going to be able to do for him...at that point." (Father 4)

Rituals enabled parenting in a variety of ways

- **Formal acknowledgement of their baby's existence and personhood.**

Ritual provided a context in which parents could formally say hello to their baby – welcome their baby into the world and acknowledge his or her reality and impact in their lives – as well as beginning to say goodbye. What I had previously termed welcoming rituals, as well as funerals, enabled parents to do both.

"It made me think he wasn't just a nobody. My boy...wasn't forgotten." (Father 4)

"It was me just accepting him into the world and then sort of saying goodbye as well." (Mother 11 – reflecting on her baby's blessing)

As her husband put it - their baby's blessing enabled acknowledgement *"...that he was a little person and not just a statistic."*

"I don't think they are as acknowledged as much if you don't have the chaplain, she made it feel like he was acknowledged and he was who he was , rather than just this baby who you get to spend some time with." (Mother 13)

Ritual, thus, enabled recognition of a particular life and death. For some parents, ritual allowed formal naming of their baby – part of recognising the baby's unique identity. This was very important for one mother.

"You know like when you think about them now like for me I can pray for them by name. I think that really helps." (Mother 14)

For another mother ritual helped to acknowledge not only that her baby existed but that he has a particular place in the story of humanity.

"People are born and people die, most people survive a lot long longer but it is saying you are part of a community of people who die, you are not just somebody who has never been." (Mother 1)

For parents whose baby died *in-utero* in the second trimester, ritual was felt to be the only formal way parents could publicly recognise the life of their baby.

"It marked her life. I just felt really, really strongly that her existence should be marked ...and that (a funeral) was the only way of doing it." (Mother 2)

However, paradoxically the same mother felt that just as importantly the funeral also marked her baby's *"not life"* i.e. that the baby had not lived a life of any fullness – her life had been drastically cut short. She had had no independent existence – life outside the womb.

For some parents, ritual was about showing respect for their baby's uniqueness and inherent value and worth. Ritual enabled some parents to feel they had *"...paid him the respect he was due."* (Father 13)

Thus, ritual marking did not just enable best possible parenting but also was deemed the most appropriate moral course of action, within some parents' cultural and religious perspectives. These parents felt a duty to formally acknowledge their baby's existence and uniqueness through ritual marking.

"...it (a blessing) kind of formalised it, made it right in that respect." (Father 11)

- **Formal recognition of the baby's belonging within the family**

Ritual enabled the baby's place in the family to be formally recognised. Moreover, ritual allowed family relationships with the baby to be affirmed and acknowledgement of the depth of love and loss felt by parents.

"He has got his place." (Mother 4)

"We were just trying to say that we are there for her. We are your family, you have 2 brothers." (Father 6)

"... to hear someone else use his name was a recognition that this was our wee boy ...bringing him into the close knitness of the proceedings. A feeling of family I suppose." (Father 11)

Ritual marking helped cement bonds between parents and their babies. One mother felt strongly that her baby's naming ceremony enabled her to develop a deeper bond with her dead baby and to relax and enjoy more fully the time she spent with him in hospital (and, thus, create positive memories – see also **Creation of significant and healing memories**) He became, for her, through their involvement in ritual marking not just a dead baby but her son.

"He was our baby. It (the naming ceremony) made me feel closer to him. It made me feel like I was his mum and I could sit and talk to him." (Mother 13)

For one father, having a funeral for his baby was a means of showing his baby how much he was loved and wanted.

"Well to know...he'll know himself that he was wanted. He is not just a baby that's not wanted and just discarded and we did, well we still love him. We'll always love him." (Father 15)

It was important for many parents that as well as recognising the baby as belonging to their family in ritual that the positive impact of the baby's role in the family's story was affirmed.

"If there are any good things that you can take out of it then maybe it reflected those things - certainly the good things such as the six months when I was pregnant."

(Mother 1)

- **Formal acknowledgement of parenthood**

Welcoming and funeral rituals were perceived as rites of passage by parents not just marking their parenthood but also the fact they were bereaved parents - who had never had the opportunity to parent this particular child outside the womb.

"One of things I remember of the words was being referred to as our baby's mummy and daddy, which was nice." (Mother 2)

"It let us feel we were parents...we had been parents briefly." (Father 11)

"It's probably the one chance that we're going to get at the moment because there is no baby to show, to say look I am a parent." (Mother 1)

- **Ongoing parenting**

Funerals enabled parental pilgrimage to the place of their baby's disposal. Half of the parents interviewed continued regularly to visit their baby's grave or the crematorium where the baby was cremated. This facilitated ritual remembering of the baby and was symbolic of a parental desire for their baby to continue to have a significant place in their family story and to remember somebody special in their lives.

"I want her to know that we are still remembering her and I want to remember her." (Mother 2)

"Anytime I want to speak to our baby, or think of our baby, of that period of time in my life, if I go to that grave it is just like clicking on something in your computer that opens up the file for me or opens the folder for me and all the memory files are there." (Father 12)

Tending their baby's grave also enabled parents to feel they were still parenting their baby in an ongoing way – doing their best for their baby.

"We can go and put some flowers down and that means we are still giving him something." (Mother 13)

Mementoes from both welcoming and funeral rituals given to the parents by the chaplain, for example, blessing cards, candles used or copies of the words said, were also utilised to aid such ritual remembering at a time appropriate to parents and in the safety and privacy of their own home.

"It was good to get the wee blessing cards and the chaplain gave us the wee candle (lit during the babies' funeral)…You can look at things from time to time and you've got those memories." (Mother – of twins -14)

Creation of significant and healing memories

Positive memories for parents were created by sharing in ritual. This enabled something meaningful to be remembered from such a distressing time. Moreover, along with the utilisation of mementoes such memories allowed parents to continue

to remember their baby and his/her place in their family in a way that they found helpful and comforting.

"It was probably the saddest experience in my life. It (the funeral) was for me a helpful and really positive bit of it and I am really glad that we did choose to see the chaplain and have that beautiful funeral and that beautiful memory will always be with us." (Mother 1)

"It is a very sort of tangible memory and it's something that we can hang onto. It probably gives us a happier memory of the hospital because it was pretty lonely sort of time in there." (Father 11)

"The memory that will stay me for the rest of my life was carrying the wee white coffin into the crematorium. It is not an unpleasant memory. It is a good memory." (Father 9)

Rituals themselves providing a focus in parents' lives

Rituals, funerals especially, provided a focus for parents' lives in the immediacy of baby death. Focussing on the funeral in the days following her baby's death was the only major source of meaning and purpose in life for one mum. It was her main reason for living at that point in time.

"I thought I cannot give up I have got the funeral. I can't just do away with myself or anything." (Mother 1)

A touching point with transcendence

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 of their situation. Some found sharing in ritual enabled them to make a connection with God. This not only resulted in a sense of parental well-being but also in a finding of meaning and hope.

"I felt really uplifted. That is the only way I can describe it and I'm not religious but it was almost like a spiritual thing." (Mother 1)

"It's almost like being put in touch with God and we've talked about not being overly religious but we still believe in God." (Father 13)

Affirmation of parents' spiritual resources

Parental beliefs, values and worldviews which provided a sense of meaning in their lives were affirmed during ritual. For some parents with Christian beliefs, ritual enabled an affirmation that their baby belonged not just to their nuclear family but to Christ's family, the Church, in heaven and on earth.

"The purpose of the funeral for me was that our baby's body was being buried but her spirit had gone on to something better and he did say that during the funeral." (Mother 16)

"He was our family and within the family, the Christian family as well. He was encapsulated within that and that he was not, not only was he part of our family, he was part of the whole Christian family." (Mother 9 reflecting on her baby's funeral)

"He was welcomed into the Christian faith." (Father 9)

Religious welcoming and funeral rituals were perceived as a symbolic assurance of their baby's eternal destiny by both those parents with beliefs in and doubts about the existence of an afterlife.

"Just in case. Cover my options." (Mother 8)

"I am not really, I don't really go to church, but I do believe in God and I do believe in an afterlife so from that, you know, the service was good because we wanted to make it meaningful here so that they could pass on to what we both believe in." (Father 14)

Part of what some parents considered best possible parenting was symbolically handing the care of their baby over to another trusted parental figure (trusted deceased relatives and/or God), within the context of ritual, who would ensure their baby was appropriately cared for in an afterlife. This was a source of great comfort and hope to parents – they believed their babies were safe and at peace.

"For me it was like God taking her." (Mother 6)

"...feel that he was sort of going somewhere to be with other people that loved him and I definitely found it a great comfort to do that and, just knowing that it had been done that he had been accepted." (Mother 7)

"It was just quite calm and peaceful and made me think that they had moved on to better place and that we would see them again. Safe in God's arms or in the palm of

his hands and I think that's how we felt ...that your mum was looking after them."(Mother 14)

Chaplains, during rituals, were also perceived as affirming those human relationships which parents found helped give meaning to life and strength for coping.

"The chaplain said that ...we'd take strength from each other and true enough, we have taken a lot of strength and we've kept on going."

(Father 5)

8.1.1.3. Aiding parents to regain some control, order and an increased awareness of reality in their situation

Restablishing some parental control

At a time when major events have happened out of parental control, ritual provided a means by which, in part, some control in life can be regained.

"...it (the funeral) does actually help you have this feel of kind of control.... having something that you can influence in the situation where you are completely unable to influence events because it has been taken from you." (Father 1)

Provision of some order in parents' lives

Rituals were perceived as –

- **Milestones in the parents' journey of grief**

Welcoming and funeral rituals helped to provide some orientation in parents' lives amidst the confusion following baby death. Moreover, rituals and other significant dates or appointments relating to their baby acted to provide parents with cairns to journey towards in the disorientating experience that is grief.

"I think it (baby's blessing) came at quite a good time because when we were in there and after the whole thing had happened I think we both felt a little bit directionless." (Father 11)

"(The funeral) Brought order to our lives again....we seemed to be just floating around aimlessly." (Father 9)

"It (the funeral) was a milestone. We were working through milestones actually I mean we are still doing it today (postnatal appointment with the obstetrician) that

was a major milestone. His birth was a milestone; the funeral was the next milestone and so on." (Mother 9)

- **Providing a sense of closure and a feeling of moving on for parents**

Both welcoming and funeral rituals enabled parents to feel some sense of closure to their experience of baby death and that their lives were taking some form of forward momentum. Thus, what I have previously termed welcoming rituals, as well as providing a context in which parents can say hello to their babies (see **8.1.1.2.**) also enabled parents to say some form of farewell.

Blessing and naming rituals specifically provided some parents with a formal sense of ending before leaving their baby in the hospital. Participating in ritual marking in the hospital gave some parents a sense that they had done all they could for their baby and to help themselves in the circumstances.

"We felt if we hadn't had the blessing we would have just left the hospital feeling really empty and it was our chance to say goodbye to him." (Mother 11)

"It (a blessing) was nice because that was like closure, that was like passing our baby on saying right that's him taken care of now and I can leave him without feeling guilty." (Mother 7)

Funerals were considered by some parents to provide an appropriate ending to their physical relationship with their baby – a time when parents literally had to physically let go of their dead babies. One father eloquently talked of his baby's funeral as an intimate leave taking – a time of story-telling and remembering as well as transition. Such a degree of personalisation was not so possible during welcoming rituals. Moreover, not all significant parental memories of their baby were created at this stage.

"It was obviously the experience was the last kind of, in a physical sense, the last connection with our baby. It was almost like…, if you weren't going to see someone for a long time you know you might sit down and meet with them and have a drink and reminisce with them over all your kind of shared experiences. It was very much like that and I think the speech or the reading from the chaplain which drew on our all experiences really reflected that and provided some kind of closure. At the end of it was … now we have reviewed what we have shared put it behind us kind of thing." (Father 1)

Some felt that their baby's funeral significantly contributed to the feeling of an end to a period of acute grieving which dominated their lives. Thus, funerals were perceived as a watershed for many people in their experience of grief and facilitated a looking forward and moving on, though not forgetting. Importantly, the funeral was also experienced as an ending to the period of limbo between the baby's birth and his or her burial or cremation, and, therefore, an end to parents' waiting for appropriate disposal.

"It was really for us to say goodbye - to have a clear ending." (Mother 2)

"...the funeral put one particular building block into the wall and let us move on to the next bit of grieving. It brought to a close a very, very bad chapter and I just wanted to move on from that bit" (Father 12).

"We were in limbo up till then. It was a way of bringing it to a natural end."

(Father 9)

"It was a sense of closure in a way that while our baby was still at the hospital mortuary we knew that episode if you like wasn't complete. I felt as though it was an ending of one ending. Obviously there were more things to come – the getting used to not having her and all that sort of thing." (Mother 16)

Parents, thus, recognised that leave-taking, letting go, was not a one off event but was an ongoing process and welcoming rituals, as well as perhaps more significantly funerals (the topic of funerals and leave-taking is further explored below), were important 'moments' in this process. As part of such intimate leave-taking, funerals were experienced as an opportunity for temporary reuniting of parents with their baby, before the finality of physically letting go.

"I carried her. I felt like I could hold her, although she was in a box. I physically could hold her again." (Father 6)

Parents also wondered that the death of a baby may be something they never completely 'get over' even if a funeral helped give them some sort of ending. There perhaps would always be unanswered questions and 'if onlys' as well as a recognition that their lives would never be the same again.

"It's not the sort of thing you'll ever get closure about what's happened. There will always be question marks over what might have been and why did it happen, but I think it helps you towards some sort of closure." (Mother 1)

For some parents it was important that their physical, as well emotional, leave-taking from their baby was a gradual process. One couple chose to see their twins and spend time with them not only in the maternity unit, but took up the offer (given to all parents in SMMP) of seeing their babies in the mortuary and in the funeral parlour prior to their funeral. For this particular couple involvement in a process of leave-taking lessened the distress of the funeral.

"It wasn't too upsetting that we weren't going to see them again. We accepted it. They were just moving on. We had seen them enough." (Mother 14)

Reality confrontation

Many parents found sharing in ritual an effective way of beginning to accept the painful actuality of their experience.

"I think at the beginning because everything was surreal, it (a blessing) made you realise that this was happening and it made it very real." (Mother 7)

"Then you see this small white coffin getting lowered into the ground and you think that is our baby in there." (Father 5)

Several parents described facing up to and accepting the reality of the death of their baby as an ongoing process which varied over time between glimpsing reality and times when reality was too hard to face or too elusive to grasp (see **7.2.1.3**)

"...we weren't going to at first (have a funeral). You just wanted it to go away; you didn't want it to be happening. But once you got down to think about stuff and that it did help to have a funeral." (Father 15)

Other parents did not feel the reality of what had happened to them had fully sunk in even several weeks later, and one mother described the fact that often she consciously chose not to confront that reality, for example, by choosing not to visit her baby's grave.

"It was like I was there (at the cemetery) seeing to things tidying or laying flowers but it was like it wasn't me - it wasn't my life. I was doing it for somebody else. I cannot say I look forward to ever going up. But in the same respect I don't feel bad if I am not going...I stand there sometimes and think how did we get to this stage?"

(Mother 12)

- **Reduced parental fantasising about disposal of their baby**

Parents sharing in a funeral ritual for their baby removed uncertainty as to how and where their baby was disposed of, and thus negating myth formation and feelings of unfinished business.

"Because you still have that thought...she's up in the hospital. My baby is still lying in the hospital." (Mother 5)

"I never really knew where he was or what was happening to him, whereas now with the funeral I know where he is. I think we would be in quite a lot of turmoil if we never knew what had happened and I really think that would make it harder to move on in life." (Mother 12)

8.1.1.4. Affirming and validating parental grief

During ritual, parents listened to their story being retold by the chaplain which enabled them to feel that their particular response to baby death had been heard and taken seriously, understood and endorsed.

"We had talked about our feelings for him. This was someone else taking an outside stance and saying openly what we were thinking and feeling." (Father 13)

Chaplains heard during co-construction parents' depth of grief and love for their baby and by relaying these during ritual they affirmed and validated parents' feelings at a time when not only did they feel vulnerable and fragile, but when they wondered whether their feelings were appropriate and culturally acceptable. Chaplains through re-telling a family's story within the context of ritual give them permission to feel and be as they were.

8.1.1.5. An opportunity to hear, to re-interpret and reframe their story

By listening to the chaplain's re-telling and, thus, interpretation of the story of their baby's life and death during ritual parents were able hear their experience set in the framework of their wider family story and what significantly informed their particular narrative, including their beliefs and worldview. This enabled some parents to set their baby's death in some sort of context, which offered hope and comfort. For others, ritual offered an opportunity to take stock and muse over what had happened.

"It was to get some feeling of reassurance that it wasn't the end of the world I suppose even although it felt that way." (Father 11)

"She just put it into perspective." (Father 13)

"She was relaying the experience to everybody and allowing us to reflect on that. ... just to listen to somebody else saying, allowed us to sit and reflect." (Father 1)

Furthermore, in facilitating parental grieving ritual significantly offered

8.1.1.6. A safe, culturally appropriate context in which to express feelings

Parents felt they had permission within the context of ritual to be themselves and express their feelings as they needed to at the time, without feeling awkward or uncomfortable.

"You are allowed to be upset and emotional." (Mother 3)

"It was very emotional. I suppose with the chaplain it was more emotional than with the midwives. I mean they are all carrying out functional aspects of the birth. I didn't feel that I could really ...I didn't really sob or anything in front of the nurse. I felt more at ease during the blessing and after the blessing." (Mother 11)

As a result, parents found participating in ritual not only cathartic but therapeutic.

"It was a good way to deal with the pain." (Father 7)

"Emotionally I would say it helped an awful lot. It gives you something to hang your grief on." (Mother 3)

8.1.1.7. Freedom from cultural restraints in order to express feelings

Paradoxically, as well as a context in which particular cultural norms are acted out, ritual also enabled liberation from stereotypical behaviour. Ritual enabled family members to transcend socially constructed cultural norms in order act out and articulate their emotions. The death of a baby touched something very deep inside members of bereaved families and ritual gave them the opportunity to act out their response to such loss in a profound and creative way, out with their normal pattern of learnt behaviour

"My dad wrote a card on the flowers. Normally it would have been my mum, my mum always writes the cards and dad never bothers to send you even a Christmas card." (Mother 2)

All the members of one baby's extended family – one parent's family of origin were predominantly Roman Catholic from the west of Scotland and the other parent was from a nominal Protestant working class family who lived in a former mining town in East Lothian – who were present at his blessing spontaneously made the sign of the cross on his forehead, following the chaplain's and his parents' example. For the baby's father's family this was more than an alien gesture in the context of everyday life but was the antithesis of culturally appropriate behaviour.

"That was another blessing because everybody was a mixed religion but we all came as one. It was a nice touch that everybody kind of did the sign of the cross on the wee man, on the baby's head." (Mother 4)

Ritual, therefore, was not only perceived by parents as an activity which bound people together but it provided a context in which the extra-ordinary was experienced and love and grace was shared.

8.1.1.8. Informal rituals performed by parents also helped to meet some of their spiritual needs

Parents created their own rituals

One couple planted a fruit tree in their garden in memory of their baby to act as an aid to ritual remembering - the tree blossoming in the spring would coincide with the time of year when their baby died and was delivered. Another father had his baby's name tattooed on his arm as a gesture of love and commitment to remembering her place in his life.

"Shows how much she means to us". (Father 15).

Seeing and holding their baby

Seeing, holding and spending time with their baby confronted parents with the reality of their baby's existence and death, as well as enabling them to parent their baby as best they could. Moreover, such an informal ritual was perceived to reduce parental regret and unfinished business.

"I am glad we saw him, but I just found it difficult to see him as a perfect little person and he wasn't alive. I am glad because I think if we hadn't seen him we would always have wondered." (Mother 11)

"I personally feel people would regret it if they didn't. I could not have."

(Mother 14)

Parents interviewed who had not seen and held previous babies who had died *in-utero* now regretted not doing so. For one couple who had terminated their pregnancy due to their baby having severe medical abnormalities, seeing their badly deformed baby affirmed their decision and reduced their feelings of guilt.

"I was able to say yeah, I can see that this baby did not have any chance of a life so that was good ....although it was quite bad, it helped us." (Mother 16)

None of the couples interviewed had misgivings about seeing their babies, though some had been fearful of doing so beforehand and midwives had helpfully talked through their concerns with them. No-one interviewed felt pressurised to spend time with their baby but some felt communication regarding seeing their baby again before leaving hospital could have been clearer

8.1.2. Specific roles of welcoming rituals in meeting parents' spiritual needs

Blessing and naming ceremonies were also perceived by parents as

8.1.2.1. Facilitating the seeing and holding of their baby

For one father seeing and holding his baby during a blessing ceremony enabled him to be reconciled with his baby who had not only died *in-utero* but was unexpectedly found at birth to be severely deformed. Initially after her birth, he had felt unable to see or hold his baby due to her deformity and as a result felt very guilty at having rejected his child (as he perceived it). However, deciding with his wife that they wanted to have their baby blessed facilitated the seeing and holding of his baby daughter. This enabled not only recognition of the reality of his baby's death but also the beginning of an acceptance of the reality of her deformity. If this father hadn't seen or held his baby he felt it would have been a source of great emotional turmoil for him in the future – he would have felt he had failed as a parent twice over.

"It is strange to say this - why should you struggle to go and see or hold your own daughter but its like I don't know what to expect. That has given me a lot of strength.... that has changed me around. I would not have lived with myself by not going back to the hospital because it was just like you had disowned..." (Father 6)

8.1.2.2. Symbolic gesture of intended parenting.

For a few parents having their baby blessed was an important gesture which symbolised how they had intended to bring their child up - within their family's religious and cultural framework. If their baby had lived they would have had their baby baptised. A baby's blessing was perceived as a gesture which was symbolic of their intended model of parenting which was based primarily on their experience of being parented. Furthermore, there was a desire that their baby should belong – be part of the same family of faith as they felt they belonged to (see also **8.1.1.2.**).

"I wanted my baby to be brought up a Catholic and now because he wasn't here why should I change that?... If anything, it probably made me more so that I wanted to have it done, because he wasn't here." (Mother 4)

8.1.3. Specific role of funeral rituals in meeting parents' spiritual needs

Funerals were perceived by parents to enable

8.1.3.1. Respectful disposal of a baby's body.

Parents felt that it was important that their baby's body should be treated with dignity and respect and disposed of in a manner appropriate to a person who had lived (albeit for a brief time) and died.

"I felt that she had gone already and that we were showing respect to her shell or call it her body." (Father 6)

One mother whose baby died at nineteen weeks gestation was unsure at the time whether having a funeral for such a small baby was appropriate or not. Retrospectively, she was glad she and her husband had opted to have a short funeral instead of deciding to allow her baby to be cremated without any ritual marking.

"I felt that a funeral or calling it a funeral seemed a bit over the top really but at the same time what were the alternatives? The alternative... you know it just wouldn't have been appropriate and I think given the chance I would have chosen what happened again. We didn't blow it up out of all proportion. It was just a very simple but giving some dignity to a wee life." (Mother 8)

8.1.3.2. Rite of passage into adulthood.

For one set of parents their baby's funeral was also perceived as a ritual marking not only their parenthood but also their 'coming of age' as adults. It was perceived retrospectively as a rite of passage into the adult realm of parenting, independent decision making and dealing with loss and bereavement. It was their first experience of close bereavement and the subsequent intensity of pain and grief. They felt they had suffered a loss only adults could experience and had made decisions that were right for them and coped with the loss their way.

"...it's a kind of rite of passage, it's a coming of age. I think, in a sense that you know, you are suddenly an adult, you are a parent." (Father 1 – age 31)

8.2. The significance of chaplaincy involvement in providing spiritual care.

Parents perceived chaplains to have a distinctive role within the health care team providing holistic, including spiritual, care.

8.2.1. Why parents requested chaplaincy involvement in ritual.

8.2.1.1. Chaplain as having ritual authority

Chaplains or a person connected with the church were considered to be culturally the most appropriate person to perform rituals by parents, irrespective of whether they were a member of a community of faith or not.

"I was brought up to think that to officiate something like that you needed someone, well sort of in authority." (Father 3)

"They kind of have kind of an authority. I mean it would not have been the same if it had been a nurse or a midwife" (Mother 8).

Moreover, chaplains were perceived to have the appropriate training, competence and experience to perform rituals. Chaplains would know the right words to say and how to say them.

"As long as they had to do with the church and that, then it felt good. It felt like the right thing, if your electrics go you don't get the plumber in, you get the electricians in. The right man for the right job." (Father 15)

"The chaplain has had training in proper public speaking... so even though you've written the words, you know what's coming it is still different you know. Especially spoken properly ...I suppose it is like the difference between reading poetry and hearing someone else read it." (Mother 3)

Having the culturally most appropriate person perform ritual marking was another way of parents doing the best for their baby – doing things properly from within their particular frame of reference.

"It's just a respectful way to do it." (Father 6)

"I felt it would not have been done right if one of us got up and conducted the service. You know sort of read the eulogy even though we had done it ourselves. We would have felt something at the back of our mind sort of niggling saying it was not done completely. You need someone, either a minister or someone like that to do it completely." (Father 3)

Such authority was also linked with ritual efficacy - the idea that a chaplain's prayers and requests of God would be more effective than those of others and the eternal destiny of their baby would be more assured.

"They are in touch ..." (Father 13)

"With God and things so you associate the chaplaincy with that and that's why a prayer from a chaplain means more than from just an ordinary person." (Mother 13)
"By having the minister there who can put a good word in for her, it's like every opportunity just to help get her there." (Mother 16)

8.2.1.2. Parents believing but not belonging

Some parents who requested chaplaincy involvement in ritual marking held religious beliefs but did not actively belong to any community of faith, and thus did not have contact with an appropriate member of that community who could perform rituals for their baby.

"We are churchless at the moment and my religious faith is such that we wanted a religious person to conduct the funeral. We may not go to church but we do have a faith." (Mother 3)

8.2.1.3. Parents believing and not wanting to belong

Other parents requested chaplaincy involvement and not a representative from a local church specifically because they did not want to feel obliged to continue links with a particular faith community.

"There's a chaplain who can assist us. We don't feel we owe him anything, he's not running a church every Sunday that we are not attending." (Father 12)

8.2.2. Significance of chaplain in performing ritual

There were two main, but contrasting, roles which parents perceived chaplains holding in tension during rituals (see also **5.1.5.** Ritual leader – priest or shaman).

"On the one hand she was trying to be with us, dealing with all this grief, and on the other, not controlling but orchestrating events." (Mother 1)

8.2.2.1. Priestly role

Whether parents had religious beliefs or not the chaplain working with them was understood as fulfilling different aspects of such a role. These included

Chaplain as orchestrator of ritual

No matter who was actively involved in participating in ritual marking and how, parents perceived a need of someone who could be trusted to take control of the situation to ensure *"...things run smoothly."* (Father 1) Chaplains were understood to hold the ritual together and guide families through the ritual by providing order and structure.

"Somebody to be there and take control." (Father 5)

"There is potential for it all to go horribly wrong unless you have got someone there to actually keep things following a structure." (Father 16)

The chaplain was perceived to create the contextual boundaries of the ritual in terms of time and space.

"He had us all. It was a little kind of group all round our baby. He just kind of said do you want to sit down and we will start the blessing now." (Mother 4)

"If you imagine him with long arms and just keeping everyone round the graveside." (Mother 5)

Chaplain as trusted mediator

The chaplain was seen by many parents as having responsibility for their baby's eternal destiny, mediating between earthly parents and a heavenly one.

"...passing our baby over to God." (Mother 12)

"She opened the door for him (baby) to go into God's house...she could show him the right path" (Mother 9)

Thus, chaplains' involvement in ritual gave comfort to parents that their babies would be safe and cared for in the hereafter (see also **8.2.1.1.**)

"I wasn't happy until the priest got there and I felt a bit more at ease when the blessing was happening. I just mean I knew he was going to be at peace and he was going to be with God." (Mother 4)

In more general terms, chaplains were understood as individuals through whom parents could make connections with God.

"A link with God. It's what a minister is – a conduit from us poor souls to God." (Mother 3)

Chaplain as teller and interpreter of stories

Chaplains were perceived as being wordsmiths, who in the context of ritual re-tell and in the process re-interpret, the story of a baby in relation to their family, and where appropriate, the divine story.

"The chaplain spoke as if our baby was part of our family and within the Christian family as well...She got over how special he was to us and how important he was to us and how special he was just to have been created." (Mother 9)

During ritual chaplains were understood to act us a spokesperson for parents saying what they wanted to say about their baby at a time when invariably they were unable to say it themselves. Chaplains were entrusted with re-telling and, thus, interpreting parents' stories, in the context of ritual. Parents perceived chaplains as being sensitive to, and respectful of, their stories – their experience, beliefs and feelings – and, therefore, telling it how it was. This was greatly appreciated.

"The chaplain did not change any of it you know. He kept to the facts and he was able to say how we were feeling, although he put it together. There wasn't, you could not have said there was anything that was in there you thought - I didn't say that, I

did not feel that...He represented us.... that was the main thing. He was speaking for us; he was saying what we wanted to have said." (Mother 2)

For a few parents the chaplain was understood as also acting as a spokesperson for their baby addressing them.

"It was almost like she was relaying what feelings our baby had for us as well as our feelings for him." (Mother 15).

Chaplain as embodying the divine story

Chaplains were understood as representing God's presence with them in their grief and pain. They were also perceived as a representative of the church – the community of faith on earth and in heaven to which parents felt they belonged (whether they were active members or had historical connections). Moreover, chaplains symbolised hope and resurrection in this life, for parents, and in the next, for their babies.

"They did represent God, a religious element. I did feel that God was in there somewhere and I got some comfort from that." (Father 8)

"A representation of an end to suffering and a chance to move on from there."

(Father 14)

"To me he represented where my boy was going." (Mother 4)

8.2.2.2. Shamanistic role

In contrast to the priestly role of maintaining order and being someone who acted as an interpreter and mediator, chaplains were also, paradoxically, perceived as creating an atmosphere within the contextual boundaries of the ritual in which families felt they had permission to be themselves and spontaneously express themselves as they needed to.

"He didn't say right everybody over here, everybody do this, everybody do that. It was just the way it happened." (Mum 4 talking about everyone present during her baby's blessing making the sign of the cross on her baby's forehead).

Parents perceived chaplains as unobtrusively contributing to the wonder and reverence of a time and space in which they experienced something special, significant and unexpected.

"I've always thought of priests as important people, but he sort of stepped back and he made everyone else feel important. He made our baby important." (Father 4)

Chaplains were felt to be holders of grief - acknowledging the reality, the ambiguities and the confusion of grief which were tangibly palpable in ritual and allowing it to be openly present, not denying it or avoiding it. (see quote at **8.2.2.**)

8.2.3. Significance of role of chaplain in co-construction

Chaplains were perceived to fulfil primarily two different roles in the process of co-construction. The role they performed depended upon parents' needs at specific moments in their grief. Both roles involved listening, thus, enabling chaplains to weave parents' particular stories into rituals but each had their distinctive qualities.

8.2.3.1.. Chaplain as unhurried supportive presence

Parents felt chaplains were individuals who were willing, when required, to be with them in the immediacy of their grief, to wait with them, to listen as they shared their stories. Chaplains provided an unhurried, attentive human presence.

"Someone so there, so present." (Father 4)

"It was someone to lean on... someone that understood." (Father 7)

Their role was understood as being story orientated rather than task orientated (as a midwife's role often was) and concerned, where appropriate, more with being with rather than doing to or telling. In this respect, parents felt a chaplain's role in providing this aspect of spiritual care was distinctive from the role of a midwife.

"Listening rather than trying to help, trying to tell you this. Her approach was so different to everybody else who was like – this is what has happened, this what is going to happen..." (Mother 1)

"I felt the chaplain had come in to reach out to us and be with us. The nurses were there for us but you felt they were dealing with lots of other people as well. They were busy." (Mother 11)

"I mean she (the midwife) came in to administer to my medical needs if you like as opposed to wanting to sit down and talk." (Mother 16)

However, if a mother's primary concern was with physical issues at any time during her stay in labour ward the company of a chaplain was not high on her list of priorities.

"Once I started to get into quite a bit of pain I don't know that I would have wanted the chaplain coming in." (Mother 16)

One mother, an active church member, was disappointed that the chaplain was not more proactive in *"...offering spiritual guidance" (Mother 10).* She had expected the chaplain to verbalise the Christian story rather than primarily just listen, out with ritual.

8.2.3.2. Chaplain as interpretative guide

Parents, once their minds turned to planning rituals for their baby, found that co-construction was an empowering experience facilitated by the chaplain who was perceived to be discerning as to how involved parents wanted to be in the process. *"He obviously gauged that we were emotionally strong enough and able enough to do something for ourselves. I could imagine it would not be the right thing for everyone."* (Mother 3)

Chaplains did not dominate construction of rituals but neither did they leave parents to make decisions unsupported or without guidance or information about cultural norms.

"The chaplain's suggestions actually brought out what we wanted." (Mother 9)

Chaplains acted as guides along parents' journeys of grief as they sought to best parent their baby and deal with their grief in a manner appropriate for them

"....a support function and as a sort of coach really...to help us deal with what we had to get through. With not having been in that situation at all ...and not having any experience you need somebody to help you along the steps ...and to benchmark the areas you need to get over or you need to be clear about in your own mind... to get forward. So for me it was a huge support and allowing us, leading us to where we need to get to." (Father 14)

Chaplains were felt not just to offer general guidance but to listen to parents' particular stories, to interpret them within the context of his/her experience, training and worldview, and to respond appropriately.

"She addressed our individual needs and wants." (Father 13)

8.2.4. Chaplain as a part of, yet apart from, the rest of the healthcare team.

For many parents, chaplains were perceived to be part of the healthcare team which worked in the maternity unit and in the community providing holistic care for their babies and themselves. Chaplains were felt to have good relationships with other healthcare professionals, in particular with midwives with whom they were experienced as working closely with.

"I do feel that the support experience that we have had has been rounded. You know they have all had a particular role - whether or not it's the midwife coming round, counsellors at SANDS, whether or not it's the doctors or the GP or what have you, or the chaplain and so on.." (Mother 1)

"The chaplain had a good rapport with the midwife as well because she was fantastic wasn't she, and she got on really well with him and it was fine." (Mother 7)

However, paradoxically, it was also important for a few parents that they understood chaplains to be outwith the immediate healthcare team who provided physical care for mother and baby and made medical and nursing decisions. This enabled parents to feel free to express their negative feelings about issues relating to these aspects of their experience.

"Things weren't going right you know the hospital was letting us down...when people were not there for us, there was somebody there... its like I have got to tell somebody this, I have got to get this off my chest here." (Father 6 whose baby was unexpectedly found to be deformed at birth)

"Yes talking about how you were feeling about the hospital and the midwives and he was listening." (Mother 6)

8.2.5. Chaplain as advocate

Parents perceived chaplains, at times, acted on their behalf not only during the process of co-construction but also during rituals themselves. Parents understood chaplains to be on their side, as someone looking out for their interests whilst they were in an emotionally fragile state. For one set of parents, the chaplain was able to

intervene on their behalf when certain practicalities that had to be dealt with to enable their twins' funeral to take place, became muddled.

"Thinking back there was a wee bit of a problem with the documentation wasn't there ... but between the funeral director and the chaplain they managed to get it all sorted out. It was something that the hospital had forgotten to give us and they just sorted it all which helped enormously." (Father 14)

Immediately prior to, and during, rituals chaplains were also able to articulate parents' wishes to funeral directors and crematoria or cemetery staff about practical issues at a time when they were unable to do so.

"...when I wanted to put the flowers on the coffin (I had spoken to the chaplain about it but not to the undertakers) they were about to close the curtains and I looked at the chaplain and she said, "Wait, hang on a minute. She's going to put the flowers on". (Mother 1)

8.2.6. Chaplain as an ongoing supportive contact

Many parents appreciated the fact that the supportive relationship the chaplain had developed with them was open-ended. The chaplain made it known to parents that he or she was available in the future to provide support but that parents would have to initiate any further meeting. This was a comfort to parents to know that they could contact someone they had trusted previously with their inner selves should they need to do so in the future. The chaplain, therefore, fulfilled a role as a safety net, which though seldom utilised, gave a sense of security and support at a time when parents felt anxious and vulnerable.

"I thought that was a very nice touch being assured that the chaplain was there and if I needed to speak to her that she would be there. It was nice to know that if I wanted to go and speak to her I could just phone her and that was very....an important thing to be available." (Mother 9)

"I think we would rather talk to him than to talk to a counsellor or anything like that." (Mother 15)

Only one parent within the timescale of the study had requested to see a chaplain again. Those who were active in their own faith community received bereavement support from church representatives. Parents also appreciated that following the chaplain's involvement in ritual, he or she, made contact by letter (enclosing a

blessing certificate or a copy of what was said or read during ritual) or telephone and that information regarding local support agencies for bereaved parents was again outlined during such communication.

8.2.7. Significance of a chaplain's way of being and relating

Parents requested chaplaincy support because they perceived a chaplain to have ritual authority but once they began to work with the chaplain, the chaplain's way of being and relating became very important. It was the chaplain's humanity and compassion, integrity and transparency that parents remembered not just what he/she said or did. The chaplain's sensitivity, discernment and empathy were considered highly significant. Chaplains by being themselves enabled parents to relax and be themselves also.

"Just the comfort you take from his character, I suppose. The way he is." (Father 5)

"I mean he has obviously got to read the situation when he comes into a room to meet people for the first time, especially after what has happened. That must be hard, but some people can tend to turn their feelings off, but he didn't which I think was nice. It made him actually a bit more human. I actually felt quite relaxed."

(Mother 4)

"He was so warm. It wasn't just a job to him." (Mother 7)

"Rather than perhaps being distant. They obviously didn't know us but they were warm, sort of normal, down to earth." (Mother 8)

"You could feel that she actually could feel what we were going through."

(Mother 9)

As a consequence, many parents felt chaplains were easy to relate to and felt valued and affirmed by their support.

"It was special, you felt special, you felt like he was making you special." (Father 7)
"That you weren't another burden, you were a person." (Mother 7)

"We felt comfortable with the chaplain which makes a difference." (Mother 13)

Such experience of chaplaincy involvement is in direct contrast to what was expected by parents before meeting a chaplain.

"There was never any awkwardness at all and I expected a lot more awkwardness and there was none of that at all." (Father 7)

"He couldn't have been more different from my preconception." (Father 12) (see **7.2.2.1.**)

8.3. Significance for parents of the immediate context in which ritual takes place.

8.3.1. Physical context

8.3.1.1. Welcoming ritual taking place in a hospital context

Parents felt that the room in which their baby's welcoming ritual took place was of no relevance, except that there was a real need for it to be quiet.

"The place was totally irrelevant, other than to say that it was very quiet which was important." (Mother 10)

Mums who could hear live babies after the delivery of their dead baby found this distressing.

"I didn't like being in that room because I could hear other babies crying. I had just lost my baby but everybody else was having them round about me." (Mother 4)

8.3.1.2. Physical context in which baby's funeral took place

For many parents the physical context in which their baby's funeral took place was of significance – being remembered as pleasant or unpleasant surroundings but also of importance because a significant proportion of parents returned to visit the cemetery or crematorium on a regular basis. Thus, some parents emphasised the need to visit the proposed site of their baby's burial or cremation before making a final decisions about funeral arrangements. A few parents had consequently made different plans after doing so.

"We went to view the area set aside for babies in our local council cemetery." (Mother 13)

"And we discussed it amongst ourselves and it wasn't quite what we expected." (Father 13)

8.3.2. Significance of people present

8.3.2.1. Family and friends

Whether parents chose to have close family and friends present was a matter of personal choice. The number of people present did not always correlate with the gestation or size of the baby. Several parents considered their baby's ritual marking as an intimate family moment – a unique opportunity when parents and baby could be a family together, and, therefore, did not want other people present.

"Deeply personal times." (Mum 10 referring to both blessing and funeral rituals)

"The blessing was very special to us because it was just for us and our baby and something you wouldn't have wanted to share with anyone else." (Mother 11)

"It was our moment." (Father 11)

During the ritual moment all that mattered in the world was what was happening and who were present in that hermeneutically sealed unit – the ritual context.

"In that moment in time it was just about us and it was the most important thing in the world to us." (Father 8)

Many parents did not want to upset relatives by inviting them and, furthermore, they felt this would add to their distress, as parents, during the ritual. Other parents did not want to feel the added pressure of real or imagined expectations about how they as parents should behave at their baby's funeral.

"I really don't think our parents would have reacted well at all to the situation. It would also have been a worry, a distraction for us." (Mother 10)

In addition, a few parents did not invite other family members as they wanted the ritual to be focussed on their baby and did not want others diverting attention onto their (parental) grief. Moreover, some parents felt it would be incongruent to invite family and friends to their baby's funeral when they had never met the baby, and, thus, would not have a sense of who they were mourning.

"How can they be sorry for this person that they never have had interaction with." (Father 13)

Many other parents valued the support of those family members and friends who attended their baby's funeral. As one father put it those family and friends who were present were "...*sharing the pain I think. Sharing the pain."* (Father 5)

8.3.2.2. Caring professionals

Midwives who were present during welcoming rituals were not only a source of support but were considered to be an integral part of the baby's story (one of the few people who had met and knew the baby) and, therefore, their presence was not only valued but was felt to be earned.

"The midwife stayed with me and it was really nice she was there to hold my hand." (Mother 7)

"She knew him intimately, she was the first person to actually hold him and see him so from that point of you it was also a thanking to the midwife just for being there and being as supportive." (Father 13)

8.3.2.3. Attitude and approach of people present during ritual

Caring professionals

Funeral directors and cemetery attendants, as well as chaplains, were perceived to carry out their roles, and treat babies respectfully, sensitively and with dignity during rituals. This was greatly appreciated by parents and felt to be a significant way in which their baby's personhood and uniqueness was acknowledged.

"The respect they showed was as they would with an adult and I think that is very important." (Mother 1)

"The chaplain and the undertakers treated our baby like they would treat any person who had lived a full life and gave her the same respect and dignity." (Mother 16)

Family and friends

Within the context of ritual created by the chaplain (see **8.2.2.1.**) many parents experienced their family and friends as being expectant, attentive and open to the present moment. This was a hallowed time and space and the attitude and approach of those participating contributed to the significance of what was shared and experienced.

"I mean the room was of no significance. We didn't, we were all too engrossed with the chaplain and what he was saying, the nice words he was saying, nothing else really..." (Father 4).

"She (baby's grandmother) just sat there and never took her eyes off the chaplain. She was amazed." (Mother 4)

Chapter 9   Co-construction of ritual

This chapter will seek to explore the implications for parents of co-constructing and then sharing in ritual marking from the results of this study (as outlined in the previous two chapters). Parents felt co-constructing and sharing in ritual marking of their baby's life and death with a chaplain enabled many of their spiritual needs to be met in the immediacy of their loss. Participation in ritual and involvement in its construction not only facilitated parental grieving but, moreover, enabled best possible parenting in tragic circumstances. The findings of this piece of research will now be explored within the context of existing relevant literature. My previous assumptions about chaplaincy support of bereaved parents and spiritual care in an acute hospital context, based on reflections on my own practice written prior to qualitative enquiry (described in the first half of the thesis), will also be examined in this and the subsequent chapter. Chapter 10 will particularly explore the theological implications of key themes identified from parental story-telling, but not explored in any depth in this chapter. Counterintuitive findings and those issues not previously thought to be of particular significance will be underlined. In addition, important aspects of parental experience which affirmed previous research or writing will be highlighted.

9.1. Parental experience of grief

This study affirmed the wide range of possible feelings evoked within parents following the death of their baby *in-utero* – some of which were found to be in common with those grieving the loss of an adult (see **3.1.2.**) and many of which other researchers have identified as feelings particular to, or intensified within, bereaved parents (see **3.2.1.**). Much of what is identified as psycho-social in medical and nursing literature relating to perinatal death is described as a spiritual issue, and explored as such, within the bounds of this study. Parents articulated a range of spiritual issues previously identified (in **4.1.3.**) as those commonly expressed by patients in an acute hospital setting, especially at times of distress or loss. What was particularly striking was the profundity of the loss of meaning and purpose experienced in parents' lives in the immediacy of their baby's death *in-utero* (see **7.2.1.2.**). Russell (1975, 198) creates a haunting image of such loss

Now she is empty, except for the tears of her womb.

Such emptiness was felt so deeply by some of the mothers (whose babies died *in-utero* from 20 weeks of gestation onwards) they revealed during interview that they had had suicidal thoughts in the days following their baby's delivery. Planning for, and focussing on, her baby's funeral significantly met one mother's spiritual need for such meaning and purpose in the days after her baby's death. In short, it gave her something to live for when it felt as if her main reason for living had been taken from her (this was her first pregnancy). This resonates with Parkes' (1996, 78) findings from his research with bereaved adults after the death of their spouse

> ...for most people in the early stages of bereavement the world is in chaos...They feel as if the most central aspect of themselves is gone and all that is left is meaningless and irrelevant – hence the world itself has become meaningless and irrelevant.

Also of heartfelt significance was parents' loss of their assumptive world (Parkes 1996) - a world which was well-ordered and just. A world in which they considered themselves and their immediate family as immortal and medical progress was such that antenatal care was felt to be infallible after the first trimester of pregnancy. Furthermore, this study confirmed previous impressions from practice of the degree of social isolation (see **7.2.1.1.**) that many parents felt following their baby's death, once they left hospital. This study's findings in relation to the lack of social support experienced by parents concur with those authors previously referred to (in **1.3.** and **3.2.5.**). Bartellas and Van Aerde (2003, 133) helpfully sum up much of what others have written and much of what I found relating to parental isolation

> Disenfranchised grief, which happens often in the case of stillbirth, is experienced when the loss is not or cannot be acknowledged openly, mourned publicly, or supported...the community in general may not recognise that a relationship has already been established between the fetus and the mother or family. Thus, the mourning person does not have a recognised right to mourn and hence does not receive support.

Furthermore, this study reinforced previous findings (see **3.2.1.**) that fathers often felt their grief, and need for support, was neglected.

9.2. Participation in, and co-construction of, ritual together enabled:

9.2.1. Parents to engage in a process of attachment to and detachment from their baby

The findings of this research verify the importance to parents of ritualising their baby's life and death (as outlined in **5.2.4.1.**) as they seek to deal with the complexity

of life and death coming together. Such a process for some parents began with seeing their baby on an ultrasound screen and remained ongoing at the time of their interview, 3 to 6 months following delivery. Such ritual remembering and ongoing parenting is facilitated by regular visits to (and tending of) their baby's grave, by the engagement with mementoes of their baby in their own home or by praying for their babies. Formal ritual moments and their co-construction were of great significance in enabling parents to form a bond with their baby whilst also acknowledging the relationship developed with him or her was not the one which was anticipated and hoped for. Thus, this study shows that these rituals have a key role in enabling parents to recognise that death is final and irreversible. Participation in them, and their formation, can help parents to develop an internal relationship with their baby that is valued, ongoing and influential in their lives. More informal ritual actions such as holding and seeing their baby or later planting a tree in memory of their baby also have importance in developing and maintaining such a bond.

9.2.1.1. Parents forming an attachment to their baby

Acting out their relationship with their baby during ritual (see **7.2.3.5.**) and talking about the significance of their relationship with their baby (as suggested by Dawson and Riches 2002 and Anderson and Foley 1998) whilst shaping its construction, assisted parents in finding a place for their baby in their story and in the narrative which they may share with their partner. Thus, an ongoing attachment with their baby may be formed, cemented or deepened during this process – a 'continuing bond' (Klass *et al* 1996- see **3.1.4.**). Memories were created that were internalised and, therefore, could be recalled, enabling the baby to become part of the ongoing narrative of parents and integrated as an 'ancestor' (Walter 1999, 75) within their wider families. Walter (1996, 22) also suggests with reference to adult bereavement

> To have a public and accurate biography told in the funeral may help mourners to find an enduring place for the deceased in their lives – not least because the recounting of it there gives them permission to continue their own recounting in the months and weeks ahead.

This study indicates that a ritual in which parents share, in itself becomes a key part of the baby's and family's story – integral to the short biography which is formed. Thus, ritual and the stories shared during its co-authoring form key memories which constitute a significant part of the baby's biography. This is of great consequence to those parents whose babies die *in-utero*. For them memories, and the opportunity to

create memories, are scarce. In addressing bereaved parents Kohner and Thomas (1995, 20) poignantly put it this way

> You may have very few memories and this is what makes them more precious. When an adult dies, there is a lifetime of memories. When a baby dies, there may be less to remember, but each memory is treasured.

This study, like Wretmark's work (1993), found participation in ritual confronted parents with the reality of their baby's life and death. However, in addition, this research highlights such sharing in ritual also offered parents the possibility of the formation of positive and life-enhancing memories to associate with their baby and their parenting of him or her. These memories are not only cherished because they enable an ongoing relationship with their baby but also because they are part of who that mother or father now is. Precious Ramotswe, Alexander McCall Smith's (2003, 13) heroine in his novel *The No.1 Ladies' Detective Agency* eloquently describes the role of memories in any of our lives

> We don't forget… Our heads may be small, but they are as full of memories as the sky may sometimes be full of swarming bees, thousands and thousands of memories, of smells, of places, of small things that happen to us and which come back, unexpectedly, to remind us who we are.

Silverman and Nickman (1996) suggest new rituals will evolve which aid the bereaved to develop and find strength from continuing bonds with the deceased and certainly this is the case in relation to baby death. Regular memorial services for bereaved parents are organised by SANDS groups and chaplains up and down the country, as well as parents being encouraged to create their own particular informal rituals (for further examples, see SANDS 1995 and Allen and Marks 1993). However, this study reveals that revisiting the way that more traditionally religious rituals are constructed and performed may also significantly help to facilitate such bonds and enable parents to have a meaningful ongoing relationship with their deceased baby. Thus, a chaplain, in facilitating co-construction and orchestrating rituals, enables '…professional intervention … (to be at least partly)[2] … focussed on facilitating the survivor's construction of a bond with the person who has died.' (Silverman and Nickman 1996)

---

[2] The words in parenthesis are mine and not Silverman and Nickman's.

Sheppy (2003), however, feels such retrospective remembrances about a human life are not what a funeral is essentially for. In his view memorial services serve this purpose. Rather, he feels their purpose is to mark the death and resurrection of a person and commit them, and their loved ones, into God's care. Bereaved parents, on the other hand, feel that their baby's funeral is about recognising their baby's unique life (and for some celebrating and giving thanks for it) as well as the reality of his or her death. This, therefore, involves the telling of the baby's story within the context of their family's and, importantly for some, the divine story. In addition, parents felt that the funeral for their baby who had died *in-utero* was also significantly about the marking of the fact that their baby did not have a life outside their mother's womb. A key element of their story, the lost hopes and dreams they had for their child, were also crucially recounted.

Parents seeing and holding their baby

Contrary to the recent findings of Hughes *et al* (2002) parents in this study did not regret seeing and holding (where possible) their baby. Parents who had had previous experience of a baby dying *in-utero* and had not seen and held their dead baby then, now regretted not doing so. This informed their decision to hold and see their most recent loss. As with Sexton and Stephen (1991), in this study it was found that mothers (and fathers) who delivered malformed babies benefited from seeing their baby after birth.

Facilitating this informal, yet profound, ritual requires great sensitivity on the part of the HCPs involved and this has implications for their training and support. The ongoing debate about this issue is best summed up by Radestad and Nordin *et al* (1996)

> A difficult balance is still to be achieved between women being forced to encounter the baby when not yet ready and others who wish the staff had given more encouragement.

9.2.1.2. Parental detachment from their baby

Paradoxically, as well as enabling parents to bond with their baby the process of ritualisation also allowed them to begin to detach from him or her - letting go physically as well as letting go psychologically of the relationship they had hoped for with their baby. Formal ritual moments provided a culturally acceptable context within which parents could express their feelings about such loss and experience the pain of separation. Furthermore, for many parents such ritual moments provided

some sense of closure and a feeling of moving on. Thus, welcoming and funeral rituals enabled parents to do grief work in terms of both a continuing bonds model and the perspective developed by Worden [(1991) – see **3.1.2.**].

Contained within both welcoming and funeral rituals for babies who die *in-utero* are both beginnings and endings. Thus, '...the most effective pregnancy loss rituals help parents negotiate this tension.' (Singh *et al* 2004, 42) Holding these dichotomous functions together during such formal ritual moments is part of the role of a chaplain; ensuring welcoming and funeral rituals give opportunity for parents to experience both. This study has emphasised that parents understand **both** welcoming and funeral rituals to have a role in enabling parents to say hello **and** goodbye to their dead babies. My previous assumption that blessings and namings primarily served to enable parents to meet and greet their baby was wrong (see **5.2.4.2.**). Parents clearly perceived such rituals as also part of the process of leavetaking. This finding correlates with Case's (1978, 12), suggestion that in order to aid what she terms '...the recognition of connection and detachment...' a suitable ritual which could be use to mark the life and death of baby dying *in-utero* in a hospital or cemetery setting should contain elements of both a baptism (i.e. welcome) and a funeral. Anderson and Foley (1998, 133) also concur that welcoming rituals '... enable the process of separation and grieving to begin.'

Welcoming and funeral rituals occur at different times in the process of the ritualisation marking a baby's life and death and are perceived by parents to have some different roles in this process (see **8.1.2.** and **8.1.3.**). Funerals were important for parents in bringing to an end the liminal period (as described by Van Gennep – see **5.1.4.)** between their baby's birth and disposal, as well ensuring their disposal was dignified and respectful. Once their babies were cremated or buried, parents had a sense of relief, being able to visualise what had happened to their baby's body and where he or she now was. This, therefore, prevented the formation of myths about how and where their baby was disposed of [as previously highlighted by Wretmark (1993)]. Parents' experience of liminality in their journey of grief did not end with the funeral but it did provide a significant milestone– a goal which they had reached, lived through and now travelled on beyond. Welcoming ceremonies, as well as facilitating some parents to see and hold their baby, were also important ritual actions which symbolised their intended approach to parenting – an action which

fulfilled (in part) personal, familial, religious and cultural understandings of what appropriate parenting should involve.

Hamilton (1999, 17) a retired Church of Scotland minister and pastoral theologian, in an article exploring how best to ritually mark a stillborn baby's life, death and birth in a hospital context, is keen to emphasise that a welcoming ritual

> ...has to avoid becoming a pre-funeral, for a funeral has a different role and other images and messages to convey.

In essence Hamilton is right - there are some differences in the form and function of these ritual moments (as described above), partly due to practical and contextual reasons. However, many of the meanings invested in these rituals by parents, as well as the variety of roles they perceived the rituals to perform, are common to both and difficult to attribute simply to one or another. *The conclusion drawn from the results of this study is that welcoming and funeral rituals should be thought of principally as part of a continuum, moments in a ritual process, which as a whole help parents to grieve (including both ongoing bonding with, and gradual separation from, their baby) and meets many of their spiritual needs.*

9.2.2. Parents to reframe their baby's life and death

Waltzlawick *et al* (1974, 95) define reframing as helping to

> ...change the conceptual and/or emotional setting or viewpoint in relation to which a situation is experienced and to place it in another frame which fits the "facts" of the same concrete situation equally well or even better, and thereby changes its entire meaning.

Co-construction of, and participation in, ritual enabled not only catharsis of parental feelings but allowed parents to talk of and act out their relationship with their baby, as well as hear their story, as interpreted by the chaplain, within the broader context of their family story and, where relevant, the divine story. This gave parents the opportunity to set their baby's life and death in some sort of context and to have time and space to begin the ongoing struggle to make sense of, or find meaning in, their experience, in relation to their beliefs and worldview. Similarly, Riches and Dawson (2000) found in their research with parents bereaved by the death of a child (of a range of ages) that being given the opportunity to have some control of, and to personalise, their child's funeral had been valuable. This enabled parents to take stock of their child's life and death, and place them within the wider setting of their family story, and all that informed it. Such reframing as outlined here is not a

particular intentional technique, in and of itself, which parallels any of those, for example, described by Capps in his book *Reframing* (1990) for utilisation in a pastoral counselling setting. However, chaplains should be aware of the opportunity for bereaved parents to reframe their story, and that of their baby, as they help parents to ritualise his or her life and death (and facilitate parental involvement in the construction of these rituals).

9.2.3. Parental (re)integration

Such activity and reflexivity (as described in **9.2.2.**) facilitated parental review and re-interpretation of their experience, potentially enabling parents to discover more of who they are and what they were becoming. Walter [(1996, 20) utilising the work of Giddens (1991)] points out that

> ...bereavement (for the post-modern person[3]) is part of the process of (auto)biography, and the biographical imperative - the need to make sense of self and others in a continuing narrative - is the motor which drives bereavement behaviour.

Opportunities for such 'personal (re)[4]integration' occur during co-construction through story-telling as Case (1978, 8) and Walter suggest. Chaplains' attentive and empathetic listening to parental descriptions of their experience helped to affirm parents that they and their stories were valued, accepted and had worth at a time when they felt vulnerable and weighed down by a sense of failure and guilt (especially those who had terminated their pregnancy due to fetal abnormality). Moreover, having the chance to help shape the content and structure of rituals, especially funerals, for their baby helped some parents to recover a sense of their creative ability and, consequently, re-enhance their self-esteem. Involvement in co-authoring ritual and in the ritual itself meant that mothers and fathers could tell of, hear about, and act out their parental feelings for, and relationship with, this particular child. Such storytelling, listening and action enabled recognition, if only partial at first, that they were not only parents but bereaved parents. Dealing with the pain and distress of their baby's death and their involvement in his or her funeral, potentially marked for some parents, their own rite of passage into adulthood. Bailey (1997, 204) is right, therefore, when she states - 'Death does change your life. It is death finally that makes you grow up.' Furthermore, experiencing the death of their

---

[3] These words in parenthesis here are mine and not Walter's.

[4] The parentheses here are mine and not Case's.

baby, participating in co-construction and sharing in ritual empowered some parents to identify, hitherto unearthed, personal resources which enabled, and in the future may again enable, them to cope with adversity. At a time when mothers (Moe 1997) and fathers may often feel they have lost a part of themselves such opportunities for reflexivity and ritual activity gave parents the opportunity to restore some sense of self. Discovering more about who they are in relation to their deceased baby and who they are in essence, through storytelling, reflection and action, gave some meaning and hope to parents in their grief. Thus, parental inclusion in shaping ritual and in the ritual itself helped to aid grieving as described within the 'dual process model' (Stroebe and Schut 1999 – see **3.1.3.**) by assisting the marking and ownership of parents' new identity as well the opportunity for the expression of grief. This study, therefore, not only affirms the transformative potential of ritual (as postulated by Driver 1991 – see **5.1.4.**) in the lives of bereaved parents, but also highlights that involvement in co-construction of welcoming and funeral rituals can also play a significant therapeutic role in their lives, following baby death *in-utero*.

9.2.4. Parenting and parental control

Naomi, a young Jewish woman in Michaels' (1998) novel *Fugitive Pieces,* recalls stories she'd heard of a mother's need, in the ghettos of a Russian city during World War Two, to parent her dead child

> The only thing you can do for the dead is to sing to them. The hymn, the miroloy, the kaddish. In the ghettos, when a child died, the mother sang a lullaby. Because there was nothing she could offer of herself, of her body. She made it up, a song of comfort, mentioning all the child's favourite toys.

Co-authoring and participating in ritual for their babies crucially fulfilled a deep need within parents to do something for their baby at a time when they felt helpless and lacking as a parent. These outlets for parental instincts, allowed them to satisfy, at least in part, their need to parent their baby and regain some control in their situation; to take ownership of the ritual (when wanted), invest time, energy and creativity in it (where possible) and, thus, make it unique for their baby. This further demonstrates how parental involvement in shaping and sharing in ritual gives bereaved parents the opportunity to meet part of their need to find some meaning and purpose in their grief. Furthermore, of profound significance to mothers and fathers were the gestures they performed in preparation for, or during, rituals. These were acts of love and care for their babies, articulating that which words could not do justice to and fulfilling

spiritual needs which at the time were only recognised in part and verbalised in fragments. Parents wanted to perform their chosen acts with

> ...dignity and pride, whatever the emotional cost. ...Satisfaction and comfort are derived from ensuring that everything about the funeral is as good as it can be.

McHaffie (2001, 228)

Therefore, such acts, performed to the best of their ability reduced parental unfinished business and parental regret.

A further expression of parental need to do the best they could for their baby was to ask a representative of the church to share in their baby's ritual. This enabled them to have someone who was perceived to be the most culturally appropriate person to perform a funeral or welcoming ritual (even in postmodern times most adult funerals in Scotland are led by a church representative) and to enhance the efficacy of that ritual. Therefore, parents felt they were affording appropriate respect and dignity to their baby as a human being and, as some parents saw it, ensuring their eternal destiny.

Being true to the postmodern trend of affirming individuality in patterns of grieving, co-construction of ritual gave parents the opportunity not only to regain some control in their situation but also to express their own grief narrative. Furthermore, parents were empowered to do so in a manner appropriate to them, through words and ritual action, without fear of judgement of that narrative and their particular expression of it. However, conversely, sharing in rituals and their co-construction significantly helped to provide a much needed degree of regulation to parental grief (Walter 1999 - see **3.1.5.**). In addition, co-construction also importantly enabled regulation of the content and structure of the rituals which parents helped to shape and then participated in. At a time when parents were unsure whether their feelings and perceptions were normal, as well as being uncertain how to express (in a culturally acceptable manner) the well of emotions within them and how their various needs (both those which could be articulated and those which could not) may be met; ritual marking and its co-construction prevented parents from being completely lost and overwhelmed. The facilitation, concurrently, of both individual expression and sensitive regulation of grief, can occur when the construction of ritual evolves from the parents' particular story and the chaplain involved works and shares ritual with parents, rather than imposing a prescribed liturgy and performing ritual for them.

9.2.5. Facilitation of an appropriate degree of regulation of grief and ritual content and form

9.2.5.1. Co-construction of ritual

Parents greatly appreciated being given a range of resources by the chaplain working with them during co-construction from which they might select prose, poems, songs, music, biblical passages or hymns, either previously chosen or written by other bereaved parents to aid personalisation of ritual content. This sharing of such cultural norms helped reduce parental feelings of isolation - parents developing an increased awareness that many other mothers and fathers had also experienced baby death *in-utero*. It also aided normalisation of their grief as parents resonated with the range of feelings and spiritual issues that others had felt and struggled with. In addition, parents appreciated chaplains sharing something of the experience of grief of previously bereaved mothers and fathers which enabled them to recognise feelings, issues or awkward social situations that they later encountered as not unusual. This complemented written material (published by SANDS) parents were given by midwives before they left the labour suite (Bartellas and Van Aerde 2003 also suggest giving parents the addresses of websites providing information about grief). Moreover, being informed of the various ways in which previously bereaved parents had been actively involved in rituals for their babies gave parents opportunities to choose how to act out their feelings (if they wished) and to meet, at least in part, some of their parenting needs. Parents, therefore, could make informed choices regarding how rituals for their babies were performed and ordered, and who and what was involved. This was of considerable value in empowering mothers and fathers to parent their baby in a manner appropriate to them and their beliefs and worldview. Thus, co-construction prevented the imposition of an alien and irrelevant liturgy on non-practising parents.

By sharing practical information about ritual marking of a baby's life and death and cultural norms regarding the structure and content of rituals, during co-construction, chaplains offered sensitive regulation of welcoming and funeral rituals, as well as of grief. This also avoided an equally inappropriate scenario in which parents could be left to flounder – having to attempt to make decisons about ritual marking with little or no information, a dearth of possible relevant resources and lack of guidance as to how to structure or shape formal ritual. Thus, the sharing of cultural norms requires discernment and self-awareness. Chaplains need to achieve a balance between

imposing prevalent cultural norms, which would include his or her own attitudes towards death and ritual as well as the accepted norms within the healthcare setting in which he or she works (see **3.2.4.**), and leaving parents virtually to their own devices in a potentially bewildering and disorientating situation. The SANDS 'Guidelines' (1995) insightfully suggest an awareness of their own response to personal experiences of, and beliefs about, death and associated rituals is key for anybody working with bereaved parents.

Parents in this study wanted to regain some measure of control in their situation and find relevant and fulfilling expressions of their parental sensibilities and beliefs which could be utilised or performed during ritual (particularly with regard to funerals). However, to do so parents required chaplaincy support during co-construction whilst they explored their options (and had these alternatives re-iterated, often several times). They also appreciated advice about the possible practical and emotional consequences of making particular choices and direction as to how the ritual could be structured as a whole. Having to create meaningful rituals without guidance would have added to parental distress and confusion, and rendered many parents overwhelmed and unable to do so in such unchartered territory. The aforementioned 'over-' and 'under-regulation' [Walter (1999, 122 and 124) uses these terms with reference to grief] of ritual construction may well mask discomfort on the part of the chaplain involved and an attempt at self–protection; an unwillingness to risk real engagement with, and exposure to, parental stories of pain and distress.

In order to achieve this balance during co-construction a chaplain, after having listened to the parent's story, may offer suggested relevant reference narratives for ritual content, and a provisional framework to enable ordering of the chosen substance, for welcoming (where possible) and funeral rituals. This is done with the aim of providing comparative markers to help facilitate informed parental decision making and, thus, enhance the opportunity for ritual ownership. The content and form of rituals can then be negotiated in light of parental preferences (where they feel able, and wish to, articulate them), according to their particular experience, feelings and beliefs.

In referring to what they consider the prevalent cultural norm within maternity units - creating an atmosphere within which mothers feel it is imperative for their

psychological well-being to see and hold their stillborn baby - Hughes *et al* (2002, 117) say this

> Our overall impression, however, was that most mothers were shocked and had no clear plan of how to manage the situation: they simply went along with whatever was expected of them.

This can also be true for other cultural norms relating to the ritualisation of a baby's life and death – parents will tend to acquiesce to prevalent models or perceived norms at a time of great vulnerability and distress. They may find it very difficult to say no to what is suggested to them, especially when the norms are outlined by a chaplain - someone who is regarded as an expert in matters relating to death and ritual. This will be equally true of other HCPs, as persons also in positions of power and authority, caring for bereaved parents whilst they relay prevalent cultural norms which are part of the protocol for dealing with baby death *in-utero* in their maternity unit. Therefore, parents should always be given plenty of time in which to absorb the cultural norms that have been described to them, and to begin to acknowledge the reality of their experience. Such norms should not solely be explained to parents in the immediacy of the labour suite but outlined beforehand (where possible and suitable) and repeated at a later date. Moreover, they should be given in written as well as in verbal form (Brown 1993) and parents should be given ample opportunity to ask questions and clarify issues.

Parents in this study experienced the co-construction of ritual as a process which they and the chaplain were engaged in, not as a one off event where instantaneous decisions had to be made. They valued and appreciated time alone, as individuals and as a couple, and in conversation with the chaplain (in person or on the phone) which allowed the formation of ritual to evolve - a period of wrestling and reflecting, deciding and then re-visiting. This was a process set in a context of confusion and ambiguity, during which reality was being confronted and avoided (as described by Stroebe and Schut 1999 – see **3.1.3.**) and beliefs were being questioned and clung onto. Mothers and fathers needed time in which to have the opportunity to share their feelings with each other (and sometimes with family and close friends) about their baby's death and the significance (or not) of ritual marking. Moreover, they needed space in which to assess the degree of involvement each sought in the construction of ritual and in its performance, to talk through their different perspectives and negotiate issues such as ritual content and form. Parents found that they changed their minds over a range of issues relating to ritual marking (including initially

whether to have a ritual or not and whether be involved in its formation), right up to and even during the ritual itself (going with their instinct in the situation). Informing parents of what assistance was available to them and what other mothers and fathers had done in the past for their baby and to help themselves, was useful to parents in this study. However, it should always be borne in mind that every parent will deal with grief in a different way and that their individual wishes and choices should be respected. What is crucial is that they have been given information about practical issues and prevalent cultural norms, in a timely and sensitive fashion, to enable them to make informed choices regarding ritual marking and bereavement support.

Cultural norms are at best potentially helpful guides and at worst anxiety heightening straightjackets as Hughes *et al* (2002) suggest in relation to parents seeing and holding their dead baby. They are, in essence, derived from what practices previously bereaved parents found helpful in dealing with their baby's death. Thus, ideally cultural norms are informed by research performed with bereaved parents, HCPs collaboratively working with, and listening intently to, bereaved parents (as in the development of the SANDS Guidelines 1995 – see **3.2.3**.) and the ongoing reflective practice of HCPs. However, there always remains the danger that some cultural norms have their foundation in benevolent assumptions made by HCPs, including chaplains, who are in positions of power and authority (whether they are fully aware of how influential they may be in parental decision making or not).

The offering of ritual marking for babies dying *in-utero*, in the second trimester of pregnancy, has become an increasingly prevalent cultural norm within healthcare, encouraged by increasingly vocal bereaved parents. Parents in this study who experienced a late miscarriage found, on the whole, involvement in co-construction and the rituals themselves of great significance in enabling formal recognition of their baby's existence and in creating tangible and positive memories of their experience. However, one mother (a doctor) articulated her initial ambivalence not only of ritual marking but her discomfort in calling what was lost at 18 weeks of pregnancy 'a baby'. She wondered, at the time, if such ritual marking was disproportionate and 'over the top'. Her husband (also a doctor), on the other hand, was keen to ritually mark his baby's life and death. In retrospect, this mother was glad her baby had been afforded the dignity and respect of culturally appropriate rituals which acknowledged the baby's impact on their family circle and the loss of what should have been.

Therefore, the sharing of cultural norms, like an account of the grieving process or grief work, needs to be descriptive – enhancing parents' awareness of what is available and outlining what behavioural and emotional responses to baby death *in-utero* other parents have made. Thus, helping them make informed choices. A prescriptive approach – making parents feel they have to agree to ritual sharing, conform to a particular form of ritual or mode of ritual construction or, indeed, conform to other people's description of their pregnancy loss which they feel uncomfortable with – is to be avoided. As Lewis and Bourne (1991) warn, such imposition of cultural norms which conflict with a person's instinctive approach to dealing with miscarriage may interfere with their own particular coping mechanisms.

9.2.5.2. Participation in ritual

It was not only sharing in the construction of rituals that enabled regulation of parental grief but, moreover, participating in ritual marking also helped to do this. Sharing in rituals aided the orientation of parents in the alien and inhospitable wilderness of grief following baby death *in-utero*. Ritual provided signposts or cairns - 'cultural landmarks' (Riches and Dawson 2002, 185) - which aided negotiation of a parent's, or couples', particular journey of grief in what was experienced as otherwise largely unknown territory.

Furthermore, participation in ritual also aided the regulation of parental grief and behaviour through the chaplains' acceptance, without judgement, of their verbal and physical expressions of grief during the sharing of ritual and its formation. In addition, during a welcoming or funeral ritual parents heard chaplains describing the depth of their parental feelings and how they struggled to deal with them, as part of that ritual. This affirmed parents in their grieving, and particular way of coping, as well as giving them permission to allow themselves to continue to do so.

In conclusion, co-construction and sharing in rituals which parents have had the opportunity to invest in and shape, helped to sensitively regulate the content and structure of ritual marking, as well parental grief itself. This not only helped parents' spiritual needs to be met but also assisted them in dealing with the psycho-social aspects of their grief.

9.3. Significance of ritual marking to parents

This study confirmed that the decision by parents to share in welcoming and funeral rituals for their dead baby was a very important one in fulfilling their need for the

public recognition of significance of their baby's life and death (Jones 1997). This was particularly true for the parents of babies delivered during the second trimester whose existence is not recognised by wider society in any other form of ritual, such as registration of their death or birth. Furthermore, like Leon (1992) in relation to funerals, this study revealed ritual marking met the parental need for acknowledgement of their baby's personhood and the depth of their love for, and grief felt through the loss of, that small person. McHaffie (2001) suggests recognition of these are key parental requirements of a funeral for a deceased neonate. As with the work of DeFrain (1986), this study, found that funerals for stillborn babies enabled others to recognise the baby as part of the parents' family. Ritual, therefore, facilitated deeper understanding by the wider community of the significance of parents' loss and their relationship with their baby. In this piece of research, moreover, parents also used the topic of ritual, especially funerals, as a common reference point in conversation to aid discourse about their baby, in an effort to reduce feelings of social isolation. In addition, ritual also enabled acknowledgement of a baby's uniqueness (as the context in which formal naming, or at least formal recognition of the baby's name, took place) and, thus, the declaration of a separate identity (Jolly 1976). Davies (1996, 60) puts it this way

> Naming is another way to acknowledge the baby's existence and individuality. A name is personal and lasting.

The uniqueness and importance of a particular baby who had died *in-utero* was not only expressed in the performance of a formal ritual itself, but was also conveyed to parents by what happened during the ritual. A chaplain's gesture of holding her baby during the baby's naming and blessing ceremony was deeply meaningful to one mother – an act she interpreted as overtly recognising her baby as special and precious. In addition, the manner in which a chaplain performed a ritual was also perceived by parents as important. Many parents described chaplains as being moved or touched by their involvement in ritual, which conveyed to parents that '…their baby was worthy of mourning…' (Kirkley-Best *et al* 1982, 20) and his or her death and birth was significant and not a 'non-event (Stewart and Dent 1994). Chaplains were also observed by parents to perform their baby's funeral in a dignified and unhurried manner which they felt communicated that their baby, and their grief, was worth taking time and trouble over. Furthermore, it was not only chaplains who treated parents and their baby with dignity and care during, and around, a time of ritual sharing. Those involved in other caring professionals did likewise (as they

would with a person who had lived a life outside the womb), further reinforcing the feeling parents had that their baby was of consequence and that their grief was valid.

A public expression of emotion in Britain due to grief or loss is, on the whole, considered culturally inappropriate. In response to Paula Radcliffe's well publicised overt display of distress during the Athen's Olympics, the Times columnist Jane Schilling (2004, 2) wrote this

...weeping for reasons of distress rather than overwhelming joy is still a fearful social misdemeanour – a catastrophic form of emotional incontinence from which onlookers recoil...

Parents, however, within the context of ritual felt safe enough to express themselves as they needed to (see **8.1.1.6.**), no matter what their gender or social background, and at the same time they also felt free from cultural restraints to act out gestures of love and care which in other contexts they would never have dreamt of performing (see **8.1.1.7.**).

As mentioned above (see **9.1.5.1.**) Bourne and Lewis (1991) caution against over-intervention on the part of carers, including encouraging ritual marking, following miscarriage though they recognise that in particular circumstances (such as recurrent miscarriage) the parental distress caused may be significant and professional support may be required. Moulder (1998) feels that the influential SANDS guidelines (1995) implicitly assume that there is a spectrum of loss during pregnancy with an early miscarriage not being experienced in the same way as a stillbirth. Some parents participating in this research project did feel their loss would have intensified had their baby died later in pregnancy and that the gestation of their baby dictated their approach to who should be present during ritual marking (see **7.2.1.6.**). However, the findings of this study concur with Mander (1994) that HCPs, including chaplains, should respond to parent's particular loss for what it means to them (at whatever gestation their baby dies *in-utero*). Undoubtedly, there were parents interviewed whose baby died in the middle of the second trimester who, influenced by their distinct personal, familial, religious and cultural story, and present situation (see **7.2.1.6.**), were spiritually distressed. Facilitating their participation in co-construction and ritual marking was an appropriate response to their particular needs. For these parents their experience was the death of a baby, a human person, not the end of a pregnancy. This study found that different facets of parental narratives shaped their attitude towards, and relationship with, their developing baby *in-utero* and after

delivery [including antenatal ultrasound scanning from early in the second trimester aiding parental attachment, as Theut (1989b) surmised (see **3.2.1.**)]. Simmons (1983, 81) citing the German theologian Jurgen Moltmann (reflecting within the context of the abortion debate) puts it this way

> For him (Moltmann), the origin of humanity is not in biological beginnings but in the atmosphere of acceptance and recognition by others, since it belongs to the essence of human life that it is accepted and affirmed, recognised and loved.

Thus, the parents in this study, who chose to ritually mark the life and death of their baby, had by the time their baby died *in-utero* begun to form a relationship of love and acceptance (to varying depths) with him or her, which they sought to recognise in ritual.

The findings of this study concur with the recommendations made by the Royal College of Nursing (2002) and SANDs (1995) that parents should be sensitively given options for ritual marking and respectful disposal of the remains of their pregnancy loss (if there are any) or baby, no matter at what gestation this occurs. Moreover, it reinforces the fact that the decisions parents make regarding ritual marking and disposal will be influenced by their unique circumstances and story, and feelings towards the fetus (in this study from the second trimester onwards). Therefore, it is imperative that the choices made should be respected by the HCPs working with them (no matter what their own perspective is). The relationship a woman or man has with a developing fetus or baby *in-utero* is highly subjective and, therefore, so will their attitude be towards disposal and possible ritual marking.

Some parents interviewed perceived ritual marking to not only enable public recognition of their baby but that such culturally appropriate behaviour for any human being provided some respect and dignity to the situation [as did asking a church representative to take an active role – (see **9.2.4.**)]. Sharing in rituals to mark their baby's life and death was, therefore, understood as part of their moral responsibility, their duty, as a parent.

Participation in ritual for their dead baby enabled parents to formally recognise their baby's place in their family and to act out their relationship with him or her (see **8.1.1.2.** and **7.2.3.5.**). As previously described (in **9.1.1.1.**) such involvement enabled parental bonding with their baby but also potentially between parents themselves. In short, sharing in formal ritual allowed parents and baby to be a family together (especially if they were shared only with the chaplain), albeit for a few moments.

This is a profound expression of what Turner (1969) felt the term '*communitas*' to be, as experienced during rituals of intense emotion (Driver 1991) and in which much meaning is invested and found (see **5.1.4.**).

9.4. Significance of co-construction to parents

Co-construction enabled authentic and relevant rituals to be formed and shared in a postmodern context, irrespective of parents' religious or social background, which reflected and valued their particular beliefs, feelings and lived experience. This study found it was important for parents to be able to choose their level of involvement in shaping ritual and to control to what extent they participated in the ritual itself. This ranged from parents writing material and selecting readings and prayers (from a variety offered by the chaplain or from their own sources) to contribute to, or form the whole of, the verbal content of their baby's funeral service to parents telling their story, including that of their baby, during co-construction and the chaplain weaving it into the ritual (see **7.2.3.5.**). The active participation of parents in ritual itself varied from the bringing of specially chosen flowers to the reading of a letter or poem specifically written or chosen by a parent for their baby (also see **7.2.3.5.**). The facilitation of parental involvement by chaplains has to be done with sensitivity and discernment as parents who feel unable to take an active role in co-construction, or indeed to attend a ritual, should not be made to feel as if they have failed their baby for a second time. Thus, for HCPs, including chaplains, - '...flexibility towards the mother's own wishes rather than insisting on mourning rituals...' (Rand *et al* 1998, 47) is important in their approach to supporting bereaved mothers (and fathers). Conversely, as Moulder (1998) points out, there may be times when parents want the HCP responsible for a particular aspect of their care, at certain times, to take control and make decisions on their behalf. Chaplains have to be sensitive to this also in offering or, indeed during, co-construction.

Wretmark (1993) makes the point that parent support groups have been instrumental in creating rituals for babies dying *in-utero* which have historically had more relevance than those produced by the liturgical committees of the major denominations of the Church in the Western world. However, as previously outlined (in **3.2.5.**) in the past decade many liturgies for such ritual marking have shown increasing receptivity to the voices of bereaved parents. Moreover, as Walter (1990) and Wretmark (1993) suggest, hospital chaplains generally do not tend to use set or given liturgies for rituals shared with bereaved parents in the context of baby death

in-utero but adapt material from various sources including - from their own and other traditions, the writing of bereaved parents and non-religious (but often deeply spiritual) poetry and prose. Reflection on the findings of this study has reinforced my belief (as outlined in **5.2.6.**) that each ritual co- created and shared (where prior interaction and co-construction is possible) by parents and a chaplain is not just personal, amended from different sources to be so with relevant names and information inserted, but is unique. Each ritual co-constructed and shared by a chaplain and a family for their dead baby is original not merely a variation on a liturgy previously devised by a chaplain (even if it is informed by sensitive reflection on prior practice). The ritual emerges from the parent's distinct story, circumstances and perceptions, and that of their feelings for their baby, as heard and interpreted by a particular chaplain (the interpretation influenced by his or her story, and all that informs it) in the specific context of their working relationship. Foskett and Lyall (1988) use the apt metaphor of the intercourse of narratives to describe this process of the meeting of stories; out of which is created something entirely new. Thus, what a chaplain should bring to any encounter with bereaved parents who seek to ritually mark their baby's life and death is not a prescribed ritual which can be tweaked and twisted in order to personalise welcoming and funeral rituals to fit any situation or story. Rather, what a chaplain should take into such a relationship where ritual is co-authored and shared (as well as a high degree of self-awareness) is primarily a set of principles to inform the practice of such.

The concept of principles underpinning the care of bereaved parents is commonplace in the field of healthcare (see **3.2.4.** - those previously described are not specifically intended to aid chaplains in the process of constructing and sharing in ritual marking, but HCPs' general approach to bereavement care). The aforementioned principles of practice which may inform the co-construction of, and performance of, ritual (to be described fully in chapter 11), along with attentive ears, their humanity (informed by his or her story and the Christian meta-narrative which informs it) and a high degree of self-awareness, are the key resources a chaplain can utilise to help meet parental spiritual needs following baby death. If these resources are used with discernment, complemented by the sensitive offering of a range of written material and options to enable parental control and involvement, relevant rituals can be shaped and shared that parents can call their own for their baby.

Furthermore, this study affirms David Stoter's (1995, 8) assertion that

...in order to be able to offer spiritual care at all, the carer must be acceptable to the person receiving the care...moving onto deeper levels needs a caring relationship or contract to be firmly established where the recipient can accept the carer as someone who can be entrusted with all their needs, hopes and fears, pains and distresses and to whom they can entrust themselves fully and totally.

The process of co-construction enabled parents and chaplain to begin to develop such a relationship, where assumptions might be cast aside, acceptance given and received, and trust established. Thus, establishing an appropriate atmosphere within which parents could be themselves and express their needs openly [and not feel subdued by the chaplain's perceived ritual authority (see **5.2.9.**)], empowering them to work creatively together with the chaplain. The findings of this study verified that patient's spiritual needs are best assessed and met within such a relationship of trust (see **4.1.4.**), where even within a short period of time intimate and troubling aspects of parental stories may be shared and concerns about the implications of various aspects of ritual and the means of their baby's disposal aired. Significantly, having the opportunity to develop a sense of the chaplain's approach and humanity, as well as professional capabilities, during co-construction, helped to reduce parental concern about further interaction with the chaplain and the subsequent ritual which developed from such engagement. Co-construction also enabled an opportunity for mutual clarification of the content and order of rituals and the roles to be played by various parties within its context. Such reviewing of ritual prior to its taking place, facilitated by the chaplain, also considerably reduced parental anxiety about, what was for most, involvement in an unknown activity. Parents sought to know in advance what was going to happen during ritual so they could prepare themselves and when a ritual did not follow their imagined internal script, this added to their distress. The chaplain's approach in managing co-construction as a process over a period of time, and not a single event, enabled parents' changing spiritual needs to be re-assessed (where appropriate and possible) and relevant adjustments made, if necessary. Parents in McHaffie's study (2001), as they did in this piece of research, found it supportive and comforting if the chaplain who shared in their baby's funeral had previously met their baby and knew something of their story. Likewise, parents appreciated continuity when the same chaplain who was involved in blessing and naming their baby, shared in his or her funeral.

Having explored the findings of my study within the context of previous relevant research and writing as well as in light of my own reflections on practice, I will now seek to engage theologically with some pertinent themes arising from parental experience of sharing in co-construction and ritual marking of their baby's life and death. The issues to be explored in chapter 10 have, in the main, not yet been examined in any depth.

Chapter 10   Theological fragments

Fragments of a variety of theological themes have emerged from the qualitative research performed with bereaved parents in this study. Several of these fragments will now be pulled together not to form a completed mosaic but rather to give an impression or suggestion, utilising these pieces, of God's involvement in the relationship between a chaplain and bereaved parents. The following themes will be explored in this chapter

- The different ways the Christian story is entwined, and shared, within the relationship between a chaplain and bereaved parents during co-construction and the sharing of ritual marking.

- The paradoxical utilisation by chaplains of their authority and vulnerability in order to meet parental spiritual needs.

- The implications of this study's findings on the selection and personal and professional development of chaplains.

- What co-constructed ritual offers the church as well as bereaved parents.

10.1. Weaving together the human and the divine

In Anderson and Foley's (1998, 118) seminal work on the relationship between narrative and ritual, they emphasise the importance of weaving together, in a funeral service '…the human and divine stories…'. Anderson and Foley underline the importance of doing so through the spoken word. However, I would like to suggest that it is not just through this means that the Judeo-Christian narrative meets with, and reciprocally touches, the human narrative of each particular family and chaplain during their encounters, including ritual sharing. In the first section of this chapter I will describe several ways by which the divine story of love and compassion may find expression in the form, words and actions of the chaplain, within the process of co-construction and in ritual sharing.

10.1.1. Embodying the divine story

The chaplain incarnates different dimensions of a human understanding of God and the Judeo-Christian tradition within a secular setting. I would suggest that a chaplain does this in two slightly different ways.

10.1.1.1. Chaplain as a representation of the divine story

A chaplain may signify something of the divine to parents irrespective of his or her individual personhood, character and way of relating. There are different perceptions about aspects of the sacred in life, and beyond life, which parents project onto a chaplain which are distinct from who the chaplain is and how he or she interacts with others. These subjective parental associations are shaped by prior experience and their cultural and religious background. This topic has already been explored (in **4.2.1.1.** and **5.2.9.**). However, there a few points that deserve further brief comment derived from reflection on this study's findings.

- Many parents undoubtedly felt that the very presence of a chaplain helped to sanctify ritual in some way – make it special and more reverential (though the approach of the chaplain and the intimate and expectant atmosphere of the ritual context which he or she helped to create also contributed to this).

- A chaplain made visible the Christ who was already present in a deeply distressing situation. He or she acted as a 'non-verbal symbol' (Wretmark 1993, 180).

- For one set of parents the chaplain was a reminder of the Easter story which correlated with their experience of their twins' deaths and the funeral as a rite of passage (as described by Van Gennep – see **5.1.4.**). The chaplain, for these parents, was associated with the pain and death of Good Friday (the experience of the death of their twins), the waiting of Holy Saturday (the period of limbo between delivery and funeral) and the hope of resurrection (for both baby in the next life and parents in this). Following the death of their babies, the chaplain's involvement in their story brought to mind the Easter story which culminated in death and suffering being overcome, and which gave these particular parents hope for their babies and themselves. It is interesting to note that only one of the parents was an active member of the church, the other recalled the story of Jesus' Passion and resurrection from his childhood.

10.1.1.2. Availability and personhood - being the divine story

The spiritual care of bereaved parents does not begin with assessment of their spiritual needs. It begins with the chaplain (or other HCP) who seeks to offer such

care. At the heart of spiritual care is the personhood and the spirituality of the care-giver.

The findings of this study (see **8.2.3.1.**) emphasises that a chaplain may convey something of God's love and care to a bereaved parent not just by what he or she represents to them, but also through the chaplain offering an unhurried supportive presence and actively listening to parental concerns (as previously described in **4.2.1.** and **4.2.3.**). In addition, parents highlighted that the manner in which chaplains made themselves available and related to them in their distress was of great significance in enabling a relationship whose depth and level of established trust was often inversely proportional to its duration. Murray and Grant (2003) in a qualitative study investigating how terminally ill patients felt their spiritual needs had been met, found that GPs who developed a relationship with patients in which they felt respected, affirmed and accepted helped, even inadvertently, to meet patients' spiritual needs.

A relationship in which personal feelings and needs are shared and explored, and ritual co-constructed, is a means by which something more than an exchange of words may be experienced or conveyed. This study revealed that relationships in which trust and rapport was developed, where parents felt they could be themselves and share the intimacies of their story were a source of hope and potential healing. As Lyall (1999, 19), in theological terms, puts it

> It is the (pastoral) relationship which is a sign of the kingdom, a metaphor of grace.

Every human being has a unique story and needs which are important to her or to him. Listening and responding to the needs of individuals was central to Jesus' ministry. He paid attention to individuals and what they sought from him – he listened to their particular story - amongst the stories of many. Jesus responded to the specific needs of individuals, not just to the general needs of people of his time, whom he encountered. For example, a woman who suffered from debilitating menstrual bleeding was singled out by Jesus from a gathered crowd after she touched his cloak and he gave her, and her story, his undivided attention (Mark 5:24-32). For those who seek to co-construct ritual with grieving parents there is a need to begin where the parents are, not where the chaplain thinks they are, and to hear their unique story and the unique story of their pregnancy and their baby. These stories are to be treated with reverence for stories help define who we are, as well what we have been and influence who we may become. Thus, it is not just the relationships in which

rituals are co-constructed or the rituals where narratives are enacted which are sacred; so too are the stories themselves. The sharing of stories, the telling and the listening, is a hallowed activity. To be story orientated, attentive to the story of a particular family and the place of their baby in it, is to be Christ-like.

In making ourselves available to a bereaved parent, being attentive to their feelings and needs in the present moment is to, therefore, offer something profound. It is to offer our inner selves as well as our physical presence. Such an offering is potentially costly yet, paradoxically, it is also an opportunity for growth. Case (1978, 18) puts it this way

> To listen is to enter the time of stillbirth. It is to take onto oneself the brokenness which is evident in the other's life and to let awareness of our common brokenness come to consciousness. It is to feel and wait…through times of weeping and panic, knowing all the while that the pain of our lives is something to move forward, into, through. We cannot avoid it and remain truly ourselves.

It is an active choice to be vulnerable (Herrick 1997), to be open to parents' stories and committed to their care; making ourselves available to bereaved parents is a loving action rather something passive happening to us. Jesus communicated God's love for people not only by what he said but by offering himself to others. An influential document produced as a Pastoral Instruction of the Roman Catholic Church within the context of the development of new methods of mass media, entitled *Communio et Progressio* (1971, 76) has something very relevant to add to the theological consideration of a chaplain making him or herself available to grieving parents. It says this

> ….he (Jesus) gave his message not only in words but in the whole manner of his life…Communication is more than the expression of ideas and the indication of emotion. At its most profound level, it is the giving of self in love.

Taking such a conscious decision is risky, as Case (1978) indicates. It involves exposing ourselves to the pain and questioning of parents, the possibility of our own wounds being re-opened and, thus, our story, and all that informs it (including our theology), being challenged and significantly changed. Therefore, to do so involves courage, as well as self-awareness (see also **10.3.1.1.**), to enable separation of feelings and issues which belong to parents and those which are ours, and the motivation to enhance the well-being of others. Campbell (1986, 33), whilst writing in the context of pastoral care, describes such qualities possessed by Jesus

> The courage of Jesus has a quality to it that is both strong and gentle. Above all, it is a courage for *others,* not a courage for his own defence or aggrandizement.

Though we can never assume we know what another is experiencing, we all do have some knowledge of pain and loss and this gives the possibility of us comprehending and sharing another's suffering for a while. Meeting parents' spiritual needs, however, is not just about suffering with them but is also to be part of that which potentially aids healing. This does not entail a chaplain attempting to take away parents' pain but a 'steadfastness' (Campbell, 1986) to stay with their questions and confusion as they wrestle with them. For parents in this study it was of great significance that a chaplain was prepared to be with them and listen to them in the midst of a myriad of conflicting emotions. In this respect chaplains were perceived as being different from other HCPs (especially midwives) in their approach to offering care. Parents, from their experience, understood a chaplain's role as initially making space for silence and listening to their stories rather than primarily being task orientated.

> ...silence is often our greatest service. By remaining *with* people, but at the same time refusing to take the escape from pain they seek, we can restore their courage to voice their deepest fears and express the anguish they find so threatening.

> Campbell (1986, 44)

Availability and chaplains' personal qualities

The findings of this study emphasise that a chaplain's ability to provide sensitive spiritual care depends not so much on his or her qualifications, skills or use of therapeutic techniques but on innate personal qualities (though the utilisation of such gifts can be enhanced through learning new skills and honing existing ones). Moreover, though a chaplain performed a variety of roles during co-construction and in sharing ritual, it was not simply by carrying out these roles that the chaplain was of help to parents. The natural attributes of the chaplain and how he or she utilised these in relating to parents was of profound significance to them. Oswald and Kroeger (1988, 29) writing about pastoral care in an American context emphasise this key point.

> A role encompasses far more than functions. For example being a good parent involves more than providing food and clothing for children, disciplining and loving them. The role of parent involves being as well as doing. A parent's character, personality and inner disciplines are more important than any specific things he does for the

child. Likewise a good pastor is far more than someone who performs certain functions for parishioners.

It was the chaplain's personal qualities and their sensitive utilisation of them in responding to parents' particular needs at different times in the process of co-construction which was paramount in enabling their spiritual needs to be met. Neil Pembroke, a pastoral theologian who has been influenced by the work of Buber and Marcel, describes in his recent works *The Art of Listening* (2002) and *Working Relationships* (2004) two essential gifts that a spiritual carer requires in order to offer others a depth of availability and attentiveness in the present moment. These attributes are compassion (associated with the notion of tenderness) and charm. From the findings of this study it is also clear that the gift of discernment is also an important quality to be possessed by a chaplain offering spiritual care to bereaved parents. These three natural abilities will now be briefly explored in relation to parents' perceptions.

- **Compassion**

Pembroke (2002) describes the biblical notion of compassion as being associated with an instinctive, intimate relationship. In the world of the Israelites compassion was linked with a Hebrew word group which indicated the type of feeling a mother has for the child of her womb. However, compassion, according to Paul, is more than a registering of an emotion; it is an expression of one's total being at the deepest level. The Greek word he uses, *splanchnon,* originally referred to the '…inward parts of the body…' or to the womb. (Pembroke 2002, 5)

Compassion, thus, infers that the carer hears or observes someone's suffering and is deeply moved and responds in a tender and loving way. Compassion is more than empathy and acceptance, which are attitudes adopted towards another that convey availability. Compassion is not a demeanour that can be assumed in certain circumstances and in certain relationships; it is a way of being.

For Pembroke (2002) the biblical understanding of compassion is closely allied to tenderness (which could also be apportioned to Jesus' way of being) and, likewise, is a quality which is gifted rather than learnt and is also observed in a carer's way of relating (in their physical as well as verbal response) to another. Pembroke (2002, 57) cites Thorne (1991, 75) when describing what tenderness may be.

> It is a word "which means both vulnerable and warmly affectionate, easily crushed and merciful, not tough and sympathetic. It seems to

incorporate both weakness and gentle strength, great fragility and great constancy."

Parents greatly appreciated the compassion and tenderness chaplains displayed towards them. This was revealed in their way of being present, including their physical responses (for example, their body language, facial expressions and, sometimes, their tears) to parental pain and the way their actions were carried out and words spoken (see **8.2.7.** and **7.2.3.5.**). Parents perceived such visible expression of the chaplains' feelings as genuine. Thus, the chaplains' transparency and congruence was a valued dimension of the supportive presence they offered.

- **Charm**

The concept of someone possessing charm is not always associated with positive connotations – a charmer being perceived as someone whose smooth talking influences the decision making of another. However, Pembroke (2004) highlights a more positive usage of the term, based on the work of Marcel (1950), which has relevance to our discussion of innate qualities possessed by chaplains, and identified by parents as having a significant bearing on the quality of spiritual care they delivered. Charm is a gift which enhances the ability of those who possess it to build up relationships with patients or clients and put them at their ease. Pembroke (2004, 79) defines a person of charm as

> ...one who lives in and through a unity of *agape* and *eros*. *Agape* is expressed through an act of self-denial in which one's own needs and desires are temporarily suspended in order to attend to the other person. *Eros* produces a passion for life, for others, for God. It is a physical and spiritual energy that animates a person and renders her attractive and engaging.

We can only be charming as carers when we are truly being ourselves, not striving to be something which we are not. Charm, therefore, is a gift which is linked to consistency of character. It involves integrity - being the same person with parents in the immediacy of a delivery room, when relaxing with other labour suite staff in the coffee room and when involved in sharing the baby's funeral a week later. We can only fully express God-given charm when we are able to accept ourselves for who we really are and live lightly with feelings of failure and shame (see also **10.3.3.1.**)[1]. The very presence of a chaplain who possessed natural warmth and a genuine interest

---

[1] Pembroke (2002) offers a helpful description of utilising such feelings, evoked by an awareness of being less than fully present with another, to aid potential self-growth and improve future practice.

in others helped bereaved parents in this study, at a time of great distress, feel able to relate to him or her and express themselves as they needed to. Moreover, the luminescence of chaplains was a source of hope and encouragement, in and of itself.

- **Discernment**

In the Old Testament, the prophet Samuel, as a boy, displayed the ability to discern the voice of God but only with the direction of his mentor Eli and after learning from his previous experience (1 Samuel 3: 1-19). Jesus in his ministry displayed a depth of discernment in his relations with others, God and himself. He discerned when it was timely to listen (as a young man in the temple listening to his elders – Luke 2: 46) and when to speak (at the beginning of his ministry declaring his manifesto in the synagogue at Nazareth - Luke 4: 16-30) or act. Jesus was aware of when is was appropriate to give of himself (he was deeply distressed at the sight of Mary and her friend weeping after Lazarus' death and he wept with them – John 11: 33-35) and when to receive (his anointing at Bethany in John 12) as well as when to stay and struggle (as in Gethsemane -Mark 14: 32-40) and when to leave (after teaching and healing in Capernaum all day Jesus saw more people coming to him and he asked his friends to take him across the lake – Matthew 8: 18). His sensitivity in relating to others was not just due to trusting his own feelings or instinct as he responded to the needs of those around him as well as his own. It was also grounded in his relationship with God and desire to do God's will. Jesus' inner life and ability to distinguish God's voice in those voices around and within him was nurtured through regular retreat from interaction with others in solitary prayer and contemplation.

Parents in this study perceived the chaplains who worked with them to possess a significant degree of discernment. For example, this innate ability was understood to help chaplains to gauge to what extent parents wanted to be involved in the co-construction of ritual marking and in the ritual itself, and whether it was appropriate for the chaplain to be present with parents at particular times, and for how long. Moreover, chaplains require discernment in the decisions they make as to whether it is appropriate to verbally respond to parents' display of emotions or to remain silent and when they should change their role during co-construction (move from being an unhurried supportive presence to being an interpretative guide) or ritual marking (from an orchestrator of ritual to a shaman). Whilst some of these dilemmas may be answered by asking parents what they need at that moment in time (though sometimes in the immediacy of their dead baby's delivery parents don't know what's

best or aren't able to articulate what they want), others cannot. A chaplain, therefore, has to utilise his or her gift of discernment.

Discernment is a difficult concept to define. However, I would suggest within the context of offering spiritual care to bereaved parents discernment is an ability to tune into the particular needs of a parent or couple, enabling a loving, and in the long term, potentially healing response to be given. In doing so, a chaplain is also seeking to attend to the prompting of the One who is the source of love and to communicate that love to the best of his or her ability in a manner appropriate to the context and needs of each particular couple or individual parent. Discernment cannot be acquired but it can be developed and honed through learning from experience and with the guidance of an insightful, prayerful other. Such ongoing deepening of our level of discernment requires attention to our inner self and, thus, discipline in making space for prayer and contemplation in our daily routine (Webster 2004-5). The practices of the faith tradition to which we belong (and those of others) may aid us in our ongoing quest to deepen our level of discernment (McCarthy 2000). The topic of developing self-awareness and chaplains attending to their own spiritual lives will be further explored (see **10.3.2.1.**).

Discernment is also about being in touch with our gut when we offer spiritual care, where so often we discover an inkling of another's spiritual needs and where the nudges and promptings of God may be recognised if we are attentive to them. If we become accustomed to listening to our inner being on our own, we may be more prepared for listening to that which is stirred in our inner core when also relating to others. Thus, self-awareness is crucial in sifting through the different voices that inevitably arise within us when we encounter birth, death, raw grief and are involved in co-constructing ritual marking. In seeking to utilise attributes of charm and compassion, which may enable God's love to be shared and the possibility of healing to occur, a chaplain has to possess, nurture and utilise the gift of discernment. In seeking to be discerning a chaplain has to be prepared to wait and suffer with parents and, thus, be actively attentive to each moment. For in doing so we may then hear something of the One whose voice we wait for when alone and with others. Acknowledging and attending to that voice will help us to respond in a loving way to the needs of parents and, as appropriate, our own.

Moreover, seeking to offer such care also sets a chaplain up to fall short, as none of us, human as we are, are as discerning and altruistic as Jesus, whose example we

seek to follow. Therefore, as well as the courage to risk and to attempt to discern our appropriate response to parents' perceived needs, offering spiritual care requires each of us to be gentle with ourselves; to be as accepting of the grace of God as much as we seek to share it with others (see **10.3.2.1.**)

In summary, utilising these natural gifts not only enabled chaplains to help mothers and fathers co-author their baby's ritual (where possible) and, thus, help meet their deep need to parent their baby as best they could. They also enabled chaplains to share in the performance of that unique ritual in a manner which conveyed the importance of each baby and the significance of their death to his or her parents (see **10.1.1.3.**). Moreover, the chaplain's way of being present and relating to parents and their babies was understood to be authentic, in that parents perceived them to be living out their faith. For the vast majority of parents during co-construction it was the incarnation, rather than the proclamation, of the love of God by the chaplain working with them which met their spiritual needs. Lyall (2001, 97) perceptively puts it this way

> For (pastoral) carers whose identity is shaped by the Christian story, what we are in our (pastoral) relationships will always take precedence over what we say.

However, one parent, an active church member, felt that a verbal expression by the chaplain of the divine story of love and care for her, her husband and baby would have helped to meet her spiritual needs during their initial encounter in labour suite, prior to her baby's blessing. For this particular mother pastoral care was primarily about proclamation rather than incarnation. This highlights how difficult it is for chaplains to accurately assess parents' spiritual needs and how best to respond in such an intense and distressing context, within a few minutes of meeting them. Moreover, this mother's reflections emphasises the importance of involving representatives of parents' own faith communities in attending to their religious needs, where possible and appropriate. There may at least be some degree of relationship already established between parents and a pastor from their own faith community and, thus, some awareness of the parents' particular story, including their theological perspective.

10.1.1.3. Words and actions – performing the divine story

As has been described (in **10.1.1.2.**) how effective spiritual care is depends not only on appropriate words being said or acts being done in response to parents' spiritual

needs. For the bereaved parents in this study, the manner in which these were performed was also important. In other words, the meeting of parental spiritual needs was significantly contributed to by a chaplain's '…way of practising.'[2] (Murray and Grant 2003, 1) In theological terms, parental spiritual needs were met only in part by a chaplain's ability '…to embody truth through role performance and role consistency.' (Capps 1984, 106) The manner in which human and divine stories were told and acted out by chaplains also conveyed something of the metanarrative which shaped their personhood and informed their way of relating.

Telling stories – human and divine

- **Interpretative Guide - telling the story of culture, ritual and grief**

Co-construction is about getting alongside, travelling with parents and being part of their story, for a while. Ritual, thus, evolves out of a shared journey and the chaplain's understanding and interpretation of it. Following his death and resurrection Christ joined two of his bereaved friends on the road to Emmaeus. They did not recognise him and as a stranger he shared their journey with them, helping his friends to interpret their recent experience in light of their metanarrative. It was only when he sat at a table with them and together they shared the ritual of a meal together that '...their eyes were opened.' (Luke 24: 31). A chaplain in offering parents spiritual care following the death of their baby does act as a companion, for a while, on their journey of grief and as a ritual leader, like Christ. However, parents in this study felt that chaplains acted not merely in these roles but, crucially, after listening to parents' stories, they acted as interpretative guides (see **8.2.3.2.** and **9.2.5.1.**) enabling not only sensitive regulation of grief but co-construction of ritual.

In A.A. Milne's (1928) *Winnie the Pooh* one of the many adventures the very likeable Pooh embarks on is to go hunting for a Woozle in the dark Forest, accompanied by his friend Piglet. Ernest Shepherd, who illustrated Milne's work, beautifully depicts the two brave sojourners walking into the unknown, unsure of what lies ahead and how they might deal with it. It is Pooh's search, he leads the way, and his companion, also frightened and rather uncertain, walks beside him. Pooh sets the pace, the direction and tone for their search and Piglet travels with him.

---

[2] Murray and Grant 2003 used this phrase within the context of GPs meeting the spiritual needs of patients living with advanced cancer.

Parents in this study appreciated chaplains being an unhurried supportive presence, someone willing to accompany them into the unknown, immediately following their baby's death – to share their anxiety, fear and be with them in their disorientation. They appreciated that the chaplain did not try to direct their search for meaning, hasten their decision making, cut short their story-telling or suppress their expression of emotion. However, like Pooh, there came a time when parents wanted to find a way forward, and an end to incessant confusion – going round in circles, retracing the same footsteps in their journey of grief. In Pooh's seeking it is Christopher Robin, who, from up a tree, sees the bigger picture of Pooh's journey and offers his insight (that Pooh in fact had been going round and round following his own footsteps in the snow not that of an ever increasing number of Woozles). This enables Pooh to reflect on his experience and come to his own conclusions. Moreover, the gentle way Christopher Robin shares his knowledge and understanding prevents Pooh from feeling ridiculous and judged but rather to feel affirmed and loved. From this study it is clear that parents, when they were ready, appreciated the fact that chaplains did not just offer companionship and a reassuring presence. It was significant for parents that chaplains also offered signposts which aided orientation in the dark landscape of grief and resources to help them verbalise their feelings and inner wrestling. Such resources also ensured memories of significant experiences of the journey were created and able to be maintained.

Chaplains, therefore, in sensitively helping to meet parents' spiritual needs in aiding the formation of ritual have to be able to change roles from being Piglet to being Christopher Robin; from accompanying to offering guidance, and back again, depending on parents' specific needs at different moments. This involves changing roles but not the essence of who we are, the manner in which we express ourselves and, thus, how we relate. Such is the need for discernment, attentiveness and integrity. There is a time for being, a time for telling - sharing something of the norms of culture, ritual and grief in the process of co-construction (and where appropriate telling of God's love in ritual) - and a time for acting.

The chaplain's role as an interpretative guide, as well as that of being a companion and sharer in ritual, is also biblically based. In Psalm 23 we find the famous shepherding image of God - the shepherd not just accompanying sheep in dark places but offering guidance as to the possible paths to follow through forbidding places. In the New Testament we find Jesus depicted as a shepherd who cares intensely for his

sheep. A shepherd-like carer does not try to remove a person in his or her care from pain nor take pain away but does offer resources and knowledge with the intention of aiding the patient to deal with the situation. Thus, a chaplain has to be familiar with the terrain of parental grief, as well as relevant resources and accurate information which parents may utilise to navigate such alien territory. These biblical images of such care infer a responsibility for the well-being of others and an empowerment, not control, of others' decision making. According to Capps (1984, 78) carers who attempt to embody such a shepherding role seek to offer a '…ministry of competent guidance.' Those who seek to utilise such an approach may be well intentioned but there is a danger of being controlling and paternalistic (see also **9.2.5.1.**). Parents in this study, however, were given guidance and information but importantly felt it was up to them whether, and how, they utilised it.

Much of Jesus ministry involved sharing parables with people. He told them stories which could potentially inform their decision-making in life, for example, the parables of the Good Samaritan (Luke 10:25-37) and Prodigal Son (Luke 15:11f). He then left listeners to ponder and to make their own choices. In the same way, chaplains offered normative narratives to parents regarding grief, ritual and cultural norms following baby death *in-utero* and then gave parents time and space on their own to decide what were appropriate choices for them in relation to their particular story and circumstances.

- **Sharing stories within the context of ritual**

  We're going to need the minister
  to help this heavy body into the ground.

  But he won't dig the hole;
  others who are stronger and weaker will have to do that.
  And he won't wipe his nose and his eyes;
  others who are weaker and stronger will have to do that.
  And he won't bake the cakes or take care of the kids …

  No, we'll get the minister to come
  And take care of the words.

From *The Minister* by Anne Stevenson (2003, 57)

Stevenson's poem sums ups parents' perceptions in this study of the chaplain's role as wordsmith and spokesperson, articulating during ritual what parents wanted to say but were unable to. Chaplains wove together different strands of a baby's, and his or

her parents' story, and the divine story (where appropriate) - how parents' felt about their baby, their loss, their hopes for his or her future care and ongoing place in their family. For those parents with Christian beliefs, deeply held or questioned, the chaplain's verbal assurance of the baby's eternal destiny (see also **10.2.1.**), of God's involvement in their distress and God's love and care for them, as well as their baby, was important.

This study confirmed how imperative it was for parents that they felt any ritual they shared in for their baby was authentic. Thus, it was highly significant to them that not only was a ritual marking of their baby's life and death personalised but that it truly reflected their experience, feelings and beliefs. Lament as well as appropriate thanksgiving, were important to acknowledge within such rituals to enable them to be something other than platitudinous and irrelevant (see **5.2.4.1.**). Both sentiments are part of the Judeo-Christian story, part of what informs a chaplain's story and his or her theological understanding of the human experience of expecting a baby (and the hopes and dreams associated with that) and then living with his or her death. Expressing parents' lament, spoken and unspoken (yet sensed by the chaplain), through use of parents' or the chaplain's own words or phrases from scripture which resonated with parents' feelings and search for meaning, validated their grief and made it real. It also revealed a chaplain's (and, thus, the church's) understanding. Byrne (2002, 264), a paediatric chaplain from the United States (where admittedly the church going population is greater than in Scotland) insightfully stresses the importance of a chaplain's verbalising feelings of lament in situations of grief and loss within a hospital context for patients and the church.

> The chaplain retrieves words which otherwise would be lost. Word upon word, sentences are built as bridges to the true self, the living God, and a loving community.

Following the death of Jesus, it was only when some of his disciples acted out or rather re-enacted their shared story around a table in Emmaus – acted out their relationship with one another and with Christ that their eyes were opened – that they could see beyond their present distress and sense of loss of meaning and purpose (Luke 24:28-35). Often it is during or after a welcoming or funeral ritual that parents begin to realise what has happened to them and their baby. Their interpreting and reinterpreting of events may continue throughout their lifetime. A welcoming or funeral ritual encapsulates, retells (or rather re-interprets), and acts out; a baby's and his or her family's story, in light of a shared grand narrative or, as often in our

postmodern world, a number of narratives (including those of the chaplain as well as the parents). Jesus told stories, during his ministry, which helped and still helps people to reinterpret their stories in light of his. Chaplains, therefore, as they co-construct and then perform rituals are not just listening to and interpreting stories they are also in the business of re-interpreting and re-framing stories, in a manner that takes into account the worldview of the parents and the chaplain himself. (see **9.2.2.**)

Acting out stories – human and divine

I have already explored (**9.2.1.1.**) the topic of ritual offering parents the opportunity to act out their relationship with their baby. Moreover, within the context of blessing ceremonies chaplains acted out God's relationship with, and love for, a baby (see **7.2.3.5.**), by making the sign of the cross on the baby's head and by holding the baby (where appropriate and possible). It was highly significant for one mother that the chaplain sharing ritual marking with her, held her stillborn baby (see **9.3.**). In doing so the chaplain, a person who in her eyes had status, authority and influence in society, was acknowledging in a profound way, the personhood and importance of her dead baby. The chaplain, by embracing her dead baby, revealed his willingness (and the willingness of the God he embodied) to be intimately involved with human suffering by entering into her family's story of grief and sharing with them their experience. Moreover, by such a gesture the chaplain proactively sought exposure to the fragility and broken-ness of her dead son and yet, paradoxically, by doing so had the opportunity to be touched by his wonder and beauty. Likewise, another chaplain dared to risk enacting God's love and compassion for parents, where she felt appropriate, by a gentle touch or an enveloping hug. These gestures conveyed sentiments and a depth of meaning, at a time when words were elusive and seemed limited or trite. Walton (2002, 5) concurs with these findings

> We will need to develop a new sensibility as to how material objects
> and physical gestures can embody what words may not.

While words were often forgotten, the demeanour, approach and actions of chaplains during ritual were not only remembered but cherished by parents as key aspects of their baby's story. Therefore, the chaplain's way of being and their tender manner of relating and acting helped form memories for parents which were meaningful - a contrast to those of the anxiety and loneliness of labour and the trauma of delivery. Chaplains, thus, embodied God's presence with a family in their grief and enacted

the story of God's love and care for them, and their baby, during ritual moments and in co-construction; a story of shared sorrow in the face of the reality of death but ultimately of hope.

10.1.1.4. Leaving as part of the human and divine story

This study confirms the importance of absence as an integral part of the spiritual care of bereaved parents (as described in **4.2.2.** and **5.2.5.**). Leaving those he cared for was also a significant part of the ministry of Jesus (for example, John 16:7). Chaplains leaving bereaved couples with time and space alone, to absorb the cultural norms and information shared with them and to make appropriate decisions together regarding ritual marking is a necessary part of the process of co-construction (see **9.2.5.1.**). Furthermore, once a funeral is over chaplains do not have sufficient resources to enable further routine follow-up visiting of parents (parents in this study, however, did appreciate an open ended invitation to contact the chaplain if they wished to, though few did). Chaplains by the necessity of their role have to learn to let go, as well as to accept parents will let go of them. Campbell (1986, 62-3) describes well the importance of leaving as well as being available to others when seeking to care for them.

> ...loving loyalty will often mean staying close to others, when they need us and when others have turned their backs on them; but equally loving loyalty can mean trusting in God's all-pervading love, when we see that the best way to help others is to enable them to reject us and let go of us.

Ultimately, chaplains as human beings can never help another to find wholeness and complete healing. Praying for those for whom we are caring for, in our own time and space, may help us maintain a healthy perspective of our role and limitations, and also give us a means of letting go of parents and babies into God's care. Cooper-White (2004, 191), from within the context of pastoral care and counselling, puts it this way

> When we pray for those who come to us for (pastoral) care or counselling, we find ourselves more able to relinquish the heroic need to rescue. We are restored to the recognition that healing and wholeness come from God, not our own interventions, and that God's love is vast enough to contain all the suffering that is beyond human efforts to save.

To sum up this section, I would like to conclude by emphasising that the divine story does indeed meet with human stories during ritual, and in its co-construction.

However, not just in their telling, as suggested by Anderson and Foley (1998), but also by the chaplain embodying and acting out the Christian narrative. For parents in this study, the divine story was revealed in the practice of these elements of ministry but of greater significance was the manner in which these were performed or incarnated. Therefore, the greatest resource chaplains have with which to the share the love of God is their humanity, as they relate to parents and their babies. Utilising their intrinsic abilities and the influence and authority invested in them, with sensitivity and open-ness, enabled chaplains to build up relationships with parents within which their needs could be assessed and appropriately responded to. Chaplains by being themselves and acting and speaking in a genuine and gentle manner enabled parents, during co-construction and ritual, as Russell an American hospital chaplain (1975, 197) puts it – '…be who they are.' In a chaplain's transparency and integrity, in the parents' distress and love for their dead baby, and in what they share together may be glimpsed something of God – both immanent and transcendent. God, whose Son and the story of that Son's interaction with humanity, helps to shape and inform the personhood and ministry of a Christian chaplain. Elaine Graham (1996, 206-7) eloquently describes such opportunities for encountering the 'Other' within human activity and interaction

> …encounter with the 'beyond' is only possible, and is forever grounded, in the immediate. Within Christian incarnational theology, this would be understood as the human and immediate being the vehicle or sacrament for the transcendent and Divine. If such a Divine and transcendent dimension is available to human apprehension, it will only be realised in the practical and concrete arena of purposeful action.

Chaplains communicate God's love in several different ways during co-construction and in the sharing of ritual. However, it is the personhood of a chaplain, the manner in which a chaplain interacts with parents and their baby and performs different roles which allows the depth of God's love and care to be shared. In the chaplain's humanity is glimpsed something of God's divinity – the divine love the Eternal Parent has for God's children, at whatever stage of development they may be, dead or alive. In Newbigin's (1988) terminology, the chaplain, and his or her way of being and relating, offered an interpretative 'lens' through which many parents in this study perceived the life and work of the church anew. For most parents this lens was very different from the one they expected to encounter (see **7.2.2.1.**)

However, it is not just the chaplain's humanity and intrinsic abilities which are utilised to help meet parents' spiritual needs through the co-construction and sharing in ritual. A chaplain's status, authority and power are also required to be used, at appropriate moments, in order for such needs to be met. The tension involved in chaplains having to be vulnerable and also authoritative at different times in their relationship whilst supporting and empowering bereaved parents will now be explored.

10.2. The paradox of power and vulnerability

For the chaplain is '…the paradox of being fully human while attempting to work heaven's magic here on earth.'

(Oswald and Kroeger 1988, 29)

This section of theological reflection will briefly explore the ambiguity of the requirement for a chaplain working with parents to be aware of the authority invested in him or her and the necessity of sharing his or her humanity in order to provide sensitive spiritual care.

10.2.1. Power, influence and authority

For many bereaved parents in this study it was of great significance to them to have someone they perceived to have ritual authority and influence (not only in the community, but with God) involved in constructing and performing a ritual for their baby. Utilising Carroll's (1991) categorisation of types of authority granted to professionally trained church workers, I will describe three different ways by which chaplains were perceived to have authority by parents in this study.

1. Chaplains were deemed to have authority purely *by means of their office*, irrespective of their personhood and knowledge (like, for example, Graham Green's [1962] 'whisky priest' in his novel *The Power and the Glory*). Chaplains were perceived by parents to have a special relationship and influence with God (see **8.2.2.1.**). They were understood to act as a trusted mediator between themselves and God, ensuring their baby went from the care of their earthly parents into the arms of their eternal Parent. Irvine (1997) argues that, unlike doctors and teachers with whom they were once on an influential par in society, the authority of clergy in our postmodern age has greatly diminished. However, this study reveals in matters of ritual, especially where the eternal destiny of a dead baby is concerned, church

representatives are perceived to have immense authority by a number of parents (and not just by church attenders). Like doctors, but in an eternal sense, chaplains were perceived to have the power over life and death.

It is interesting that contrary to the view of contemporary liturgist Paul Sheppy (2003, 103), an English Baptist minister and member of the Churches' Funeral Group, who perceives that most people at the beginning of the twenty-first century '…do not see death as the gateway to eternal life…', the majority of bereaved parents in this study, church-goers or not, certainly did. Parents, I suspect, did not want to believe their baby's short life was at an end and their pregnancy totally in vain. Moreover, some parents expressed the desire to be reunited with their baby again in the hereafter and to once more assume a parental role. The findings of this small study concur with a larger piece of research performed in London by Young and Cullen (1996). They found that most people they interviewed on the topic of death did not have particular ideas about resurrection or heaven. Rather, those interviewed had the notion that they would be re-united with those whom they loved; such ideas being formed from family lore rather than through church attendance. Though the parents in this study also only had vague notions of what heaven may be like, for some a key role that the chaplain played during ritual was as a religious functionary; a representative of the church ensuring their baby was fit for heaven by acting out and telling the story of God's love and care for him or her. Grainger (1997, 35) puts is this way

> The qualifications for heaven are religious and the purpose of the funeral is to render the dead religiously acceptable.

2. In this study chaplains were understood to have authority due to their *perceived expertise* – their acquired knowledge, competency to shape and perform rituals and their training (see **8.2.2.1.**). This was of significance to parents in relation to the chaplain acting as an interpretative guide during co-construction and as an orchestrator and performer of ritual.

3. Chaplains had authority within the maternity unit amongst the wider healthcare team because of their *personal credibility*. They were known as sensitive and experienced individuals who sought to work with parents and other HCPs, rather than impose their own beliefs and practices. Midwives' trust in the chaplain's capabilities enabled them to feel comfortable enough to refer even initially reluctant parents to them (see **7.3.2.2.**) Such authority is earned rather than given with a role.

What is clear from the results of this study is that chaplains have power and authority within the relationships they form with distressed and disempowered bereaved parents, as well as with other HCPs. In fact, parental expectations of chaplains (based on their previous experience of clergy or the church) was that they anticipated such power being abused or misused by chaplains and this caused many parents to hesitate when chaplaincy services were offered to them (see **7.2.2.**). Even parents who requested chaplaincy support, of their own accord, anticipated the chaplain taking control and performing a prescribed liturgy in a formal and distant manner. On the other hand, it was important for parents (as discussed above utilising Carroll's schema) that they felt chaplains possessed some form of authority (what form or forms varied from parent to parent) in order to enable their spiritual.needs be met. Therefore, a key issue for chaplains is to what extent we are aware of the power and influence we may exert in a particular relationship and set of circumstances, and how such power and authority is utilised. Forrester (2000, 74) emphasises this point

> A person-in-community is in fact part of a web of power relationships which may heal or harm, support or destroy. Care and service are not *alternatives* to the exercise of power, nor ought they to be (as they sometimes are) disguises for rather unsavoury and manipulative uses of power, but rather they are actualities which require the proper use and deployment of power.

Jesus was sought out by the people of his time because of the knowledge and insight he exhibited as a teacher and the power he revealed as a healer. By proposing significant revisions to Jewish law, Jesus sought to assert authority (Haley 1986) and his teaching was certainly perceived by listeners as being authoritative (for example, in Matthew 7: 28-9). Capps (2004. 184), in his insightful article *Jesus as Power Tactician*, argues that Jesus was a highly skilled and discerning user of power and authority, who sought to empower others '…who by necessity or choice, were outside or alien to the religiopolitical establishment'.

Jesus empowered many people, who, because of their status or standing, illness or affliction, were socially ostracised and isolated. In his relationship with others, Jesus enabled those on the margins to feel wanted and welcomed. Moreover, he facilitated reflection on their beliefs and aided their search for meaning. Jesus' reputation went before him –word got around from people who had seen and heard Jesus and this stimulated others to want to meet him. He established his credibility and authority enabling him to have the opportunity of being with people and responding to their needs. This Jesus did, not only by his actions and the content of his teaching (who he

chose to be with and what he shared with them), but also in his way of being with and relating to others.

Chaplains, too, require discernment and wisdom to utilise power and authority in order to meet parental spiritual needs. Moreover, it is also crucial for chaplains to gain the trust of those we seek to support. However, unlike Jesus, to be able to respond to parents' spiritual needs, chaplains are dependant on developing and maintaining credibility and positive relationships with those in positions of power and authority (other HCPs, especially midwives) in the context in which they minister. Other HCPs not only work with the chaplain to assess and help meet spiritual needs but facilitate appropriate chaplaincy access to parents.

In this study it was clear that chaplains required authority , as orchestrators of ritual, to set contextual boundaries within which feelings could be safely expressed and acted out and something of the sacred experienced. One couple in the study perceived chaplains as having a maternal role in doing so (see **8.2.2.1.**) – metaphorically enfolding and embracing all present, when they were at most vulnerable. Durston (1998, 219) puts it this way

> They (the mourners) are only able to relax … in a context in which they are confident that someone or something else can "hold them together". If they can depend on another person or situation in this way, then they can engage in what has been described as "regression to childhood dependence". They can let go because they feel they are in a safe place where another will hold onto them.

Such an image is similar to that of Jesus desiring to show his love for Jerusalem in Matthew 23:37 'How often have I longed to gather your children, as a hen gathers her brood under her wings; but you would not let me.'

During co-construction there is a need for chaplains to exhibit a high degree of self-awareness as there is the opportunity for chaplains to utilise our influence to shape rituals to primarily meet our needs and create rituals which relate more to our feelings and experience than the parents'. Any attempt by a ritual leader to dictate the whole content and form of ritual and not to give parents an opportunity play a part in co-authoring ritual may be utilising power and authority as a means of distancing him or her-self from parental grief and pain. Parents in this study also appreciated the fact that chaplains used their authority and personal attributes of compassion and discernment to help them act as an advocate for parents, in preparation for, and during ritual marking (see **8.2.5.**).

Therefore, in offering care to another there is the need to discern the appropriate level of power to utilise, and not deceive ourselves that we are not in a position of authority (see also Jim Cotter's poem at **4.2.5.1.**). It is about choosing the degree to which we make ourselves available to or vulnerable with others, as Jesus did, and relying on God's guidance to aid us in this (Herrick 1998). As those in possession of knowledge about grief, baby death and disposal, as well as being perceived to have ritual authority, chaplains will always be in a position of power when in a relationship with bereaved parents. However, in order to be of support and comfort, there is a need in the immediacy of baby death, to choose to expose ourselves to the pain and soul-searching of parental grief. Spiritual care

> ...is not about eschewing power. It is rather about using the appropriate power to serve God's purposes in those for whom we care.

Herrick (1998, 58)

10.2.2. Risk and vulnerability

In this section I will seek to pull together the various threads in this thesis which relate to the theme of chaplains choosing to be vulnerable with bereaved parents in course of offering them spiritual care.

> The biblical tradition is not about control but about vulnerability...

Brueggemann (1991, 17)

The gospel imperative Brueggemann highlights is a key theme which has not only emerged from theological reflection on parental perceptions but has been central to the qualitative research methodology and means of doing theology employed in this thesis. Both require an open-ness to the experience and stories of others and being so means a revisiting of, and perhaps adjusting existing theory/theology and future practice.

10.2.2.1. Aspects of spiritual care for bereaved parents which involve risk and vulnerability include a chaplain

Risking to be open to the pain and grief of parents

> Love is the greatest of all risks
>   to give myself to you
>   do I dare...do I dare
> leap into the cool, swirling living waters
>   of loving fidelity.

Vanier (1973, 25 cited in Campbell 1986, 26)

What underpins a chaplain's approach to co-constructing and sharing in ritual with parents whatever our experience, feelings and beliefs is *agape* and in loving we cannot avoid having to risk. Love is the motivation of God to be open to the pain of the bereaved parents; God who is not distant but is touched and moved by suffering, as asserted by Moltmann (1974), and whose vulnerability is embodied by the chaplain. This topic has been fully discussed in **10.1.1.2.**

Risking being self

It was significant for parents in this study that they perceived chaplains to be who they really were and allowed how they really felt, at particular moments, to be revealed. Such integrity and compassion (see **10.1.1.2.**) was central to sensitive care being offered. Hiding behind a professional persona during either co-construction or in sharing ritual itself is a barrier to not only developing relationships with parents but to incarnating God's love. In offering spiritual care what is required of chaplains is to risk being ourselves - which is easier said than done.

Risking to let go of the control of co-construction

It is a risk for chaplains to empower parents to make a ritual their own during the process of co-construction, and not keep hold of the control of its content and form themselves. What may be created may not resonate completely with chaplain's own beliefs, worldview or aesthetic tastes (when such dissonance is overwhelming or the chaplain feels the implications of a particular action may be potentially detrimental to the parents' spiritual or emotional well-being this should be raised and talked through). By taking such a risk chaplains are not only enabling rituals, particularly funerals, to be claimed by parents but 'reformed' (Walter 1990, 281), revitalised, and be relevant for a postmodern generation.

Aiding parents to take control of shaping a ritual for their baby not only requires risk-taking on the part of the chaplain but also humility. This implies not only that chaplains perceive parents are of 'equal standing' (Ballard and Pritchard 1996, 159); their worldview, beliefs and interpretation of their situation are just as valid as the chaplains. Moreover, humility also refers to chaplains surrendering control of theologising. Instead of doing theology for them (as they expected), parents' appreciated the fact that during co-construction chaplains encouraged them to articulate their own beliefs about, and questions of, God arising from their lived experience and where possible wove them into the shared ritual. Thus, chaplains not

only empowered parents to take ownership of rituals for their baby but also to do theology, whether they considered themselves to be particularly religious or not. Furthermore, chaplains also supplied them with the appropriate resources to enable them to do both. Ballard and Pritchard (1996, 160) make the following insightful comment about the historical relationship between clergy and theology which is also equally applicable to the traditional perspective of clergy in relation to funeral liturgies.

> This (letting go of the control of theology and of ritual construction)[3] is a deeply sacrificial task for clergy who have been used to thinking that this is their own special preserve, a body of professional knowledge which can be dispensed and controlled at their will.

Risking acting as a shaman during ritual – the paradox of enabling pain and peace to be held

Hockey (1993, 146) found in her study of the approach to funerals by Sheffield clergy and their congregations, that ministers were uncomfortable with high expressed emotion during funerals as they were often associated with 'unscripted' behaviour. In this study parents perceived it was important that the chaplain orchestrated the rituals they shared in (see **8.2.2.1.**) but also found chaplains taking on the paradoxical role of shaman (see **5.1.5.** and **8.2.2.2.**) of great therapeutic benefit. Chaplains helped to create an atmosphere within which grief, and its expression, was allowed to be and parental acts of love for their baby performed. Despite the loss, distress and confusion felt sharing in ritual marking, without exception parents talked of the comfort and strength they found during, and after, their participation. (see **8.1.**). During ritual, with the chaplain acting as shaman (and the manner in which he or she did so) and the awe and attentiveness of those present, peace was shared and the pain of grief transcended. Thus, sharing in ritual marking was a sacramental experience and the following verse of a hymn usually sung during a more formally recognised sacrament reflects something of the symbolic intimacy and beauty of what was shared

> Put peace into each other's hands
> and like a treasure hold it,
> protect it like a candle-flame,
> with tenderness enfold it.
>
> Kaan (1998)

---

[3] The words in parenthesis are mine and not Ballard and Pritchard's.

A chaplain fulfilling the role of shaman during ritual is to allow him or herself to be touched and moved and run the risk of being overwhelmed, while trying to being open to the moment – the feelings of the parents, the impact of the baby's physical features or his or her coffin, the re-telling of the baby's and family's story and the acting out of relationships. However, it is also not to be so overcome by the intensity of the moment so as not to be able to orchestrate and perform the required elements of the ritual.

Risking enabling ritual to being baby/God centred

'… the Word became flesh: he made his home among us…' John 1:14.

In a manger and on a cross we see God in weakness and fragility, not in authority and power. In his or her beauty and broken-ness, vulnerability and powerlessness, a dead baby reminds us of One born of human flesh who died, not the death of the important and influential, but of one whose true worth and uniqueness was not fully recognised at the time by those outside a small circle. It is, therefore, appropriate that a baby has centre stage during his or her blessing and funeral - for those who gathered in grief and wonder around a baby to mark his or her life and death also may glimpse something of God. Thus, not only by sharing in ritual can parents and chaplain glimpse something of God but in the baby him/herself the story of the divine and the story of that family meet. Chaplains by risking to make rituals we share in centred on the baby (as in **8.2.2.2.**), whose life and death we are helping to mark, rather than on ourselves and our power and authority, enables the ritual also to be truly God-centred.

Risking failure – the risk of not getting it right

Offering spiritual care to highly distressed or shocked parents in the aftermath of their baby's death is far from easy. It is hard for parents to verbalise that which is racing around within them and, thus, for chaplains it is difficult to assess parents' spiritual needs within often a short and intense space of time. To seek to enter into such a context and to attempt to connect with bereaved parents is to risk: it is to risk not getting it right. It is to risk failing parents and colleagues, and falling short of our own aspirations. How we might deal with such shortcomings, real or imaged, will be explored in **10.3.2.1.** Making mistakes or misjudgements only truly results in failure when we do not attempt to learn from them and utilise these experiences to inform our future practice (see also **4.2.5.2.** - Margaret Lyall's thoughts in relation to the risk

of touching). In addition, offering ourselves to bereaved parents is to risk discovering, through not always getting it right, more of whom we are and of the God who not only forgives us but works through us.

Chaplains will naturally always have anxieties about, and fears of, meeting parents for the first time. To risk is to feel uncomfortable as we encounter the unknown, as we enter a situation of intimate grief in which the only certainty is the unpredictability of what we will find. These feelings provide a 'touching point' with the parents' anxieties and fear, and those of the other HCPs we work with (Kelly 2002). Cassidy (1991, 75), a former medical director of a hospice, in exploring Jesus' fear of what he may face in and after Gethsemane helpfully says this

> We don't often think of Jesus with his legs turned to jelly – or any hero, for that matter. It doesn't quite fit with our idea of what it means to be brave. It's a pity, that, because bravery is about living with fear, not about being spared it.

In the end, however, it is our faith in Christ, the ultimate risk-taker, our belief in the value of seeking to embody his way of relating and ultimately our reliance on his love and support, which enables chaplains to risk, not without fear but also with hope.

10.2.2.1. Chaplains as vulnerable – contrary to parental expectations

Parents' experience of working with chaplains forced them to re-appropriate their expectations of chaplains' 'intentionality' (Capps 1984, 64). Expecting chaplains to utilise their power and authority to prevent real engagement with them and their baby, parents were pleasantly surprised to encounter human beings who were prepared to risk making themselves available to them. In doing so chaplains were, like Jesus, behaving, relating and being contrary to all expectations.

> He (Jesus) shocked people and perplexed his disciples. They expected him to behave as a traditional holy man, to fit into the accepted pattern, to nurture and defend his purity and authority against pollution and questioning.
> But Jesus touched lepers, sat at table with notorious sinners, mixed with quislings and prostitutes. And then he took a towel and washed his disciples' dusty feet ...humble self-giving which was at the same time a challenge to the principalities and powers and an exemplification of the authentic nature of Christian ministry.

> Forrester (2000, 72)

Therefore, securing the appropriate individuals, who have the aforementioned gifts and abilities, as chaplains is paramount. In addition, ensuring the ongoing nurture of the humanity of chaplains already in post, including particularly our spirituality, is made a priority in our lives, and in the life of the church and health service, is a key prerequisite in enabling chaplains, along with other HCPs, to maintain our ability to give of ourselves in order to help meet bereaved parents' spiritual needs.

10.3. Selection, sustaining and training of chaplains

10.3.1. Implications of this study's findings for the selection of chaplains

In the following section I will seek to suggest some of the important attributes of those who might be considered suitable to meet the spiritual needs of bereaved parents whose baby has died *in-utero,* according to the perceptions of parents themselves. This discussion, therefore, has implications for health boards and faith communities in their selection of suitable candidates for chaplaincy work in maternity units.

10.3.1.1. Self-awareness

I have created you
in my own image.
Do you think that I

Crave for security?
Go out upon
a limb, the way I do:

Create a world,
be crucified,
and be obedient

Only to what you are.[4]

(From *The Good Boy* by Sydney Carter 1974, 22)

As has been suggested, much of what offering sensitive spiritual care involves is risk; the kind of risk which resonates with God's willingness to go out on a limb with us, and for us, and the rest of God's creation. However, as Carter points out, this first

---

[4] The italics here are the authors.

requires some awareness of who and what we are, including having some insight into the natural abilities we do, and don't, possess. Therefore, as chaplains seek to go out on a limb and risk being available to, and being transparent with, bereaved parents we need to have some idea of the internal resources we have to utilise. There is a need for an awareness of our own story, including any greater narratives that may shape our story and inform our motivation to become involved with those who are vulnerable and distressed. However, more than that, there is also a need for open-ness to the possibility that during any encounter our story may be challenged, and indeed significantly changed, by what takes place (as discussed in **10.1.1.2.**). This may not just affect how we approach our work as chaplains and how we relate to the hospital context, but it may also profoundly alter our interpretation of own personal story, as well as our interpretation of the wider narratives that inform it. Thus, a key issue in selection of chaplains is not only the willingness of a candidate to risk being open to ongoing transformation and re-formation but to have an awareness of who he or she is before embarking on such a journey.

What follows is a brief resume of aspects of a pastoral carer's personhood and possible future role which they should be have some awareness of. These include their

Spirituality (see **10.3.1.2.**)

Power and authority - invested in chaplains by parents and the wider community (see **10.2.1.**)

Sexuality

This study confirms the importance of self-awareness with respect to how we feel about our bodies and their use in communicating with others, of the same or opposite sex, through touch in non-erotic caring relationships (as explored in **4.2.5.1.**). Our feelings about our body's and their various functions and fluids are also closely related to how we feel about physical dimensions of dealing with baby death *in-utero*.

Response to the physical aspects of working in a maternity unit

This relates to a chaplain's awareness of how he or she may respond to the physical aspects of labour, birth and death, for example, the pain of contractions, blood, macerations on a baby's skin, handling a sixteen week fetus/baby or the discomfort of a mother's lactating breasts in the days following stillbirth. Such elements of life

are reminders of our human fragility and, particularly to males, that areas of a woman's body associated with shared erotic pleasure, sensuality and joy are also potentially sources, and reminders, of pain and grief. Those who seek appointment as chaplains in acute hospitals require some awareness as to whether they could deal with the sheer physical messiness and pain which childbirth and baby death potentially involves.

Mortality (including previous losses, wounds and bereavements)

Dealing with death and grief, undoubtedly confronts any of us with our own mortality, the mortality of those we love and, perhaps too, those we hope to love. Moreover, how we deal with the wounds of others is dependent on how we have dealt, or not, with our own wounds. Muse (2000, 256-7), an American counsellor trainer, insightfully says this

> The question is whether we will be wounded stealers or wounded healers. Self awareness is a key ingredient in determining the difference...When recognised and owned by the pastor rather than projected onto others, woundedness is part of the wellspring of authentic motivations for ministry and can become a means of understanding and compassion for others. Unrecognised it becomes a barrier to love and effective ministry as pastors unconsciously seek to heal their woundedness by compulsively interfering with or ignoring what they perceive as similar wounds in others.

Limitations – personal and professional

As humans working in a stressful and draining environment, it is essential chaplains are aware, or are capable of becoming increasingly aware, of their limitations. Each one of us has a limited supply of emotional, spiritual and physical resources which we can utilise to deal with particular situations and the cumulative effect of dealing with death and loss. A prospective chaplain also requires to be someone who has an awareness of his or her potential role in offering spiritual care as part of a wider healthcare team. Furthermore, he or she has also to be prepared to discover more about, and respect the roles of other HCPs and representatives of local faith communities. There is a requirement for chaplains to recognise the boundaries of our role and allow midwives, doctors, administrators and other religious representatives to get on with theirs. Chaplains need to be able to recognise when meeting the specific needs of a particular parent or couple is beyond our area of expertise or personal resources and be able to refer parents to other colleagues, faith leaders and supportive agencies (see **4.2.5.2.**)

Support system

How aware is any prospective chaplain of the importance of having appropriate support in place to help them deal with emotional and spiritual issues raised by working with bereaved parents? Are they the type of person who is self-aware enough to realise when they require particular help and support? More than that has the applicant a social network which can help maintain a healthy balance in their life (see **10.3.2.1.**)?

Peter Speck (1978, 41), a former hospital chaplain, sums up the importance of a HCP's self awareness in caring for bereaved parents.

> It is only as we feel sure of ourselves and our reactions that we feel able to be with someone as opposed to going to do things to that person.

10.3.1.2. Spirituality and theology

Formation and reformation in a community of faith

There is a need for prospective chaplains to have a spiritual basis or underpinning to their life – a system of beliefs and values informing their decision making and way of life, as well as an awareness of opportunities through which they may glimpse the transcendent in the midst of life. Moreover, chaplains need some sort of spiritual home where we can be nourished and nurtured as spiritual beings, and ideally a spiritual director with whom we can reflect on the possibilities of God's presence on our ongoing inward as well as outward journey. As chaplains we require to have a sense of our own spiritual needs and how those needs may be met in different facets of our life - through work and worship, leisure and learning, being and doing, in company and alone. A chaplain also needs to be rooted in a particular spiritual perspective or faith tradition to aid the nurture of our personhood and ability to relate to and be available for others. Charles Gerkin (1997, 107-8), an American pastoral theologian, describes the importance for Christians to be participants in a local worshipping community.

> One learns to feel, act, and think in conformity with a religious tradition that is, in its inner structure, far richer and more subtle than can be explicitly articulated. One's primary knowledge is not *about* the religion, nor what the religion teaches, but rather how to *be*...To belong to that community is to share in a life of ritual, prayer, and action that continually reminds the members of the community who they are and who they are to be in the world.

As described in **5.2.5.**, a chaplain requires an awareness of what his or her beliefs are and a developed pastoral theology - an understanding of how our theology informs our practice and being open to how our practice may inform our theology. As well as being a source of motivation and inspiration, a chaplain's faith may be a potential source of comfort and solace. The Christian tradition offers a variety of ethical and theological perspectives, derived from biblical sources, which offers a chaplain a framework within which to engage with, and interpret, the complexities of human experience. A belief system is therefore required which informs not only intellectual reasoning but which shapes the way a chaplain is, and how he or she acts out his or her faith. Being part of such a tradition over a period of time, enables a *habitus* to occur – '…a disposition of the mind and heart from which action flows naturally, in an unselfconscious way.' (Forrester 2000, 5) A Christian chaplain is, thus, able to work in a secular institution with bereaved parents (who invariably will not have a church-orientated faith), a context of pain and distress, because '…their own identity has at its centre a theology funded by the Christian narrative.' (Lyall 2001, 163)

Underpinning such aspirations of living out our faith with integrity, whether in offering spiritual care or in personal relationships, is faithfulness (White 2002). Being faithful, according to White, in our day-to-day living, our relating at home and at work is the key to maintaining our humanity and human identity within the post-modern context of rapid social change and fragmentation. Faithfulness does not resist change and personal growth, but enables each one of us to hold onto the essence of who we are and how we interact with others and God. How do any of us maintain our faithfulness, or indeed our desire to be faithful? White (2002, 88) makes a positive and helpful response to this question

> The sustained will to be faithful is best formed within a relationship to God embodied in a character-forming community and set of social practices. This relationship with God may or may not be explicitly realized in these practices; nonetheless, the specific value of a confessing and worshipping community, forming the character of a confessing and worshipping self, certainly needs to be recognised.

Our identities as individual human beings do have an essential degree of constancy and yet our identities evolve with time. Therefore, having some awareness of how our identity may be re-shaped and re-formed over time by being in contact with, and open, to the stories of others is important for chaplains. However, so too is, paradoxically, endeavouring to hold onto the essence of who we are and what

fundamentally motivates and inspires us to be who we are becoming and do what we will do.

> This pattern is rooted in God. God's being is dynamic, but he/she does not lose any part of it within that dynamism. God holds his own experience of change within his own being. This helps define God's identity. In this way God is both responsive and essentially unchanging.

(White 2002, 150)

Love not dogma

It was of significance that parents interviewed in this study appreciated being supported by chaplains who sought to respond sensitively to their perceptions of their baby who had died *in-utero* (as early as 16 weeks of gestation) as a person who had a considerable impact on their lives. Rather than enter into a debate about theology and personhood chaplains are required to respond to parents' actual spiritual needs and set about working with parents in both a caring and therapeutic manner. A prospective chaplain's theology will inform their approach to spiritual care, as well as how they may relate to parents and their babies. However, they should neither seek to impose their beliefs on parents nor be should their theology be so rigid in nature as to prevent a loving, compassionate response to the particular needs of a family.

Grainger (1998, 117), a former hospital chaplain with an interest in ritual, refers to the changing mindset of many ritual leaders (including chaplains) in relation to being prepared to share in funerals for babies who have died *in-utero* in the second trimester.

> This change has been brought about by a much greater awareness of the emotional needs of bereaved parents leading to an attitude of mind on the part of many clergy which pays more heed to pastoral concern than dogmatic orthodoxy.

What is required for chaplaincy is not dogma but the embodiment of God's love in response to pain and grief.

Living with paradox

James Fowler (1996 and 1995) formed, from his engagement with psychological perspectives of the development of self in childhood, a schema for describing stages of faith which a person may sequentially inhabit at different times in their lives. Chaplaincy work with bereaved parents in a postmodern context requires those

selected to be mature in their faith and with some experience of dealing with pain and suffering in their own lives. Fowler's (1996, 65) description of 'Conjunctive faith' (which he feels may be discovered and lived out in early midlife and beyond) articulates the approach to faith that chaplain's require to provide sensitive spiritual care and to retain a sense of personal integrity.

> In the transition to the Conjunctive stage one begins to make peace with the tension arising from the realization that truth must be approached from a variety of different directions and angles of vision...faith must begin to come to terms with indissoluble paradoxes: the strength found in apparent weakness; the leadership that is possible from the margins of society and groups but not from the centre; the immanence *and* the transcendence of God.

In short, prospective chaplains require a faith that can live creatively with paradox and tension, for example, during ritual a chaplain holds paradoxical roles (as priest and shaman) sharing an event which has ambiguous aims (to connect and disconnect parents with and from their babies). They also require a theological understanding of ministry, and sense of self, that does not require them to be always in control and the centre of ritual attention. Whether a prospective chaplain has such a faith perspective and depth of self-awareness should be thoroughly explored at an interview for appointment both for his or her well-being and that of the distressed parents he or she may work with.

10.3.1.4. Gifts

As has been highlighted in **10.1.1.3.**, the essential requirements for chaplains are not so much the acquired skills or theological sophistication that an individual has but the natural abilities she or he possesses. Those involved in selecting chaplains have to ask themselves during interview - what sort of presence does the candidate have in the room? Is he or she engaging, warm, easy to relate to, relaxed with him or herself and able to put others at ease? Does he or she possess the necessary charm to be able to build a rapport with other HCPs and develop relationships with bereaved parents (from a variety of cultural and religious backgrounds) in distressing situations? Thus, the selection of chaplains is not just about assessing a person's qualifications and experience. It is also about listening to one's gut feelings and discerning whether they have the right personal attributes for such a multifaceted role.

Prospective chaplains have to possess compassion and tenderness, charm and discernment. They are required to be people of integrity and mature in faith and self-

awareness. They have to possess the ability to be available for and attentive to others, but also to be able to leave and let go. Those applying for chaplaincy posts need the desire to glimpse something of God in their daily encounters but not seek to be God-like - omni-present and omni-competent. Prospective chaplains must be willing to give of self but be able to hold onto what is the essence of their self. They need to be team players – open to the work of the Other and respectful of the role and abilities of others. Candidates for a chaplaincy post can have worked at developing their self-awareness, honed their counselling skills and reflected on their previous practice to enable past experience to inform future care. However, without possessing inherent gifts which enable connections with patients and other HCPs in times of grief and loss to be made, the care they may offer will be superficial and impersonal.

10.3.2. Implications of this study's findings for chaplains' personal growth and professional development.

This study has revealed that an individual's personal attributes are central to his or her capacity to fulfil a chaplaincy role. Clearly a chaplain's personhood informs his or her practice and, when open to reflection on experience, a chaplain's practice may reshape or reform elements of his or her character or identity. Thus, a chaplain's personal growth and professional development are closely linked. The findings of this study suggest that there is a need to prioritise the sustaining and nurturing of the personhood and spirituality of chaplains by health boards and faith communities, as well as by the chaplains themselves, in order to maintain high standards of spiritual care being offered and to further develop relevant and creative approaches. Therefore, proactive measures are required to enable chaplains to mature and develop as persons as well as reflective practitioners. Similar observations are made by the Church of Scotland's Board of Ministry in a report to the General Assembly entitled *Ministers of the Gospel* (Church of Scotland 2000, 17/24)

> ...those called to the ministry of Word and Sacrament, ministers (and other church representatives in chaplaincy[5]) of the Gospel in the 21st century must be reflective practitioners, collaborative leaders and formative learners...the theology and practice of ordained ministry...requires a clear capacity and commitment among all ministers of the Gospel to deep reflection, genuine collaboration and continuing formation as persons in Christ and practitioners in ordained ministry.

---

[5] The words in parentheses are mine and are not found in the *Ministers of the Gospel* report.

Thus, in order for chaplains to nurture their own humanity and spirituality, as well as their practice and theology, an ongoing commitment to making time and space in order to do so is required. Built into the rhythm of work and play, ministering to and receiving from, requires an attentiveness, both individually and corporately, to our inner worlds and our interactions with others, and what of God may be glimpsed in both.

10.3.2.1. Nurturing chaplains' humanity and spirituality

Parents perceived a chaplain's support of them to be emotional and spiritually draining for the chaplain. Such personal costs are paralleled in the ministry of Jesus as he responded to the needs of the bereaved and the sick, for example, we read in Mark 5:26 that as a woman is healed of her heavy menstrual bleeding that '…power had gone out of him…'

In James Wood's novel *The Book against God* (2003, 245-6), his central character Tom Bunting, is listening intently to a recording of a live performance of a Beethoven concerto. So taken is Bunting with the beginning of the piece that he asks his wife if she could stop the record to allow him to enjoy again its first few chords. As he listened a second time Bunting hears not only the melody but something more.

> Yet there was another sound, not musical. Something like a man sniffing. It was the pianist breathing! – heavy, almost impatient, as if he were wrestling with the music to secure its great medial serenity. The pianist was breathing quite hard through his nose as he wrestled with this sweet sound. It was the sound of hard work, but it was also the sound of existence itself – a man's ordinary breath, the give and take of the organism, our colourless wind of survival, the zephyr of it all. The evidence of human effort, of pain was intensely moving…

Like playing music, like staying with a melody that has been composed, being with another in distress is painful and requires much effort and attention. Making our self available to the confusion and searching of a bereaved parent is energy sapping work – being attentive to the present moment means listening and responding to what is reverberating within and around us. What is understood from the story of another can touch the raw areas of our story from recent or childhood times (as explored in **10.3.1.1.**).

A key question, therefore, is how do chaplains sustain and nurture their emotional and spiritual lives in order to repeatedly enter into situations and relationships where they are confronted with a myriad of emotions and an array of questions to which

there are no easy answers. In this respect the following are important for chaplains to consider.

Chaplain's relationship with God and self

..then he went up the hill by himself to pray. It had grown late and he was there alone.' (Matthew 14: 23)

Both during co-construction in the listening to parental stories, and during ritual when parents respond to their stories being recounted by another, the chaplain involved is experiencing and holding pain – for a while. However, there comes a point when there is a need to hand over those feelings of loss and dereliction onto a Greater Being whose shoulders are far broader and more able to carry the cumulative weight of such expressed emotion. The pain of others can touch and move us, facilitate reflection and growth, but also has the potential to overwhelm us over a period of time. It is not ours to keep but to hand over, not just so that we, as chaplains, have sufficient spiritual and emotional resources available to make room for and be attentive to the pain of the next bereaved person we care for, and the next… More that that we, as human beings, need enough of both for ourselves so that the rest of life can be lived fully.

And yet in the effort of each moment being with, and being receptive to, the pain of another and of self is the promise of something more, something shared and something other.

> The present moment is significant, not as the bridge between past and future, but by reason of its contents, contents which can fill our emptiness and become ours if we are capable of receiving them.

(Hammarskjold 1966, 67-8)

In receiving such moments as gifts – as moments of grace – our lives may be enhanced, even paradoxically in the midst of death and grief. Subsequent reflection on what we have experienced during ritual and in its co-construction, with parents may improve our understanding of how we relate to others in particular situations of distress. Indeed, such contemplation only has real meaning when it deepens our engagement with others (Marcel 1950, cited by Pembroke 2002). Moreover, such reflection as well as increasing our self-awareness also aids our ongoing journey into the mystery of God. Such a deepening of understanding of self, of what we can make available to others and of God's involvement in our lives and in our encounters, is an ongoing sojourn. Pembroke (2002, 218) helpfully puts it this way whilst also making

a comparison with learning psychotherapeutic techniques as a sole means of meeting people's spiritual and needs

> A person with the requisite ability and diligence can master interventions in a few short years. It takes a life-time, however, to even begin to grasp what it means to share in a real meeting with another human being.

Opportunities for creativity and depth of insight may be enhanced by the company of a supervisor or spiritual director along the way. It is interesting that chaplains are not required at present to have either to practice (though steps are being taking in Scotland for supervision to become a statutory requirement to enable a more professional approach to the care they provide, in line with other carers such as social workers and counsellors).

> Many people do not know themselves, because they proudly believe they can give birth to themselves. The fact is that none of us can reveal ourselves to ourselves, unless we first reveal ourselves to another.

(Quoist 1986, 19 cited by Stoter 1995, 151)

Whilst supervision and spiritual direction could be considered as two separate activities both involve a confidential relationship with a wise and discerning other who can potentially aid us, amongst other things, to grow in our knowledge of self. Whilst spiritual direction is more concerned with '…understanding ourselves in the light of God…' (Goodacre 1983, 115), supervision has managerial and educative (including possible ongoing theological reflection), as well as supportive aspects (Moore and Levison, 2003)[6]

Such potentially illuminating relationships also contain possibilities of recognising and owning our own needs within the helping relationships we are involved in. Cooper-White (2004, 110) emphasises the importance of this dimension of self-awareness for carers.

> The capacity to become *aware* of one's own feelings and then to consider in a reflective vein what such feelings might be communicating – about both one's own needs for healing and the needs of the helpee – are the essential skills for…caring genuinely and empathetically for another.

(Cooper-White 2004, 110)

---

[6] Aspects of supervision concerned primarily with improving practice rather than nurturing one's spirituality or basic humanity will be considered in **10.3.3.2.**

Irvine (1997) suggests that our identities are shaped in relationship with others, as McFadyen (1990) postulates, as well as by exploration of our inner selves. The movement towards personal wholeness and integration is seeking a balance between attention to these two contrasting worlds. Thus, there is a need for chaplains to attend to the world of being and waiting – recognising and responding to voices from within. Attending to the part of our self which gratifies our egos through doing, achieving and receiving affirmation from others is also important. However, giving priority to this part of our makeup results in our identity, for ourselves and others, being equating with activity and responding to others' needs. Thus, there is a danger that our identity becomes tied up in our role rather than in who we really are. Much energy may be utilised in keeping up the pretence, with little left for listening and responding to personal needs.

In developing self-awareness and, thus, our spirituality, on our own or with another, is again to risk. It is to risk being open to new understandings of self and God discovered within and from encounters with others. It is to explore more deeply the possibilities of God within us and around us. Au and Cannon (1995, 22) helpfully cite the mystic and theologian Teilhard de Chardin on this issue - 'Let us leave the surface, and without leaving the world, plunge into God.' Like the risk involved in seeking to be available for others, the risk of entering into the unknown places of our inner selves and having to dealing with pain and fear that is awakened within us, as well as possibilities for further enlightenment, is also very real. Hammarskjold (1966, 65) articulates this ongoing search as follows

> The longest journey
> Is the journey inwards.
> Of him who has chosen his destiny,
> Who has started upon his quest
> For the source of his being
> (Is there a source?)....
>
> Between you and him is distance,
> Uncertainty –
> Care....

Such seeking, like the delivery of spiritual care, therefore, requires a chaplain to have courage as well as a sense of commitment to prayer and reflection. It also means a chaplain requires a lightness of touch with him or her self. As Pembroke reminds us (2004, 30) – '...nurture of the self requires patience. Harshness towards the self stunts growth.'

Chaplains require the ability to laugh at and to live gently with ourselves as mistakes are inevitably made in caring for others and we will never be able to be wholly attentive to the needs of another. Matthew 19: 19 reminds us '…to love your neighbour as yourself…' as opposed to the version so beloved of those with a Protestant work ethic – '…love your neighbour more than yourself…'

However, the struggle to love our self as much as we love those whom we seek to care for is not just experienced by Presbyterian clergy. Georges Bernanos (1977, 251) in the last paragraph of his insightful account of the life of a parish priest in rural France who is nearing death says this

> How easy it is to hate oneself! True grace is to forget. Yet if pride could die in us, the supreme grace would be to love oneself in all simplicity – as one would love any one of those who themselves have suffered and loved in Christ.

Thus, perhaps the most important aspect of our relationship with God and ourselves which enables us to make ourselves available for bereaved parents is a belief in God's love for us. To love others requires of us that we feel we are loved and are loveable in our own right. Muse (2000, 258) insightfully puts it this way

> *Belovedness* is what provides the most essential ingredient for healthy psychological development that leads to compassion and conscience.'

Play and the company of significant others

A prerequisite of being a chaplain is possessing a sense of humour and a predeliction for play. The sense of playfulness required for chaplaincy is beautifully depicted in a Punch cartoon which takes off an illustration found in *The House at Pooh Corner* (Milne 1928, 104). Winnie the Pooh and some of friends are standing on a bridge over a stream playing at poohsticks. The caption underneath the cartoon reads 'I'm fed up of playing poohsticks let's go down the arcade and get ourselves tattooed.' Whether poohsticks or decorating our bodies is our favourite pastime or not, play and enabling the expression of the child within us is an important way of recharging our spiritual batteries. Play offers a balance in life to the intensity and layers of loss experienced in labour ward or at a graveside and lived with later. However, making time in which to play, for play's sake, is counter to the prevalent healthcare and ecclesial cultures of doing and achieving. Michael Hare Duke (1994, 76-7), onetime Pastoral Director of the Clinical Theology Association wryly sums up much of what I have been trying to highlight in relation to a chaplain's self-nurturing, in his poem entitled *Playtime*

It takes a kind of courage
to find time for play...

Yet the time I take off
from industrious striving
to watch, enjoy my friendships, delight in touch and taste
nourish my true self...

Dreams, imagination and God's laughter in creation
invite me out of my industrious solemnity,
to take the task of playing seriously
until my marred manhood
is recreated in the child I have denied.

Fostering a life which is well-rounded, finding a balance between work and leisure, is important for chaplains (as indicated in **4.2.2.**), as is making time to enjoy our personal relationships. In the company of those who love us and accept as we are, and not for what we can do or be for them, there is opportunity for restoration (Herrick 1998). In the love for us, by others, we may glimpse something of the unconditional love of God, for whom we are a 'beloved' son or daughter and in whom God takes 'delight' (Matthew 3:17).

In responding to the ever changing spiritual needs of others in the present moment there is the challenge for us as chaplains to attend to our own dynamic spiritual journey and needs which also, as we are as much human as those we care for, change through our experience and sharing of life with others.

10.3.2.2. Developing chaplains' practice and theology

By co-creating and sharing in appropriate rituals with parents for their babies and by then reflecting on such experiences, chaplains not only have the opportunity to learning how to improve our care for such families. We also have the opportunity to learn more about ourselves. As Wilson (1971, 145) in his study of hospital chaplaincy puts it

> The hospital is a place where we have to face ourselves as we are: it is therefore a place of potentially liberating insights.

Put another way, in the terms of a hermeneutical approach (Capps 1984) to providing spiritual care there is the opportunity to let encounters with others read us, if we are prepared to risk developing our own self-understanding through ongoing reflection on practice.

Who we are and what we believe informs our practice but equally our practice can influence who we are becoming and how we understand God and, thus, the

outworking of our evolving theology in our future care. For example, Jacobs (1988, 21) describes how close attention to the stories we hear in caring relationships may have significant implications for our unfolding theology

> ..listening is the precursor to understanding, to interpreting, and to help the teller interpret (albeit in the simplest terms) the significance of the story now, in this place, at this time, and with this listener. There may be times when listening to the narrative in this way will go beyond pastoral care, to the making of a personal theology.

However, exploring the creative dynamics between experience and reflection, and theology and practice can only happen if time and energy are set aside to attend to such activity.[7] This not only means chaplains, and the teams to which we belong, including regularly within our normal rhythm of work time for individual and corporate reflection. It also requires team leaders or co-ordinators (within chaplaincies and maternity units), health service managers and church leaders or departments (with responsibility for chaplaincy services) encouraging and giving personnel permission to do so. Thus, potentially improving future practice but, just as importantly, enabling the opportunity for deepening self-awareness, heightening understanding of relationships within teams and a rich resource of theological insight to inform the life and work of the wider church. This is what we now shall now go on to consider.

10.4. Co-construction of ritual marking – meeting needs and offering opportunities to grow

The model of working with bereaved parents to co-construct ritual for their baby not only enables many of their spiritual needs to be met. It also affords the opportunity of the church, in the form of the chaplain, to grow and learn.

10.4.1. Significance of co-constructing ritual for chaplaincy and the church

As introduced in **10.3.2.2.** reflection on practice offers the opportunity to utilise the experience of what we have heard and shared in to influence our theology and, thus, future practice. Such reflection has implications not only for the work of individual chaplains, chaplaincy teams and interdisciplinary work with other HCPs. It has

---

[7] For a helpful schema to aid reflective practice see Schon (1983). Carroll (1986) offers a pertinent exploration of Schon's approach within the field of ministry and Lyall (2001) likewise, within the particular context of pastoral care.

implications for the church and its paid workers and members caring for others in a variety of institutional and community settings.

Not only do chaplains have the opportunity to wrestle with theology and theodicy by involvement in co-construction but also to learn a new language and new metaphors which convey something of the mysteries of life, death and suffering as well images of God and an afterlife (see also **5.2.6.**) In our postmodern era, church language and metaphors no longer are part of the majority of peoples' everyday lives. Parents struggling to make sense of the death of their baby use a variety of sources which are part of their own everyday experience to articulate their ideas and beliefs. In hearing, using and taking seriously such insights and word-pictures chaplains have the opportunity not just to utilise these as resources for individual rituals, but as resources for our own personal spiritual development and the deepening of the church's understanding of postmodern life as well as how people in this era relate to suffering, death and God.

Furthermore, this model of co-constructing ritual also enables chaplains to develop their own theological and psychological understanding of what sharing in ritual marking in itself is about. In engaging with parents and reflecting on what parents bring to and invest in co-construction and ritual moments chaplains can benefit, not just by becoming more sensitive to and aware of relevant issues, but also by reflecting on and gaining insight from what it is that chaplain, families and staff are actually sharing together during ritual. This is an ongoing process, as each ritual moment is unique. The church, therefore, in the form of the chaplain, has the opportunity to grow and learn, to hear and understand, to experience and to interpret through working with those who seek ritual marking at what is a time of major trauma and transition in their family's story. Thus, the church through the work of chaplains may adopt a 'listening posture', and the possibilities associated with it, rather than simply just the more traditional stance of proclamation (Scott 2000, 18).

In adopting such an approach to ritual construction with those who are not active members, the church in form of the chaplain, is perceived not to have to over-riding control or ownership of ritual. Neither is the church perceived to impose an alien language, stories and actions but is experienced as being prepared to risk, to be open and take seriously the story, and means of expressing that story, of parents. In other wards, to engage with them where they are and to respond to their real needs and not their assumed needs. Therefore, what the chaplain embodies is the church as learner

not just teacher, the church as listener and just teller, the church as a receiver and not just a giver and the church as vulnerable and not omnipotent. This has implications not only for how the church is perceived to act but what the church may be. Webster (2002, 128) puts it this way

> My vision of the Christian identity is that it is not simply the *foundation*, the jumping off point, for our activity. It is also the *product* of our activity. We may undertake certain activities because we are Christian but in undertaking these, the nature of our Christian identity changes. We see new visions of God and of humanity, and have to reconceptualize our faith accordingly. Identity and experience are locked in a mutually enhancing cycle – changed by one another. In the encounter between church and society, the trick is to ensure that Christianity is neither lost in translation, nor left unaffected by it.

10.4.2. Significance of co-constructed ritual for bereaved parents

I have already explored several significant consequences of the process of co-construction for parents in **9.4.** However, in addition I also wish to reflect theologically on the importance of co-constructed ritual marking for those bereaved parents who have some Christian belief but do not belong to the church (and may have no wish to belong), and those whose worldview is informed by an eclectic mix of narratives

10.4.2.1. Co-construction offers parents an enhanced means of expressing themselves

This study reveals that even in this postmodern era the bereaved who would not regard themselves as confessional Christians still have a need to utilise the language, images and metaphors of the Christian narrative to help them articulate their theological wrestling, search for meaning and their hopes for their deceased loved one, within and out with the bounds of ritual, as they grieve. The use of the bible as a rich literary resource, as well as a religious one, which contains vivid descriptions of the human struggle to make sense of loss and God's possible involvement (or not) in such experience as well what may be shared in meaningful human relationships has already been explored (in **5.2.6.**). Moreover, the utilisation of the prayers, hymnody and music of the Christian tradition as a reservoir from which may be found a wide range of human responses to the mystery of death, and what may be beyond, has also been discussed (in **5.2.6.**). In this study bereaved parents found such resources being made available to them, along with others from a variety of faiths and secular literary genres, helpful in aiding the co-construction of relevant funerals. It is interesting to

note that though the majority of parents would not have called themselves religious nearly every ritual performed which was co-constructed had a religious element within it – for some this may only have been a reference to God or an afterlife in a prayer or a blessing and for others their Christian beliefs pervaded the whole of the ritual performed. Therefore, the following point made by Grant *et al* (2004, 15) is of significant relevance.

> The language of spiritual care, while requiring to be inclusive and contemporary, must however not reject or destroy the language of religion that many, even those who are not religious, are familiar with and use.

What was paramount to the parents interviewed was the opportunity to choose from such a range of resources. This not only enabled parenting and enhanced parental ownership of the ritual; it gave a means by which parents could find expression (albeit partially) of their innermost feelings, hopes and conflicts, at a time when they were struggling to find the language or images to do so. Furthermore, this approach avoided the imposition of an alien liturgy and language which had the potential of causing more confusion and distress than the parents already felt.

In a broader context, the church in our postmodern world, where people are seeking a relevant means by which to express their response to tragedy and trauma (at a personal or global level), has a role, which could be further developed, in facilitating rituals appropriate to the spiritual, and not merely religious needs, of local, national and international communities. For the church to be able to do so her rituals leaders need to be prepared to risk listening to and working with those who are not active in local faith communities. This would involve letting go of power and the control of ritual construction and using the ritual authority invested in them by communities with discernment and humility. Here is an opportunity for the church to aid those with no particular faith attachment to create opportunities for expression of their grief and their search for meaning which emerges from real experience and need of ordinary people (in funerals, memorial services and other ritual markings). In order to empower this process the church has to offer an array of the rich human, symbolic and written resources available from within its various traditions. Webster (2002, 122) offers valuable insight

> Those who are well practised in the design of worship and liturgy could be seen as being gifted with a rare generic skill: the use of the language of ritual to create dramatic and moving forms of expression which enable the articulation of truths which cannot be articulated in

any other way...the use of ritual and the deployment of the symbolic'
are an enormously important for building emotional resilience and
health, both for individuals and communities.

Putting such a vision into practice would involve utilising the time, talents and
energy, not only of paid church workers, but the laity who possess the gifts described
in **10.1.1.2.** (such a scheme is currently, for example, being explored within the
Church of Scotland by the Board of Parish Education). A more detailed exploration
of the implications for the mission of the church by utilising such a model of co-
constructing ritual within the context of spiritual, as well as pastoral, care in a parish
setting is out with the remit of this thesis.

Chapter 11 Concluding thoughts and recommendations for future practice and research

Based on reflections of this study's findings, this final chapter will offer some recommendations for future practice for those with a concern for the spiritual care of bereaved parents. These recommendations will have implications for NHS policy-makers, those managing staff and for HCPs (including chaplains). In addition, I will also make some proposals as to how the church may improve the spiritual care she provides for parents. Finally, suggestions will be made for further research into issues related to those explored in this study, but outwith its specific remit or its resources.

11.1. Recommendations for the NHS

The voices of bereaved parents need to continue to be heard when shaping the services provided for their holistic care. Spiritual care has an important place within that care. Receiving sensitive spiritual care is of significant value to bereaved parents and contributes to their feeling of satisfaction with the overall care they and their baby receive.

11.1.1. Recommendations for policy makers

The following issues require to be considered by policy makers within the NHS when considering how the spiritual needs of bereaved parents may best be met.

- **Recommendation**: those responsible for midwifery staffing levels have to take into account the time required by midwives for assessment of spiritual needs and sharing of information about ritual marking and chaplaincy support, as part of providing holistic care (see **7.2.2.3.**).

- Likewise, providing parents with opportunities to co-construct personalised rituals and sharing in rituals, especially funerals, is time consuming for chaplains (see **7.2.3.1.** and **7.2.3.2.**). Few parents draw upon the support of local faith communities and many, therefore, depend upon chaplains for ritual marking. In our postmodern society with reduced religious affiliation and a re-discovery of the power and meaning of rituals, the demands on chaplains to co-construct and share rituals with parents can only increase (see **8.2.1.**).

Recommendation: chaplaincy provision within maternity units requires ongoing monitoring.

- **Recommendation**: spiritual care policy documents need to take into account that many not affiliated to faith communities still have religious beliefs and utilise the language and imagery of faith traditions to express spiritual issues (see **8.2.2.1.** and **10.4.2.1.**).

- **Recommendation**: the provision of suitable facilities (separate from labour and postnatal wards) where bereaved parents and their families can spend time with their baby after delivery in privacy and where welcoming rituals may be performed is important (see **8.3.1.1.**).

11.1.2. Recommendations for health service managers

HCPs (including chaplains) providing support for bereaved parents in hospital and community settings require the support and understanding of the hospital managers responsible for the delivery of maternity units in the following particular areas.

11.1.2.1. Training

Recommendation: ensure new staff who will be working with bereaved parents have the appropriate training to enable them to

- be familiar with legal issues and hospital protocols relating to baby death and disposal and the role of the funeral director (see **3.2.1.**)

- be familiar with local provision of practical, emotional, and social support for parents, including the local SANDS or Miscarriage Association groups and other bereavement support and counselling services (see **3.2.3.** and **8.2.6.**)

- be familiar with a variety of models of grief, parental experiences of grief and general principles of care to enable appropriate responses to parents' specific needs (see **3.1.** and **3.2.4.**)

- be familiar with the *post-mortem* changes in babies should parents wish to see their baby after time has elapsed following delivery (see **8.1.1.8.**).

- have the basic communication skills (see **7.2.2.3.**) necessary to facilitate listening and timeous and sensitive sharing of information, and encouragement to develop their self-awareness (in the areas outlined in **10.3.1.1.**)

- have training in assessment of spiritual (including religious) needs and an awareness of how those needs may be met through utilising their own human resources (see **3.2.4.** and **10.1.1.2.**) and through appropriate referral (see **7.2.2.3.**),

for example, to the chaplaincy service or the representative of a local faith community.

11.1.2.2. Ongoing professional and personal development

Recommendation: managers should also help to facilitate ongoing professional development by providing staff with the opportunity to

- update themselves on relevant research relating to the holistic care of bereaved parents (see **3.2.**) and grief theory (see **3.1.**) by attending appropriate study days and having access to relevant journals and textbooks

- participate in reflective practice with their peers and colleagues from a variety of disciplines involved in caring for bereaved parents (see **10.3.2.2.**).

Furthermore, to enable HCPs to utilise their innate abilities and humanity to the full as resources for responding to parents' spiritual needs, managers are required to ensure that staff have the opportunity to nurture their humanity.

Recommendation: ensuring staff have adequate time off and take all their holidays to aid refreshment and have their particular spiritual needs met in ways relevant to them outside their working environment (see **10.3.2.1.**)

Recommendation: in relation to chaplaincy services managers, should ensure that

- supervision for chaplains is normative and as such requires to be budgeted for (see **10.3.2.1.**)

- key criteria in the selection of chaplains (along with church representatives) includes the candidates' possession of natural abilities to enable them to relate sensitively to parents and staff in stressful situations, as well as relevant experience, training and theological education (see **7.2.3.1.1.** and **8.2.7.**).

11.1.2.3. Staff support

HCPs working with bereaved parents also require spiritual care and emotional support (see **3.2.4.**) of an informal (from colleagues and senior staff) and, where necessary, formal (for example, from a bereavement counsellor employed by the hospital or staff counselling service) nature. Much of the support a chaplain may offer (and receive from) staff is of a one-off informal nature but, depending on the skills and resources of the chaplain, a more ongoing supportive relationship may be entered into. The chaplain being utilised as a source of staff support depends very

much on the relationship and level of credibility he or she has established within a maternity unit. This requires time, patience and availability. Multidisciplinary debriefing following baby death may also be helpful provided a skilled individual facilitates the discussion (a role a chaplain may take on where appropriate) who prevents a medicalisation of its content (which may divert from an open a sharing of feelings and reflection on experience).[1]

Recommendation: attention to the emotional and spiritual needs of staff requires to be made a priority (consultation with staff is required as to what their needs are and how they may be appropriately met).

Chaplains have a role in helping NHS policy makers and managers fulfil the above requirements through making themselves available as a resource to provide appropriate information, guidance, training and staff support (see **7.2.6.**). In addition, and in a more subtle way, chaplains can also help to raise the profile of the spiritual needs of parents and staff by helping to create a culture, over a period of time, where the issue of spirituality and spiritual care is given due attention (see **11.1.3.5.** below).

11.1.3. Recommendations for chaplains

The following are some implications for the practice of chaplains offering spiritual care to bereaved parents.

11.1.3.1. Training

Recommendation: chaplains working in maternity units require the same basic training as other HCPs. In addition, they need

- a knowledge of the role of the various non-chaplaincy colleagues they work with, including staff working in the community (for example, community midwives, social workers and health visitors), and how they can contact them (see **8.2.5.** and **8.2.6.**)

- a knowledge of the religious and cultural needs of the various faith and ethnic communities (see **3.2.6.**) living in their hospital's locale (a working relationship with a representative of each would be helpful but at the very least the chaplaincy office should have an up-to-date list of appropriate contact telephone numbers).

---

[1]For further discussion on the spiritual care of HCPs see David Stoter's book *Spiritual Aspects of Health Care* (1995). Stoter is an experienced hospital chaplain and was Chairman of the Council, National Association for Staff Support (for staff in the health care services).

11.1.3.2. Building relationships with staff

Recommendation: prioritising time in which to proactively develop relationships with other HCPs.

This not only will enable chaplains to offer support to, and receive support from, healthcare colleagues; it will help to facilitate chaplains' access to patients who have spiritual needs which may be met by companionship and ritual marking, but have no awareness of chaplaincy services or negative expectations of them (see **7.2.2.3.** and **8.2.4.**). In the relationships chaplains develop with, and through the training they offer to, other HCPs there is an opportunity to underline the support and care chaplains provide is spiritual, and not just religious. This can be further reinforced in literature made available to staff and parents outlining chaplaincy services.

11.1.3.3. Guidelines informing the co-construction of ritual

There may not be an opportunity to enter into a relationship with parents in which ritual may be co-constructed (especially in the case of welcoming rituals) due to the immediacy of delivery or through respecting parents' wishes (see **5.2.1.**). The following, on the whole, have more relevance to the co-construction of funeral rituals but should also be borne in mind when co-constructing welcoming rituals (depending on the specific circumstances and parental needs). These recommendations (building on what is laid out in **5.2.5.**) are not to be rigidly followed to put spiritual care in a straitjacket but are to be utilised with creativity, sensitivity and discernment with the parents' particular story at the forefront of a chaplain's mind.

Initial meeting to specifically co-construct ritual (previous encounters may have been primarily focussed on providing an unhurried supportive presence)

Recommendations:

- meet in person with parents, ideally in their own home (see **7.2.3.3.** and **7.2.3.4.**)

- time should be given to develop a rapport with the parents (see **7.2.3.1.** and **9.4.**)

- assess what parents' spiritual needs are in the present moment by listening to their story; be aware that those needs may have changed since a previous encounter (see **7.2.3.1.** and **8.2.3.1.**)

- allow parents to vent their feelings and search for meaning (see **7.2.3.1.**)

- ask parents what they want to do for their baby and for themselves, only after their story has been told (see **7.2.3.1.**)

- a chaplain should clarify his or her understanding of the parents' needs and explain what can be done to try to meet them. In doing so the chaplain should make clear what a chaplain's role is (see **8.2.2.** and **8.2.3.**) and is not (see **7.2.2.1.**).

- ask about parental beliefs (for example, in an afterlife) and any connection with a faith community (see **7.2.3.5.**, **8.2.1.2.** and **8.2.1.3.**)

- cultural norms regarding baby death and ritual marking and practical information about disposal options should be shared at parent's pace (see **7.2.3.2.** and **9.2.5.1.**)

- describe practically what will happen during ritual (see **7.2.3.1.**) and opportunities for ongoing parenting (see **8.1.1.2.**)

- offer a variety of written religious and secular resources of different genres to parents to look at in their own time relating to the content of ritual (see **7.2.3.1.**)[2]

- encourage parents to think about the consequences of their decisions relating to ritual, for example, mode of disposal, having others present (including the baby's siblings) at ritual and choosing music. In doing so, use examples of other parents' experiences and feelings and evidence of research (see **7.2.3.1.** and **3.2.2.**)

- utilise feelings, phrases, metaphors of parents' story to weave into ritual and check with parents how this feels to them (see **7.2.3.5.**)

- emphasise co-construction is a process (see **7.2.3.5.** and **7.2.3.2.**) and that parents can contact the chaplain prior to ritual taking place for clarification, further information or guidance or to inform chaplain of decisions made or altered. It is important to say to parents that they can change their mind about the content of ritual at any time or about practical issues relating to it (see **9.4.**)

- parents should be encouraged to take time to make decisions, including their level of involvement in co-construction and participation in ritual (see **7.2.3.2.** and **9.2.5.1.**)

---

[2] Examples of sources from which chaplains may select material to offer to parents are given in appendix 14.

- encourage parents to consider the participation/presence of their other children or family members, where appropriate (see **5.2.6.**)

- ensure parents have written information regarding practical issues related to disposal, normal grieving (see **5.2.5.1.**) and sources of support (see **9.2.5.1.**)

- suggest parents visit place of disposal before funeral, especially if burial chosen (see **8.3.1.2.**)

- briefly review what has been covered during meeting and give opportunity for parents to ask further questions and seek clarification before encounter ends

Subsequent meeting (where necessary) or telephone conversation(s)

Recommendations:

- clarify mutually agreed content of ritual, including the order and roles of parties participating to enable mutual understanding and agreement of what will be said and done by whom and when (see **9.2.5.1.**)

- details of arrangements (including transport to and from place of disposal) for funeral should be confirmed with funeral director and a written note sent to the parents to confirm date, time and place

- check again for any further questions and give reassurance that there is room for flexibility and spontaneity whilst being clear about parameters (see **7.2.3.5.** and **9.2.5.1.**)

11.1.3.4. Guidelines for sharing ritual

Recommendations:

- ritual should be short and simple yet unhurried (see **7.2.3.5.**)

  (often parents may wish time alone together at end of ritual – chaplain may have to act as their advocate to create this)

- at the commencement of ritual introduce self and state why everyone is there and what is going to happen (often parents own description of their understanding of ritual can be used here)

- let actions and gestures and symbols speak for themselves (see **5.2.6.**)

- affirm family's spiritual resources (see **8.1.1.2.**)

- use comprehensible language with which parents are comfortable (see **7.2.3.5.**)

- use parents' preferred or pet names for baby, siblings and themselves (see **7.2.3.5.**)

- use silence (see **5.2.6.**)

- make creative use of music (see **5.2.6.**)

- tell it how it is – ritual evolves from a family's story and the chaplain's interpretation of that – lament and thanksgiving (see **7.2.3.5.**)

- set baby and parents' story in context of the wider family, human and divine story (see **8.1.1.5.**)

- give symbols or words (typed out) used in the ritual or to commemorate ritual action to parents as a memento (see **8.1.1.2.**)

- hold baby and talk about baby's features during a welcoming ritual or afterwards (see **7.2.3.5.**)

Underpinning these guidelines is the key concept that in giving parents as much information and guidance as they need, a chaplain can enable them to parent their baby the best way they can in tragic circumstances. It is their ritual for their baby and a chaplain has the privilege in sharing ritual with them, not doing it to or for them.

11.1.3.5. Creating a culture in which the spiritual aspect of parents and staff is given due attention

Chaplains by their personhood and practice, potentially may be a reminder amidst the technology, administrative protocols and constant busyness of twenty-first century maternity units of the '…habits and practices necessary to sustain the care of those in pain…' (Hauerwas 1986, 82).

What the chaplains may serve as reminders of within our technologically and goal orientated western healthcare culture, specifically in relation to caring for bereaved parents, includes

- Assessment and attention to parents' spiritual needs is not an optional extra but a necessity as part of the holistic care of bereaved families (see, for example, **8.1.**).

- There are times when it is important to be story-orientated rather than task-orientated i.e. being with and not doing things to or for parents, can be significant for them (see **8.2.3.1.**).

- The meeting of parental spiritual needs involves the establishment of caring relationships (see **7.2.3.1.**) and, where appropriate, co-constructed ritual moments (**8.1.1.**).

- Ritualising babies' lives and deaths through a process of informal and formal ritual moments not only may meet some parental, and HCP's, spiritual needs but also aid their grieving (see, for example, **8.1.1.2.** and **8.1.1.3.**).

- The greatest resource that any HCP has to draw from when supporting distressed bereaved parents is their humanity (see **8.2.7.**).

- Being touched and saddened by baby death is normal and sharing an expression of genuine feeling with parents and colleagues may be significant to them as well as to the HCP concerned (see **3.2.4.** and **7.3.2.5.**)

Therefore, what a chaplain may personify and show in practice (and potentially encourage reflection on) is the capacity for any HCP with a degree of personal compassion to be able to support parents in their grief, from their own intrinsic human resources. Moreover, they may, if sufficiently transparent and honest, reveal that doing so is both draining and challenging but that it is normal and perfectly permissible to find it so. Mutual support and encouragement (see **10.3.2.1.**) training and reflection on practice and personhood (see **10.3.2.2.**) are, thus, essential for chaplains to be involved in with other HCPs. This will be to the chaplain's benefit, the well being of those they work with, the culture they inhabit and the parents they care for. The chaplain, therefore, has an important role in helping to form

> An emotionally open communication between staff (which) can help to create the right atmosphere for a more emotionally open communication with the parents.

> Speck (1978, 41).

This points to a vital wider question. How can a culture be created in the NHS which will aid the ongoing support and nurturing, not just of chaplains', but of all its staff (especially those whose humanity and mortality is potentially challenged on a daily basis) on individual and corporate levels? [3] The exploration of such a question is out with the remit of this thesis.

---

[3] A research project funded by the Scottish Executive is currently exploring how the culture within hospitals may be changed to enable the spiritual and emotional dimensions of HCPs' lives be sustained.

11.2. Recommendations for the church

11.2.1. Education of theology students

Recommendations:

- candidates in the church training for some form of pastoral role (who may in time become hospital chaplains) should be required to acquire basic tools, within practical or pastoral theology classes, to enable them to engage in ongoing reflective practice

- students should have experience of reflecting theologically on practice with a supervisor and colleagues in the context of a clinical placement and, thus, also have the opportunity to explore the resources they have to offer and the implications of making themselves available to another in a caring relationship. In such an environment there is an '…emphasis on personal learning, and not on the acquisition of skills…' (Tieleman 1996, 14). This will enable students not only to become comfortable with the idea of supervision, but how to use it effectively

- supervision in both clinical and parish settings should be complemented by faith accompaniment or spiritual direction in order that students may deepen their inner journey, and an awareness of self and God in their outer one also.

11.2.2. Selection of chaplains

See **11.1.2.2.**

11.2.3. Ongoing professional personal development of chaplains

Recommendations:

- denominations should liaise with health service managers to ensure that chaplains are receiving relevant supervision, support, time off (see **11.1.2.2.**) and training (see **11.1.2.1.**).

- denominations should ensure that chaplains have access to spiritual direction which is appropriate to their individual needs (see **10.3.2.1.**).

11.2.4. Ongoing education of the church

Recommendations:

- chaplains and those working in parish settings should gather on occasional study days to share experiences and reflect on current practice and research relating to the care of bereaved parents.

- inviting bereaved parents and chaplains to share something of their experience with the wider church would also serve to raise members' awareness of the difficulties parents, who live with miscarriage and stillbirth, face and break through the wall of silence (see **3.2.5.**) on this subject.

11.2.5. Liturgy

As has been emphasised, parents in this study felt strongly that the liturgies of the church should be used as descriptive resources not as prescribed programmes in the co-construction of rituals (see **10.4.2.1.**).

Recommendation:

- the church, in the form of chaplains and liturgists, need to continue to engage with bereaved parents and the support groups which voice their concerns and experience, in order to create a range of prayers, blessings and hymns (in non-church jargon) which could help to meet the needs of parents in the immediacy of their baby's death. A range of such relevant, including secular, sources are to be found in appendix 14. Examples of a blessing service and non-religious funeral are offered in **5.2.2.** and **5.2.3.**

11.3. Recommendations for further research

Further research is required in the following areas which are related to the findings of this small exploratory study. These areas include

- Research into the role of ritual and the significance of its means of construction in meeting the spiritual needs of a larger cohort of parents, including those from a variety of religious and cultural backgrounds.

- Research into the role of ritual remembering and tending of their babies' graves in the lives of bereaved parents.

- Research into the role of memorial services for bereaved parents.

- Research into the spiritual needs of chaplains and other HCPs caring for bereaved parents, and how those needs are met or not.

- Research into developing or identifying indicators which may alert midwives to those parents who would benefit from seeing and holding their baby or not.

11.3.1. Comparative studies

- Compare the adjustment to baby death *in-utero* of parents who co-constructed and participated in ritual marking with the adjustment of those bereaved parents who chose not to do so.

- Compare the spiritual needs of parents experiencing miscarriage, with those living with stillbirth and neonatal death and how those needs were met.

- Compare the significance of ritual following miscarriage or stillbirth for parents with living children and those with fertility problems with no children.

- Compare the role of ritual marking in the adjustment to baby death of those parents who have firm religious beliefs with those who do not.

- Compare the significance of co-constructing and participating in ritual for bereaved mothers with their importance for fathers in meeting their respective spiritual needs.

11.4. A summative thought

The importance of ritual in the lives of the bereaved is underlined by Yann Marcel in his novel *Life of Pi* (2002, 285). Marcel describes the intimate relationship which develops between a Bengal tiger and an adolescent called Pi Patel who spend several months together in a lifeboat after being shipwrecked in the middle of the Atlantic Ocean. Pi describes his leave-taking of the tiger, whom he has named Richard Parker, when the small boat finally reaches land.

> I wept like a small child. It was not because I was overcome at having survived my ordeal, though I was. Nor was it the presence of my brothers and sisters, though that too was very moving. I was weeping because Richard Parker had left me unceremoniously. What a terrible thing it is to botch a farewell. I am a person who believes in form, in the harmony of order. Where we can, we must give things a meaningful shape...It's important in life to conclude things properly. Only then can you let go. Otherwise you are left with words you should have said but never did, and your heart is heavy with remorse.

Martel's reflections highlight not only the spiritual needs of Pi to acknowledge the end of a unique relationship but he highlights the gap which ritual can fill in meeting such needs. Such is the importance of ritual at a time of endings and new beginnings to help reduce unfinished business which can be carried with us. Moreover, such is the significance of ritual that it offers possibilities of meaning and order in times of distress. Perhaps, if Pi's leave-taking from his feline friend had been planned and Pi had had someone who could have offered him guidance, resources and time and space in which to reflect upon his relationship with Richard Parker, he might have constructed a relevant ritual to act out the significance of their relationship and mark its physical ending. In doing so, Pi may not only have found a suitable way of expressing his feelings but found some meaning in doing so. Perhaps too, he would have been left not only with a memory of their leave-taking but well-formed memories of their shared journey which would have sustained him in the uncertainty of the future that lay ahead.

Bibliography

Ainsworth–Smith, I. and Speck, P. 1999 *Letting Go – Caring for the Dying and Bereaved.* (2nd edn.) London: SPCK.

Allen, M. and Marks, S. 1993 *Miscarriage – Women Sharing from the Heart.* New York: John Wiley.

Anderson, H. and Foley, E. 1998 *Mighty Stories, Dangerous Rituals.* San Francisco: Jossey-Bass.

Autton, N. 1968 *Pastoral Care in Hospitals.* London: SPCK.

Au, W. and Cannon, N. 1995 *Urgings of the Heart.* New York: Paulist Press.

Baby Naming Society *A Naming Ceremony for babies lost during pregnancy or who have died around the time of birth.* Kempsey, Worcester: Baby Naming Society.

Bailey, R. 1997 *Scarlet Ribbons – a priest with AIDS.* London: Serpant's Tail.

Bailey, S. 1996 *The Well Within: Parables for living and dying.* London: DLT.

Ballard, P. and Pritchard, J. 1996 *Practical Theology in Action.* London: SPCK.

Barry, C. 1998 Choosing Qualitative Data Analysis Software: Atlas/ti and Nudist Compared in *Sociological Research Online* 3(3): 1-16.

Bernanos, G. 1977 *The Diary of a Country Priest.* Translated by P. Morris. (Reprint) Glasgow: Collins.

Bartellas, E. and Van Aerde, J. 2003 Bereavement Support for Women and their Families after Stillbirth. *Journal of Obstetrics and Gynaecology Canada* 25(2): 131-138.

Bazeley, P. and Richards, L. 2000 *The NVivo Qualitative Project Book.* London: Sage.

Bell, C. 1997 *Ritual: Perspectives and Dimensions.* Oxford: Oxford University Press.

Bellamy, J. 1998 Spiritual Values in a Secular Age In *The Spiritual Challenge of Healthcare,* edited by M. Cobb and V. Robshaw, 183-197. Churchill Livingstone, Edinburgh

Bender, H. and Jordan, M. 1994 Context for Qualitative Research. In *Research in Pastoral Care and Counselling,* edited by L. Vandecreek, H. Bender and M. Jordan, 71-74. Journal of Pastoral Care Publications.

Bender, H. and Jordan, M. 1994 Initial Principles and Disciplines. In *Research in Pastoral Care and Counselling,* edited by L. Vandecreek, H. Bender and M. Jordan, 75-87. Journal of Pastoral Care Publications.

Bender, H. and Jordan, M. 1994 Preparations. In *Research in Pastoral Care and Counselling,* edited by L. Vandecreek, H. Bender and M. Jordan, 89-98. Journal of Pastoral Care Publications.

Birch, M. and Miller, T. 2000 Inviting Intimacy: the interview as therapeutic encounter. *International Journal of Social Research Methodology* 3(3): 189-202.

Bohler, C. 1987 The Use of Storytelling in the Practice of Pastoral Counselling. *Journal of Pastoral Care* LX1 (1): 63-71.

Bourdieu, P. 1977 *Towards a Theory of Practice.* Cambridge: Cambridge University Press.

Boulton, D. and Hammersley, M. 1996 Analysis of Unstructured Data. In *Data Collection and Analysis,* edited by R. Sapsford and V. Jupp, 282-297. London: Sage.

Bourne, S. 1968 The Psychological Effects of Stillbirths on Women and their Doctors. *Journal of the Royal College of General Practitioners* 16: 103-112.

Bourne, S. and Lewis, E. 1991 Perinatal beareavement: a milestone and some new dangers. *British Medical Journal* 302 (6786): 1167-1168.

Bowlby, J. 1980 *Attachment and loss. Vol. 3. Loss: Sadness and Depression.* London: Hogarth.

Boyle, F. 1997 *Mothers bereaved by stillbiirth, neonatal death or sudden infant death syndrome.* Aldershot: Ashgate.

Bridges, W. 1991 *Managing Transitions: Making the Most of Change.* Reading, Mass.:Perseus Books.

Britten, N. 1996 Qualitative interviews in medical research. In *Qualitative Research in Health Care*, edited by C. Pope and N. Mays, 28-35. London: B.M.J. Publishing Group.

Brown, C. 2001 *The Death of Christian Britain.* Routledge: London.

Brown Y. 1993 Perinatal Loss: A Framework for Practice. *Health Care for Women International.* 14: 469-479.

Brown Y. 1992 The crisis of pregnancy loss: a team approach to support. *Birth* 19(2): 82-89.

Brueggemann, W. 1991 *Interpretation and Obedience.* Minneapolis: Fortress Press.

Buie, E. 2004 Question-mark over religious observance in the classroom. *The Herald* April 28:4.

Bunard, P. 1987 Spiritual Distress and the nursing response, *Journal of Advanced Nursing* 12: 377-382.

Campbell, A. 1986 *Rediscovering Pastoral Care* (2nd edn.) London: DLT.

Capps, D. 2004 Jesus as Power Tactician. *Journal for the Study of the Historical Jesus* 2(2): 158-189.

Capps, D. 1990 *Reframing.* Minneapolis: Fortress Press.

Cormell, M. 1990 *Miscarriage.* Unpublished dissertation: University of Surrey.

Carr, W. 1985 *Brief Encounters.* London: SPCK.

Carroll, J. 1991 *As One With Authority: reflective leadership in ministry.* Louisville, Kentucky: Westminster/John Knox Press.

Carroll, J. 1986 *Ministry as Reflective Practice: A New Look at the Professional Model.* Washington D.C.: Alban Institute.

Carstairs, V. and Morris, R. 1991 *Deprivation and Health in Scotland.* Aberdeen: Aberdeen University Press.

Carter, S. 1974 *The two-way clock* (reprinted in 2000). London: Stainer and Bell.

Case, R. 1978 When Birth Is Also a Funeral. *Journal of Pastoral Care* XXXII (1): 6-21.

Cassidy, S. 1988 *Sharing the Darkness.* London: DLT.

Cecil, R. 1996 *The Anthropology of Pregnancy Loss.* Oxford: Berg.

Church of England 2000 *Common worship: services and prayers for the Church of England.* London: Church House Publishing.

Church of England 1989 *Funeral Service for a Child dying near the time of birth.* London: Church House Publishing.

Church of England 1980 *The Alternative Service Book.* Oxford: Mowbray.

Church of Scotland 2004 Report to the General Assembly of the Panel on Doctrine. In *Reports to the General Assembly*, 12/1-12/8. Edinburgh: The Church of Scotland Board of Practice and Procedure.

Church of Scotland 2002 Report to the General Assembly of the Board of National Mission. In *Reports to the General Assembly*, 20/5-20/102. Edinburgh: The Church of Scotland Board of Practice and Procedure.

Church of Scotland 2000 Report to the General Assembly of the Board of Ministry. In *Reports to the General Assembly*, 17/3-17/25. Edinburgh: Church of Scotland Board of Practice and Procedure.

Church of Scotland 1994 *Common Order*. Edinburgh: St Andrew's Press.

Clebsch, W. and Jaekle, C. 1967 *Pastoral Care in Historical Perspective*. NewYork: Harper.

Cobb, M. 2001 *The Dying Soul: Spiritual Care at the End of Life*. Buckingham: Open University Press.

Cobb, M. 1998 Assessing Spiritual need: an examination of practice. In *The Spiritual Challenge of Healthcare*, edited by M, Cobb and V, Robshaw, 105-118. Edinburgh: Churchill Livingstone.

Coffey, A and Atkinson, P. 1996 *Making Sense of Qualitative Data*. Thousand Oaks, Ca.: Sage.

Collins, P. 1998 Negotiating Selves: Reflections on 'Unstructured' Interviewing. *Sociological Research Online*. 3(3):1-19.

Cooper, J. 1980 Parental Reaction to Stillbirth. *British Journal of Social Work* 10: 55-69.

Cooper-White, P. 2004 *Shared Wisdom – use of self in pastoral care and counselling*. Minneapolis: Fortress Press.

Corr, C., Nabe, C., and Corr, D. 1997 *Death and Dying, Life and Living*. (2nd edn.) Pacific Grove, CA: Brooks/Cole.

Cotter, J. 1990 *Healing – More or Less*. Sheffield: Cairns Publications.

Cree, V. 1992 *Social Work's Changing Task*. Univ. of Edinburgh. Unpublished PhD.

Cuisinier, M., Kuijpers, J., Hoogduin, C., de Graauw, C. and Janssen, H. 1993 Miscarriage and Stillbirth: Time since the loss, grief intensity and satisfaction with care. *European Journal of Obstetrics and Gynaecology and Reproductive Biology* 52: 163-168.

Davie, G. 1994 *Religion in Britain since 1945 – believing without belonging*. Oxford: Blackwell.

Davis, D. 1996 *Empty Cradle, Broken Heart – Surviving the Death of Your Baby*. Golden, Colorado: Fulcrum.

DeFrain, J. and Martens, L. 1986 *Stillbirth: the invisible death*. Lexington, Mass.: D.C. Heath and Co.

De Mello, A. 1986 *One Minute Wisdom*. Garden City NY.: Doubleday and Co.

Dey, I. 1995 Reducing Fragmentation in Qualitative Research. In *Computer Aided Qualitative Data Analysis*, edited by U. Kelle, 69-79. London: Sage.

Dey, I. 1993 *Qualitative data analysis*. Thousand Oaks, Ca.: Sage.

Dominica, F. 1997: *Just My Reflection: Helping parents to do things their way when their child dies*. London: DLT.

Driver, T. 1991 *The Magic of Ritual – Our Need for Liberating Rites that Transform Our Lives and Our Communities*. San Francisco: Harper.

Dunn, D. 1995 *Elegies*. London: Faber and Faber.

Fickling, K. 1993 Stillborn Studies: Ministering to Bereaved Parents. *Journal of Pastoral Care* 47(3): 217-227.

Forrester, D. 2000 *Truthful Action*. Edinburgh: T.& T. Clark.

Foskett, J. and Lyall, D. 1988 *Helping the Helpers – Supervision and Pastoral Care.* London: SPCK.

Fowler, J. 1996 *Faithful Change – The Personal and Public Challenges of Postmodern Life.* Nashville: Abingdon Press.

Fowler, J. 1995 *Stages of Faith – The Psychology of Human Development and the Quest for Meaning (reprint).* San Francisco: Harper & Row.

Freud, S. 1984 Mourning and melechonia. In *The Pelican Freud library volume II,* edited by A. Richards, 251-268. Hammondsworth: Penguin.

Furman, E. 1978 Death of a new born: care of the parents. *Birth and the Family Journal* 5:214-218.

Gardiner, A. 1997 Confronting the abyss: the relationship between bereavement and faith. In *Interpreting Death – Christian Theology and Pastoral Practice,* edited by P. Jupp and T. Rogers, 120-129 London: Cassells.

Gare, A. 1995. *Postmodernism and the Environmental Crisis.* London: Routledge.

Gerkin, C. 1997 *An Introduction to Pastoral Care.* Nashville: Abingdon Press.

Giddens, A. 1991 *Modernity and self-identity.* Oxford: Polity.

Giles, P. 1970 Reactions of Women to Perinatal Death. *Australia and New Zealand Journal of Obstetrics and Gynaecology* 10: 207-210.

Goodacre, N. 1983 Direction, Spiritual. In *A Dictionary of Chrsitian Spirtuality,* edited by G. Wakefield, 114-115. London: SCM Press.

Gorer, G. 1965 *Death, Grief and Mourning.* New York: Doubleday.

Grainger, R. 1998 *The Social Symbolism of Grief and Mourning.* London: Jessica Kingsley.

Grainger, R. 1988 *The Message of the Rite.* Cambridge: Lutterworth Press.

Grant, E., Murray, S., Kendall, M., Boyd, K. and Tilley, S. 2004 Spiritual issues and needs: perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. (Submitted for publication)

Green, G. 1962 *The Power and the Glory.* London: Penguin.

Green, R.1987 *Only Connect.* London: DLT.

Haley, J. 1986 The Power Tactics of Jesus Christ. In *The Power Tactics of Jesus Christ and Other Essays* (2nd edn.), J. Haley, 24-51. Rockville, MD: Triangle Press.

Hamilton, D. 1999 When birth and death come together: The right rite? *Scottish Journal of Healthcare Chaplaincy* 2(2):15-18.

Hammarskold, D. 1966 *Markings* (2nd edn.). Translated by W. H. Auden and L. Sjoberg. London: Faber and Faber.

Hare Duke, M. 1994 *Hearing the Stranger: Reflections, Poems and Hymns.* Sheffield: Cairns Publications.

Hauerwas, S. 1986 *Suffering Presence: theological reflections on medicine, the mentally handicapped, and the church.* Notre Dame, Ind.: University of Notre Dame Press.

Hay, D. and Hunt, K. 2000 *Understanding the Spirituality of People who don't go to Church.* Final Report of the Adult Spirituality Project, Nottingham University.

Health Education Council, National Association for Mental Health and the National Stillbirth Study Group 1979 *The loss of your baby.* London: HEC.

Herbert, M. 1998 Perinatal bereavement in its cultural context. *Death Studies* 22: 61-78.

Herrick, V. and Mann, I. 1998 *Jesus wept: reflections on vulnerability in leadership.* London: DLT.

Herrick, V. 1997 Limits of vulnerability. *Grove Pastoral Series* 71: Grove Books.

Hertz, R. 1997 Introduction: Reflectivity and Voice. In *Reflexivity and Voice*, edited by R.Hertz, vii-xvii. Thousand Oaks, Ca.: Sage.

Heyse-Moore, L. 1996 On Spiritual Pain in the dying. *Mortality* 1(3): 297-315.

Highfield, M. and Cason, C. 1983 *Spiritual Needs of Patients: are they recognised?* Cancer Nursing 6(3): 187-192.

Hiltner, S. 1958 *Preface to Pastoral Theology*. Nashville, Tenn.: Abington Press.

Hockey, J 1993 The acceptable face of human grieving? The clergy's role in managing emotional expression during funerals. In *The Sociology of Death*, edited by D. Clark, 129-148. Oxford: Blackwell Publishers/The Sociological Review.

Holdsworth, J. 2003 *Dwelling in a strange land – exile in the bible and in the church.* Norwich: Canterbury Press.

Hughes, P. and Riches, S. 2002 Psychological aspects of perinatal loss. *Current Opinions in Obstetrics and Gynecology* 15: 107-111.

Hughes, P., Turton, P., Hopper, E. and Evans, C. 2002 Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 360: 114-118.

Hunt, K. 2003 The Spirituality of Non-churchgoers. In *Predicting Religion*, edited by G. Davie, P. Heelas and L. Woodhead, 159-169. Aldershot: Ashgate.

Institute of Cemetery and Crematorium Management 2004 *Policy Document for the Disposal of Fetal Remains*. London: Institute of Cemetery and Crematorium Management.

Irvine, A. 1997 *Between Two Worlds*. London: Mowbray.

Jackson, S. 1992 The Listening Healer in the History of Psychology. *American Journal of Psychiatry* 149(12): 1623-1631.

Jacobs M. 1988 The Use of Story in Pastoral Care (Part One: Hearing Stories), *Contact* 95: 14-21.

Jaques, M. 2004 *The death of intimacy*. Guardian September 18: 21.

Jolly, H. 1976 Family Reactions to Stillbirth. *Proceedings of the Royal Society of Medicine* 69: 835-837.

Jones, M. 1997 Mothers who need to grieve: the reality of mourning the loss of a baby. *British Journal of Midwifery* 5(8): 478-481.

Kaan, F. 1998 Put peace into each other's hands. In *Common Ground - a song book for all the churches*. Edinburgh: St Andrews Press.

Katz, J. 2001 Introduction. In *Grief, Mourning and Death Ritual*, edited by J. Hockey, J. Katz, and N. Small, 1-15. Buckingham: Open University Press.

Kelly, E. 2002 On being a hospital chaplain. *Expository Times* 113(7):242-243.

Kennell, J., Slyter, H. and Klaus, M. 1970 The mourning response of parents to the death of a newborn infant. *New England Journal of Medicine* 283(7): 344-349.

Kersting, A., Fisch, S. and Baez, E. 2002 Psychosocial care of mothers after stillbirth. *Lancet* 360: 1600.

Kerevan, G. 2001 Faithful cynics of a new nation. *The Scotsman* 30 April: 3.

Kim, K. and Jacobs, S. 1991 Pathological grief and its relationship to other psychiatric disorders. *Journal of Affective Disorders* 21: 257-263.

Kirkley-Best, E., Kellener, K., Gould, S and Donnelly, W. 1982 On Stillbirth: An Open Letter to the Clergy. *Journal of Pastoral Care* XXXVI (1): 17-20.

Klass, D. 1984 Bereaved Parents and The Compassionate Friends: Affiliation and healing. *Omega, Journal of Death and Dying* 15(4): 353-373.

Klass, D. 1988 *Parental Grief: Solace and Resolution.* New York: Springer.

Kline, J., Shrout, P, Susser, M. and Warburton, D. 1980 Environmental influences on early reproductive losses in a current New York study. In *Human embryonic and fetal death,* edited by I. Porter and E. Hook. 225-240. New York: Academic Press.

Kubler-Ross, K. 1969 *On Death and Dying.* New York: MacMillan.

Klass, D. 1996 The Deceased Child in the Psychic and Social Worlds of Bereaved Parents During Resolution of Grief. In *Continuing Bonds: New Understandings of Grief,* edited by . D. Klass, P. Silvermann and S. Nickman 199-215. London: Taylor and Francis.

Kohner, N. and Thomas, J. 1995 *Grieving after the death of your baby – a book for parents and families.* Bourne End, Bucks.: Child Bereavement Trust.

Kuller, J. and Katz, V. 1994 Miscarriage: a historical perspective. *Birth: Issues in Perinatal Care and Education* 21(4):227-228.

Kuse-Isingschulte, M., Beutel, M., Hahleweg, B., Stauber, B., Stauber M. and Schneider, K. 1996 Psychological coping with stillbirth. Course of grief response. Influential factors, treatment satisfaction and patient management needs. *Gerburtshilfe Frauenheilkd* 56(7): 380-389.

Lartey, E. 2003 *In Living Colour: An Intercultural Approach to Pastoral Care and Counselling* London: Jessica Kingsley.

Lartey. E. 2001 *Global views for Pastoral Care and Counselling: Post-modern, post-colonial, post-Christian, post-human, post-pastoral.* (address given at the 7th Asia-Pacific Congress on Pastoral Care and Counselling): www.council-icpcc.org/materials/globalvi_1.htm

Leon, I. 1992 Perinatal loss; a critique of current hospital practices. *Clinical Paediatrics* 31(6): 366-374.

Lewis, A. 2001 *Between Cross and Resurrection – A Theology of Holy Saturday.* Grand Rapids, Michigan: Eerdmans.

Lewis. E. 1987 Stillbirth. In *A Dictionary of Pastoral Care,* edited by A. Campbell, 268. London: SPCK.

Lewis, E. 1976 The Management of Stillbirth: Coping with Unreality. *Lancet* 2: 619-620.

Lewis, E. and Page, A. 1978 Failure to mourn a stillbirth: An overlooked catastrophe. *British Journal of Medical Psychology* 51: 237-241.

Lindemann, E. 1944 Symptomatology and management of acute grief. *American Journal of Psychiatry* 101: 141-148.

Liturgy Office of the Bishops' Conference of England and Wales and International Commission on English in the Liturgy (of the Roman Catholic Church) 1991 *Order of Christian Funerals.* London: Geoffrey Chapman.

Lyall, D. 2001 *Integrity of Pastoral Care,* London: SPCK.

Lyall, D. 2000 Pastoral care as Performance. In *The Blackwell Reader in Pastoral and Practical Theology,* edited by J.Woodward and S. Pattison, 311-319. Oxford: Blackwell.

Lyall, D. 1999 Pastoral Counselling in a Post-modern Context. In *Clinical Counselling in Pastoral Settings,* edited by G. Lynch, 7-21. London: Routledge.

Lyall, M. 1997 The Pastoral Counselling Relationship – A Touching Place. *Contact Pastoral Monograph* 7. Edinburgh: Contact Pastoral Trust.

Lyotard, J-F. 1994 The postmodern condition. In *The postmodern turn,* edited by S.Seidman, 27-38. Cambridge: Cambridge University Press.

Macfarlane, A. and Mugford, M. 2000 *Birth Counts – statistics of pregnancy and childbirth. Volume 1, text.* London: The Stationary Office.

Macfarlane, A., Mugford, M., Henderson, J, Furtado, A., Stevens, J. and Dunn, A. 2000 *Birth Counts – statistics of pregnancy and childbirth. Volume 2, tables.* London: The Stationary Office

Mander, R. 1994 *Loss and Bereavement in Childbearing.* Oxford: Blackwell.

Marcel, G. 1950 *The Mystery of Being*, Vol. 1. London: The Harvill Press.

Martel, Y. 2002 *Life of Pi.* Edinburgh: Cannongate.

Matthews, M. and Kohner, N. 2002 Pyschsocial care of mothers after stillbirth (letter). *Lancet* 360:1600.

McCall Smith, A. 2003 *The No.1 Ladies' Detective Agency.* London: Abacus.

McCarthy, M. 2000 Spirituality in a Post-Modern Era. In *The Blackwell Reader in Pastoral and Practical Theology*, edited by J. Woodward and S. Pattison, 192-206. Oxford: Blackwell.

McFadyen, A. 1990 *The Call to Personhood: A Christian Theory of the Individual in Social Relationships.* Cambridge: Cambridge University Press.

McHaffie, H. 2001 *Crucial Decisions at the beginning of Life.* Abingdon (Oxon): Radcliffe Medical Press.

McHaffie, H. and Fowlie, P. 1996 *Life and Death Decisions.* Hale, Cheshire: Hochland and Hochland.

McSherry. W. 2000 *Making Sense of Spirituality in Nursing Practice* Edinburgh: Churchill Livingstone.

Methodist Church 1999 *The Methodist Worship Book.* Peterborough: Methodist Publishing House.

Middleton, J. and Walsh, B. 1995 *Truth is stranger than it used to be.* SPCK: London.

Miller, J., Williamson, E., Glue, J., Gordon, Y., Gruddzinskas J. and Sykes, A. 1980 Fetal loss after implantation. A prospective study. *Lancet* 2(8194): 554-556.

Milne, A.A 1928 *The House at Pooh Corner.* London: Metheun & Co.

Milne, A.A. 1926 *Winnie-the-Pooh.* London: Metheun & Co.

Mitchell, K. 1989 Ritual in Pastoral Care. *Journal of Pastoral Care* 43(1): 68-77.

Moe, T. 1997 *Pastoral Care in Pregnancy Loss.* Binghampton, New York: Haworth Pastoral Press.

Moltmann, J. 1975. The Humanity of Living and Dying In *The Experiemental Hope*, edited and translated by M. Meeks, 158-171. London: SCM Press.

Moltmann. J. 1974 *The Crucified God.* London: SCM Press.

Moore, A. and Levison, C. 2003 Chaplains' Perceptions of Supervision. *Scottish Journal of Healthcare Chaplaincy* 6(2): 16-20.

Moulder, C. 1998 *Understanding Pregnancy Loss.* Basingstoke: MacMillan.

Murray, J. and Callan, V. 1988 Predicting adjustment to perinatal death. *British Journal Medical Psychology* 61(3): 237-244

Murray, S. and Grant. E. 2003 Spiritual Issues and needs – perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. *Focus on research.* Scottish Executive Health Department Chief Scientist Office. www.show.scot.nhs.uk/Publications/ExecSumms/OctNov03/Murray.pdf

Narayasammy, B. 1991 *Spiritual Care- a resource guide.* Lancaster: Quay.

NHS Services Scotland 2002 *Scottish Health Statistics – Abortions.* Edinburgh: NHS National Services Scotland.

Nelson, G. 1999 Hospitals. In *Chaplaincy: the Church's Sector Ministry*, edited by G. Legood, 75-82. London: Cassells.

Newbigin, L. 1989 *The Gospel in a Pluralistic Society*. Grand Rapids, Michigan: Eerdmans.

NHS National Services Scotland. 2002 *Scottish Perinatal and Infant Mortality and Morbidity Report*. Edinburgh: NHS National Services Scotland.

Nicol, M. 1991 *Loss of a Baby: Understanding Maternal Grief*. London: Bantam.

Nouwen, H. 1978 *Creative Ministry*. Garden City, NY.: Image Books.

Nouwen, H. 1977 *The Living Reminder*, New York: Seabury Press.

Nouwen, H. 1975 *Out of Solitude*, London: Harper Collins.

Nouwen, H. 1972 *The Wounded Healer*. Garden City, NY.: Doubleday and Co.

Oakley, A. 1981 Interviewing Women: a contradiction in terms. In *Doing Feminist Research*, edited by H. Roberts, 30-61.London: Routledge.

O'Connor, T. 2002 Guest Editorial: Dante, Qualitative Research and Wonderings. *Journal of Pastoral Care and Counselling*. 56(4): 313-315.

O'Connor, T., Koning, F., Meakes, E., McLarnon-Sinclair, K., Davis, K. and Loy, V. 2001 Quantity and Rigour of Qualitative Research in Four Pastoral Counselling Journals. *Journal of Pastoral Care and Counselling*. 55(3): 271-280.

Orenstein, D. (ed) 1994 *Lifecycles Vol. 1: Jewish Women on Life Passages and Personal Milestones*. Woodstock, VT: Jewish Lights Publishing

Oswald, R. 1999 *Transforming Rituals*. Washington D.C.:Alban Institute.

Oswald, R. and Kroeger, O. 1988 *Personality Type and Religious Leadership*. Washington D.C.: Alban Institute.

Page, R. 2000 *God with us – synergy in the church*. London: SCM Press.

Parkes, C. M. 1996 *Bereavement: Studies of Grief in Adult Life* (3rd edn.). London: Penguin.

Parkes, C. M. 1972 *Bereavement: Studies of Grief in Adult Life* London: Tavistock.

Pastan, L. 2003 The Five Stages of Grief. In *Do Not Go Gentle: poems for funerals*, edited by N. Astley, 14-15. Tarset, Northumberland: Bloodaxe.

Pastoral Instruction of the Roman Catholic Church 1971 Communio et Progressio. In *Church and Social Communication* (2nd edn.) 1997, edited by F-J, Eilers, 69-115. Manila: Logos Publications.

Pembroke, N. 2004 *Working Relationships- Spirituality in Human Service and Organisational Life*. London: Jessica Kingsley.

Pembroke, N. 2002 *The Art of Listening*. Grand Rapids, Michigan: Eerdmans.

Peppers, L. and Knapp, R. 1980 *Motherhood and Mourning*. New York: Praeger.

Pierce, P. 2003 *Miscarriage and Stillbirth – the changing response*. Dublin: Veritas.

Quoist, M. 1986 *The Breath of Love*. Translated by N. Smith. Dublin: Gill and Macmillan.

Radestad, I., Nordin, C., Steineck,G. and Sjogren, B. 1996 Stillbirth is no longer managed as a non-event: a nationwide study in Sweden. *Birth* 23(4): 209-215.

Radestad, I., Steineck, G., Nordin, C. and Sjorgren. B. 1996a Psychic and Social Consequences of Women in Relation to Memories of a Stillborn Child: A Pilot Study. *Gynecologic and Obstetric Investigation* 41: 194-198.

Radestad, I., Steineck, G., Nordin, C. and Sjorgren. B. 1996b Psychological complications of stillbirth – influence of memories and immediate management: population based study. *British Medical Journal* 312: 1505-1508.

Ramshaw, E. 1987 *Ritual and Pastoral Care*. Philadelphia: Fortress Press.

Rand, C., Kellner, K., Revak-Lutz, R. and Massey, J. 1998 Parental Behaviour after perinatal death: twelve years of observations. *Journal of Psychosomatic Obstetrics and Gynecology* 19: 44-48.

Regan, L. 1991 Recurrent miscarriage. *British Medical Journal.* 302(6776): 543-544.

Reed, P. 1998 The re-enchantment of health care: a paradigm of spirituality. In *The Spiritual Challenge of Healthcare,* edited by M. Cobb and V. Robshaw, 35-55. Edinburgh: Churchill Livingstone.

Reinharz. S. 1997 Who am I? The Need for a Variety of Selves in the Field. In *Reflexivity and Voice,* edited by R. Hertz, 3-20. Thousand Oaks, Ca.: Sage.

Riches, G. and Dawson, P. 2000 *An Intimate Loneliness.* Buckingham: Open University Press.

Rogers, C.R. 1961 *On Becoming a Person.* Boston: Houghton Mifflin.

Rosenblatt, P. 1996 Grief that does not end. In *Continuing Bonds; New Understandings of Grief,* edited by D, Klass, P, Silvermann, and S, Nickman, 45-58. London: Taylor and Francis.

Ross, L. 1997 The nurse's role in assessing and responding to patients' spiritual needs. *International Journal of Palliative Care* 3(1): 37-42.

Royal College of Nursing 2002 *Sensitive disposal of fetal remains.* London: Royal College of Nursing.

Royal College of Obstetricians and Gynaecologists 1985 *Report of the RCOG working party on the management of perinatal deaths.* London: Chameleon Press.

Rubin, H.J. and Rubin, I.S. 1995 *Qualitative Interviewing – the Art of Hearing Data.* London: Sage.

Russell, W. 1975 My Baby's Dead. *The Journal of Pastoral Care* 29(3): 196-201.

Salt, S. 1997 Towards a definition of Suffering. *European Journal of Palliative Care* 4(2): 58-60.

Samuelsson, M., Radestad, K. and Segesten, K. 2001 A Waste of Life: Father's Experience of Losing A Child Before Birth. *Birth* 28(2): 124-130.

Sandelowski, M. 1995 Qualitative Analysis: What It Is and Where to Begin. *Research in Nursing and Health.*18: 371-375.

SANDS 1995 *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals.* London: SANDS.

SANDS 1992 A Dignified Ending. London: SANDS.

SANDS 1991 *Guidelines for Professionals: Miscarriage, Stillbirth and Neonatal Death.* London: SANDS.

SANDS 1986 *Stillbirth and Neonatal Death.* London: SANDS.

Schon, D. 1983 *The Reflective Practitioner.* New York: Basic Books.

Scott, T. 2000 Chaplaincy – a resource of Christian presence. *Scottish Journal of Healthcare Chaplaincy* 3(1): 15-19.

Sexton, P. and Stephen, S. 1991 Postpartum mother's perception of nursing interventions for perinatal grief. *Neonatal Network* 9(5): 47-51.

Shilling J 2004 Get mad, drunk or lustful, just don't start blubbing. *The Times T2.* Friday 15 October: 2.

Scottish Executive 2002 *Guidelines on Chaplaincy and Spiritual Care in the NHS in Scotland.* NHS HDL (2002) 76. Edinburgh: Health Department, Scottish Executive.

Seidel, S. and Kelle, U. 1995 Different Functions of Coding in the Analysis of Textual Data. In *Computer Aided Qualitative Data Analysis,* edited by U. Kelle, 52-61. London: Sage.

Seth, D. (ed) 1997 *Rabbi's Manual*. Wyncote, PA: The Reconstructionist Rabibinical Association.

Sheppy, P. 2003 *Death, Liturgy and Ritual - Vol. 1*. Aldershot: Ashgate

Shields, C. 2003 *Unless*. London: Fourth Estate.

Shuchter, S. and Zisook, S. 1993 The course of normal grief. In *Handbook of bereavement: Theory, research and intervention*, edited by M. Stroebe, W. Stroebe, and R. Hansson, 23-43. Cambridge: Cambridge University Press.

Silverman, P. and Nickman, S. 1996 Concluding Thoughts. In *Continuing Bonds; New Understandings of Grief*, edited by D. Klass, P. Silvermann, and S. Nickman, 349-355. London: Taylor and Francis.

Simmons, D. 1983. *Birth and Death: Bioethical Decision-Making*. Philadelphia: Westminster Press.

Simmonds, A. 1997 Pastoral Perspectives in Intensive Care: Experiences of Doctors and Nurses with Dying Patients *Journal of Pastoral Care*. 51(3): 271-281.

Singh, P., Stewart, K. and Moses, S. 2004 Pastoral Care Following Pregnancy Loss: The Role of Ritual. *Journal of Pastoral Care and Counselling* 58(1-2):41-53.

Skene, C. 1998-99 Individualised Bereavement Care. *Paediatric Nursing* 10(10): 13-16.

Small, N. 2001 Theories of grief: a critical review. In *Grief, Mourning and Death Ritual*, edited by J. Hockey, J. Katz, and N. Small, 19-48. Buckingham: Open University Press.

Smith, J. 1998 *Towards hope, normality and achievement: how parents cope with childhood cancer*. Univ. of Edinburgh. Unpublished PhD.

Smith, N. 1988 Epidemiology of Spontaneous Abortion. *Contemporary Reviews in Obstetrics and Gynaecology*. 1: 43-48.

Smith, T. 1998-9 Pastoral and Ritual Response to Perinatal Death: A Narrative of a Departmental Policy Change. *Journal of Supervision and Training in Ministry* 19: 25-33.

Speck, P. 1997 Bereavement and Belief: an Anglican perspective. In *Interpreting Death – Christian Theology and Pastoral Practice*, edited by P. Jupp and T. Rogers, 98-109. London: Cassells

Speck, P. 1988 *Being There*. London: SPCK.

Speck, P 1978 Easing the pain and grief of stillbirth, *Nursing Mirror* 146: 38-41.

Stevenson, A. 2003 The Minister. In *Do not go gentle – poems for funerals*, edited by N. Astley, 57. Tarset, Northumberland: Bloodaxe Books.

Stewart, A. and Dent, A. 1994 *At a Loss – Bereavement Care when a Baby Dies*, London: Balliere Tindall.

Stokes, J. 1999 Ministry of Presence and Presence of the Spirit in Pastoral Visitation. *Journal of Pastoral Care* 53(2): 191-99.

Stoll, R. 1979 Guidelines for Spiritual Assessment. *American Journal of Nursing* September: 1574 – 1577.

Stoter, D. 1995. *Spiritual Aspects of Healthcare*. London: Mosby.

Strange, F. 1996 Handover: an ethnographic study of ritual in nursing practice. *Intensive and Critical care Nursing* 12 (2): 106-112.

Strauss, A. and Corbin, J. 1998 *Basics of Qualitative Research*. Thousand Oaks, Ca.: Sage.

Stringham, J., Riley, J., and Ross, A. 1982 Silent Birth: mourning a stillborn baby. *Social Work* 27(4):322-327.

Stroebe, M., Gergen, M., Gergen, K. and Stroebe, W. 1996 Broken Hearts or Broken Bonds? In *Continuing Bonds; New Understandings of Grief*, edited by D. Klass, P. Silvermann and S, Nickman, 31-44. London: Taylor and Francis.

Stroebe, M., Hansson, R. and Stroebe, W. 1993 Contemporary themes and controversies in bereavement research. In *Handbook of Bereavement*, edited by M. Stroebe, W. Stroebe, and R. Hansson, 457-475. Cambridge: Cambridge University Press.

Stroebe, M. and Schut, H. 1999 The Dual Process Model of Coping with Bereavement: Rationale and Description. *Death Studies* 23: 197-224.

Stroebe, M. and Stroebe, W. 1991 Does grief "grief work" work? *Journal of consulting and Clinical Psychology* 59: 57-65.

Stroebe, M., Stroebe, W., Schut, H., van den Bout, J. and Zech, E. 2002 Does Disclosure of Emotions Facilitate Recovery From Bereavement? Evidence From Two Prospective Studies. *Journal of Consulting and Clinical Psychology* 70 (1): 169-178.

Stroebe, W. and Stroebe, M. 1987 *Bereavement and Health: The Psychological and Physical Consequences of Partner Loss*. Cambridge: Cambridge Univ. Press.

Stroebe, W., Stroebe, M. and Dommittner, G. 1988 Individual and situational differences in recovery from bereavement: A risk group identified. *Journal of Social Issues* 44(3): 143-158.

Theut, S., Pedersen, F., Zaslow, M, Cain. R, Rabinovich, B. and Mori, J. 1989 Perinatal Loss and Perinatal Bereavement. *American Journal of Psychiatry* 146(5): 635-639.

Theut, S. 1989 Influence of Ultrasound on Parents' Reaction to Perinatal Loss (letter). *American Journal of Psychiatry* 146(12): 1646.

Tieleman, R. 1996 Changing belief in a changing culture. *Contact* 119: 12-14.

Thomas, J. 1997 The Child Bereavement Trust: caring for bereaved families. *British Journal of Midwifery*. 5(8): 474-477.

Thomas, J. 1990 Supporting parents when their baby dies. *Nursing Standard* 5(6): 52-53.

Thomas, R.S. 1993 *Collected Poems 1945-1990*. London: Phoenix.

Thomas, V. and Striegel, P. 1994-5 Stress and Grief of a Perinatal Loss: integrating qualitative and quantitative methods. *Omega* 30(4): 299-311.

Thomson, A. 1981 Stillbirth. *Contact* 72:2-9.

Thompson, N. 2002 Introduction. *In Loss and Grief: A Guide for Human Services Practitioners*, edited by N. Thompson, 1-22. Basingstoke: Palgrave.

Thorne, B.1991 *Person-Centred Counselling: Therapeutic and Spiritual Dimensions*. London: Whirr Publishers.

Turner, V.1969 *The Ritual Process – Structure and Anti-Structure*. London: Routledge and Kegan Paul.

Uniting Church of Australia 1994 *A Service to follow the birth of a stillborn child, or the death of a newly-born child*. Melbourne: Joint Board of Christian Education.

Van Gennep, A. 1908 *The Rites of Passage*. Translated by M.Vzedom. and G. Caffee. 1960 London: Routledge and Kegan Paul.

Vanier, J. 1973 *The Tears of Silence. London*: DLT.

Walter, T. 1999 *On Bereavement – The Culture of Grief*. Maidenhead: Open University Press.

Walter, T. 1997 The ideology and organisation of spiritual care: three approaches. *Palliative Medicine* 11: 21-30.

Walter, T. 1996 A new model of grief; bereavement and bibliography. *Mortality* 1(1): 7-25.

Walter, T. 1990 *Funerals and How to Improve Them*. Hodder and Saughton: London

Walton, H. 2002 Speaking in signs: narrative and trauma in pastoral theology. *Scottish Journal of Healthcare Chaplaincy* 5(2): 2-5.

Watzlaawick, P., Weakland, J. and Fisch, R. 1974 *Change: Principles of Problem Formation and Problem Resolution*. New York: W.W. Norton.

Webster, A. 2004-5 Bad Karma. *Living Spirituality News*. Winter: 2-3.

Webster, A. 2002 *Wellbeing*. London: SCM Press.

White, V. 2002 *Identity*. London: SCM Press.

Willis, R. 1999 To What Shall We Liken the Hospital Chaplain. *Journal of Pastoral Care* 53(4): 391-394.

Wilson M. 1971 *Hospital – a place of truth: a study of the role of the hospital chaplain*. Birmingham: University of Birmingham.

Wolf, J., Neilson, P. and Schiller, P. 1970 The emotional reaction to stillbirth. *American Journal of Obstetrics and Gynaecology* 108: 73-77.

Wood, J. 2003 *The Book against God*. New York: Farrar, Straus and Giroux.

Woodhead, L., Heelas, P. and Davie, G. 2003 Introduction. In *Predicting Religion*, edited by G. Davie, P. Heelas and L. Woodhead, 1-14. Aldershot: Ashgate.

Woodward J. 1997 *Some Straw for the Bricks? – Developing Standards for Spiritual, Religious and Cultural Care*. Middleton, Warwickshire (unpublished)

Woof, W. and Carter, Y. 1997 The grieving adult and the general practitioner: a literature review in two parts (part 2). *British Journal of General Practice* 47: 509-514.

Worden, J. W. 1991 *Grief Counselling and Grief Therapy*. (2nd edn.). New York: Springer.

Worden, J. W. 1983 *Grief Counselling and Grief Therapy*. London: Tavistock.

Wraight, H. and Brierly, P. (Eds.) 1999 *UK Christian Handbook 2000/01. Milleneum Edition*. London: Christian Research/Harper Collins Religious.

Wretmark, A. 1993 *Perinatal Death as a Pastoral Problem*. Uppsala: Bibliotheca Theologiae Practicae.

Young, M. and Cullen, I. 1996 *A Good Death: Conversations with East Londoners*. London: Routledge.

Zisook, S. and Schuter, S. 1991 Depression through the first year after the death of a spouse. *American Journal of Psychiatry* 148(100): 1346-1352.

Scripture References

Quotations from scripture (unless stated) are taken from
The Revised English Bible 1989 Oxford and Cambridge: Oxford University Press and Cambridge University Press.
Also used –
Good News Bible 1991 Swindon and Glasgow: The Bible Societies and Harper Collins.
Authorised Version 1979 Iowa Falls, Iowa: World Bible Publishers.

Appendices

1. Checklist for interviews (my assumptions of issues important to parents prior to interviews) – informed my interview guide

2. Study Information Sheet – sent/given to parents with letter of invitation to participate in the study

3. Letter of invitation to parents

4. Lothian Universities Hospital NHS Trust (of which the Royal Infirmary of Edinburgh is a part) Chaplaincy Team's Mission Statement

5a. Demographic details of participating parents.
5b. Explanation of the use of deprivation categories as aiding the demographic description of participants in the study

6. First version of interview guide.

7. Final version of interview guide

8. Reply slip to enable parents to indicate parents' response to invitation to participate in the study

9. Follow up letter

10. Form chaplain filled in to outline details of bereaved parents who met study criteria

11. Details of modes of recruitment

12. Consent form

13. Letter informing medical practitioners of parents' participation in the study

14. Resources to aid chaplains and parents co-construct rituals to mark the life and death of a baby who has died *in-utero*

Appendix 1   Checklist for Interviews

Role of Ritual

Confrontation of reality of life and death of baby
Enable parents to experience pain of loss
Help or facilitate letting go
Affirm love and depth of grief felt for baby
Affirm uniqueness and special place of baby in family
Framework in which parents safely can express feelings
Establish order
Reaffirm meaning, beliefs or values (including sources of hope) or provide framework in which search for meaning, ambivalence and theological questions expressed,
Framework for encountering transcendence, mystery of life, death and what may be beyond.
Bonding of family and friends/community – facilitating support
Providing a marker for memories/aid to storytelling
Mark transition, role adjustments for family members
Thanksgiving
Acknowledgement of human limitations/guilt/failure
Forgiveness/acceptance/recognition of best possible parenting done

Content of Ritual

Extent to which ritual personalised – baby and family's story included in ritual – including beliefs, values
Family's feelings adequately and accurately reflected
Language and imagery relevant and comprehensible
Gestures and symbolism appropriate
Extent of family's involvement in planning content

Other issues related to ritual

Environment
Who was present – baby's siblings, family, friends, healthcare staff – and their significance, attitude and behaviour
Participation of family and others in ritual – including flowers, carrying coffin
Making arrangements for ritual

Relationship with chaplain

Parents' expectations of chaplain
What chaplain represented – before, during, after - ritual
Degree of respect shown to parents - their beliefs, feelings, choices
Communication skills of chaplain
Chaplains response to baby
Role of chaplain in ritual/family story
Personhood – e.g. integrity, way of being- of chaplain

Appendix 2

Study Information Sheet

Study Title
The Role of Blessings, Baptisms or Naming Ceremonies and Funerals in Grieving the Death of a Baby – Listening to the Voices of Bereaved Parents

Invitation
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it, if you wish, with friends, relatives and your GP. You can contact the chaplaincy at the Royal Infirmary of Edinburgh, if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

Hospital chaplains, as part of the healthcare team working in maternity units and in the community, seek to support parents around the time of death of their baby in a way that is appropriate to their feelings, beliefs and life situation. Some parents choose to ask a hospital chaplain to help them mark the life and death of their baby by performing with them a blessing/baptism/naming and/or funeral service.

This study hopes to hear from bereaved parents about their experience of what the chaplain did with them for their baby – what was helpful and what was not so helpful. The study aims to deepen the understanding of chaplains, doctors and midwives as to what the needs of parents are around the time of their baby's death, especially in relation to blessings/baptisms/namings and funerals. Therefore, information shared by parents will help chaplains, and other healthcare professionals, to think more about the way they support parents and influence their way of working in the future.

This study will run between July 2002 and October 2003.

Why have I been chosen?

You have been asked to take part in this study because a hospital chaplain, working within the Royal Infirmary of Edinburgh, has spent time with you putting together and perform a blessing/baptism/naming and/or a funeral service for your baby in the past four months.
In total the parents of twenty babies who have died will take part in this study.

Do I have to take part?

It is entirely up to you to decide whether to take part or not. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I do take part?

If you agree to take part the researcher (Ewan Kelly) will arrange a suitable time and place to meet with you, in order to interview you about your experiences of what the chaplain did with you, for your baby. The interview will last about an hour to an hour and a half. However the interview can be stopped at any time if you wish. Should you wish to talk more the interview can be extended or arrangements can be made to meet again.
The interview will be **tape-recorded** to enable the researcher to have an accurate record of what is said. The researcher may also take a few notes during the interview.

You may choose to be interviewed alone, with your partner, or with another supportive person. You may choose to be interviewed in a place where you will feel comfortable – either in your own home or in the chaplaincy at the Royal Infirmary of Edinburgh, Lauriston Place. The interview will take place at a time convenient to you and when you are least likely to be interrupted.

What are the possible disadvantages of taking part?

You may feel that it would be too upsetting to talk to the researcher about what the chaplain shared with you and your baby.
This is an issue to consider and you may want to talk with others about this before agreeing to take part.

What are the possible benefits of taking part?

Though there may be no definite benefit to you in taking part, researchers in previous studies who have interviewed bereaved parents found that many parents valued the opportunity to talk about their experiences.
The information gained from this study may help chaplains, doctors and midwives improve their support for bereaved parents in the future.

What if I get upset during or after the interview?

The interview can be stopped at any time and for any reason. The interview can be re-started after an appropriate pause, at a later date, or you can withdraw from the study.

Bereavement support is available from the following should you wish it -

Barbara Herkes,
Bereavement Counsellor,
Simpson's Centre for Reproductive Health,
Royal Infirmary of Edinburgh,
Edinburgh,
0131-242 2569

Edinburgh SANDS,
Craiglockhart Sports Centre,
177,Colinton Road
Edinburgh
0131-622-6263

Will my taking part in this study be confidential?

All information which is collected about you during the study will be kept strictly confidential. The only people who will hear the tape recording of your interview, apart from Ewan Kelly (the researcher in this project), will be a secretary who will type out the recordings and possibly a former hospital chaplain and experienced independent researcher who will listen to a small number of the tapes to check that Ewan Kelly is responding appropriately to what is being said and is enabling parents to speak freely. All tapes will be securely stored until they have been typed out and then they will be shredded. Your name will not be on any typed material.
Ewan Kelly has the full support of his chaplaincy colleagues working in the Simpson to carry out this study. They hope you will feel free to talk about what was not so helpful as well as helpful, in relation to the support they offered.
If you choose to take part in the study your GP and the hospital consultant whose care you and your baby were under will be notified.

What will happen to the results of the research?

A report of the study, which can be sent to you by the researcher if you wish a copy, will be prepared for the Chief Scientist's Office (part of the Scottish Executive Health Department) in October 2003, The results of this research will also form part of the researcher's PhD which will be completed in 2004 and may be published in journal(s) read by chaplains and other healthcare professionals.
Neither you, nor any other participant, will be identified in any report or publication.

Who is organising and funding the research?

The researcher is a lecturer and part-time PhD student in the School of Divinity of the University of Edinburgh and is an honorary chaplain at the Royal Infirmary of Edinburgh. The study is funded by the Chief Scientist's Office (part of the Scottish Executive Health Department), but the researcher will not be receiving any payment for carrying out this study.

Who has reviewed the Study?

The Lothian Research Ethics Sub-Committee on Paediatrics and Reproductive Medicine has reviewed the study.

Contact for Further Information

Should you wish further information about the study, please contact Anne Mulligan or Iain Telfer, Dept. of Spiritual and Pastoral Care, Royal Infirmary of Edinburgh. 0131-242 1190.

Local Independent Advisor

This person, who is not linked with the study in any way, can give impartial advice if required.
The local independent advisor for this study is –

Tom Gordon,
Chaplain,
Marie Curie Centre,
Fairmile,
Frogston Road West
Edinburgh
0131-470-2209

For more written information about taking part in a research study linked to healthcare you can write to - Consumers for Ethics in Research (CERES), who will send you a leaflet entitled 'Medical Research and You'. This leaflet gives more information about research in healthcare and looks at some questions you may want to ask. The address to write to is -

CERES, PO Box 1365, London N16 OBW.

Letter of Invitation to Parents

Dear Name of Parent

Research Study
The Role of Baptisms, Blessings or Naming Ceremonies and Funerals in Grieving the Death of a Baby – Listening to the Voices of Bereaved Parents

I am writing to invite you to help with the above research project which seeks to hear from parents about their experience of baptisms, blessings or naming ceremonies and funerals performed for their baby by hospital chaplains working in the Simpson.

The aim of the study is to deepen the understanding of chaplains, doctors and midwives about what the needs of parents are around the time of their baby's death. The information shared by parents will help chaplains and other healthcare professionals think more about the way they support parents and influence their way of working in the future.

The study has the full support of the consultants working in the Simpson. The details of this study and what it would involve if you chose to take part can be found in the enclosed Study Information Sheet. I would be very grateful if you would take time to read it.

I am a hospital chaplain currently working within the Simpson and the main researcher for this study. I will be doing the interviews and hope that you will feel able to take part in this research project. However, you should feel under no obligation to do so.

I would be very grateful if could you fill in and return the form attached to this letter, using the enclosed stamped addressed envelope. If you are willing to be interviewed as part of the study I will telephone you to arrange a time to meet, once I receive your reply. If you indicate you do not wish to take part you will not be contacted again.

Thank you very much for reading this.

Yours sincerely,

Ewan Kelly
(Researcher)

Appendix 4

Lothian Universities Hospital NHS Trust Chaplaincy Team's Mission Statement

Our primary role is to be available 24 hours a day to offer confidential non-judgemental support to patients, families and staff appropriate to their beliefs and life situation. As part of the healthcare team in the hospital, we are here to listen, to pray or simply to wait with people of all faiths or of none. Where patients wish to be visited by their own religious leader, a chaplain will be pleased to contact them for you.

DEMOGRAPHIC DETAILS

Any ritual with any reference to God or to an afterlife is denoted as religious

Inter-view No	Age	Ritual and Mode of Construction	Depr Cat	Gestation of Baby	Type of Loss	Previous pregnancies/other children	Religious Affiliation as children	Religious Affiliation as adults	Ritual - rel or non-rel	Type of Chaplain
1	Mother 33, Father 31	Co-constructed funeral	4	20+/40	Natural	none	Mum - C of E, Dad - C of S	None	non-rel	generic
2	Mother 38	Co-constructed funeral	4	18/40	termination for fetal abnormality	3-year old	C of S	None	rel	generic
3	Mother 39, Father 45	Co-constructed funeral	3	18/40	Natural	7-year old	Mum – Congregational Church Dad - C of S	Mum and Dad – nonactive C of S	rel	generic
4	Mother 30, Father 25	Co-constructed blessing	4	fullterm	Natural	none	Mum – RC, Dad - none	Mum – active RC, Dad - none	rel	RC
5	Mother 31, Father 40	Co-constructed funeral	6	22/40	termination for fetal abnormality	2 previous stillbirths, 7-year old	None	None	rel	RC
6	Mother 35, Father 35	Minimum co-con blessing Co-constructed funeral	4	22/40	Natural	6 and 4-year old	Mum – RC, Dad - Protestant	None	rel	RC
7	Mother 29, Father 27	Co-constructed blessing and funeral	3	22/40	Natural	Previous loss at 22/40	Mum and Dad – C of S	Mum - nonactive RC, Dad - none	rel	RC
8	Mother 31, Father 32	Co-constructed blessing and funeral	1	19/40	Natural	2-year old	Mum - C of S, Dad - RC	Mum - none, Dad - nonactive RC	rel	RC and generic
9	Mother 45, Father 48	Co-constructed funeral	4	20+/40	Natural	3-year old	Mum - C of S, Dad - Free Church	Mum and Dad – nonactive C of S	rel	generic
10	Mother 34	Minimum co-construction blessing	2	20+/40	Natural	none	C of S	Baptist	rel	generic
11	Mother 42, Father 40	Co-constructed blessing	1	18/40	Natural	none	Mum and Dad – C of S	Mum and Dad – nonactive Cof S	rel	generic
12	Mother 35, Father 34	Co-constructed funeral	3	16/40	Natural	none	Mum and Dad – C of S	Mum and Dad – nonactive Cof S	rel	generic
13	Mother 31, Father 33	Co-constructed blessing and funeral	4	26/40	Natural	4-year old	None	None	rel	generic
14	Mother 32, Father 35	Co-constructed blessing and funeral	1	Twins 25/40	Natural	none	Mum - RC, Dad – C of S	Mum - RC, Dad - none	rel	RC
15	Mother 31, Father 39	Co-constructed funeral	4	22/40	Natural	4-year old	None	None	rel	generic
16	Mother 42, Father 41	Co-constructed funeral	2	20+/40	termination for fetal abnormality	previous miscarriage and 3-year old	Mum - RC, Dad – C of S	Mum - nonactive RC, Dad - none	rel	generic

Appendix 5b

Use of deprivation categories (depr. cat.) as a means of aiding the description of demographic details of participating parents

With healthcare studies deprivation categories are commonly used as indicators of levels of social deprivation within a particular area. The various categories used are linked to postcode areas and are listed on a scale from 1 to 7. The higher the numerical value of the deprivation category the higher the level of unemployment, overcrowding in households and the prevalence of occupants not have higher education qualifications in that postcode area (Carstairs and Morris 1991).

Appendix 6

Interview guide – initial version

1) Content of Ritual

Tell me about what you remember of what you and **name of chaplain** did together for **name of baby** in the hospital

What were the important bits, for you, of what was said or done?

And/or..

Tell me about what you remember of **name of baby's** funeral.

What were the important bits, for you, of what was said or done?

How well did what **chaplain's name** shared with you for **baby's name** in the hospital reflect how you felt at the time?

How well did what was said and done at **baby's name** funeral reflect what you felt at the time?

How well did what **chaplain's name** shared with you for **baby's name** in the hospital reflect what you believe?

How well did what was said and done at **baby's name** funeral reflect what you believe?

Tell me about how **baby's name** blessing/baptism/naming was organised?

Looking back could it have been organised in another way?

Looking back would you change anything that was said or done during the baptism/blessing/naming?

How involved did you feel in putting together **baby's name** funeral?

Looking back would you change that or anything else about the funeral?

2) Role of Ritual

Tell me what **name of baby's** blessing/baptism/naming was about for you?

What did it mean to you?

What did it allow you to do?

How do you feel about it now?

And/or ..

Tell me what **baby's name** funeral was about for you?

What did it mean to you?

What did it allow you to do?

How do you feel about it now?

3) Issues related to ritual

Can you tell me who was there when **chaplain's name** blessed/baptised/named **baby's name**?

What did it mean to have them there?

Did they do or say anything at the time that you remember?
How did they react to you and your baby?

Do you remember much about the place where the blessing/baptism/naming took place?

Can you tell me who was all there at **baby's name** funeral?
What did it mean to have them there?
Who was involved in the funeral service and in what way?
What did people do and say that you remember at the funeral?
How did the people there relate to you and your baby?

What made you choose to have your baby buried/cremated?
What made you choose that particular place?

4) Relationship with chaplain
Tell me about how **chaplain's name** worked with you.
What was helpful?
What was not so helpful?

What do you remember about **chaplain's name** during **baby's name** blessing/baptism/naming?
And/or
What do you remember about **chaplain's name** during the funeral?

Tell me, before you met **chaplain's name** what did the term chaplain mean to you?
What did you expect of the chaplain?

What were your reasons for asking a chaplain to become involved?
What, if anything, did **chaplain's name** stand for as he/she performed the blessing/baptism/naming and/or funeral?

Appendix 7

Interview guide – final version

1) Content of Ritual

Tell me about what you remember of what you and **name of chaplain** did together for **name of baby** in the hospital

What were the important bits, for you, of what was said or done?

What were you expectations beforehand of **name of baby's** blessing/baptism/naming

Where was your baby during the baptism /blessing/naming?

How do you feel now about seeing/not seeing and holding/not holding your baby? And/or..

Tell me about what you remember of **name of baby's** funeral.

What were the important bits, for you, of what was said or done?

What were your expectations beforehand of **name of baby's** funeral?

If didn't have welcoming ritual – did you see/hold your baby in the hospital or afterwards?

How do you feel about that now?

How well did what **chaplain's name** shared with you for **baby's name** in the hospital reflect how you felt at the time?

How well did what was said and done at **baby's name** funeral reflect what you felt at the time?

How well did what **chaplain's name** shared with you for **baby's name** in the hospital reflect what you believe?

How well did what was said and done at **baby's name** funeral reflect what you believe?

Tell me about how **baby's name** blessing/baptism/naming was organised?

Looking back could it have been organised in another way?

Looking back would you change anything that was said or done during the baptism/blessing/naming?

How involved did you feel in putting together **baby's name** funeral?

Looking back would you change that or anything else about the funeral?

2) Role of Ritual

Tell me what **name of baby's** blessing/baptism/naming was about for you?

What did it mean to you?

What did it allow you to do?

How do you feel about it now?

And/or ..

Tell me what **baby's name** funeral was about for you?

What did it mean to you?

What did it allow you to do for your baby and yourself?
How do you feel about it now?

3) Context of ritual

Can you tell me who was there when **chaplain's name** blessed/baptised/named **baby's name**?
What did it mean to have them there?
Did they do or say anything at the time that you remember?
How did they react to you and your baby?

Do you remember much about the place where the blessing/baptism/naming took place?

Can you tell me who was all there at **baby's name** funeral?
What did it mean to have them there?
Who was involved in the funeral service and in what way?
What did people do and say that you remember at the funeral?
How did the people there relate to you and your baby?

What made you choose to have your baby buried/cremated?
What made you choose that particular place?

4) Chaplain

Tell me about how **chaplain's name** worked with you.
What was helpful?
What was not so helpful?

What do you remember about **chaplain's name** during **baby's name** blessing/baptism/naming?
And/or
What do you remember about **chaplain's name** during the funeral?

Tell me, before you met **chaplain's name** what did you associate the term chaplain with?
What did you expect of the chaplain?

What were your reasons for asking a chaplain to become involved?
How did the chaplain become involved?'
What, if anything, did **chaplain's name** represent as he/she performed the blessing/baptism/naming and/or funeral?
Why did you ask a chaplain to perform ritual and not a member of the family, friend or (in case of a blessing) a midwife or doctor?

Appendix 8

Research Study

The Role of Baptisms, Blessings or Naming Ceremonies and Funerals in Grieving the Death of a Baby – Listening to the Voices of Bereaved Parents

Please tick the appropriate box below -

I am willing to be interviewed as part of the above study ☐

I am not willing to be interviewed as part of the above study ☐

Name...

Address...

....

Contact telephone no...

Appendix 9

Follow up letter to parents

Dear

Research Study
The Role of Baptisms, Blessings or Naming Ceremonies and Funerals in
Grieving the Death of a Baby – Listening to the Voices of Bereaved Parents

Recently I wrote to you inviting you to take part in the above research project which seeks to hear from parents about their experience of baptisms, blessings or naming ceremonies and funerals performed for their baby by hospital chaplains working in the Simpson.

The aim of the study is to deepen the understanding of chaplains, doctors and midwives about what the needs of parents are around the time of their baby's death. The information shared by parents will help chaplains and other healthcare professionals think more about the way they support parents and influence their way of working in the future.

As I had not heard from you that you did not wish to be interviewed I was wondering whether you felt able to take part in this research project. More information about the project can be found in the Study Information Sheet or by contacting the chaplaincy office.

I would be very grateful if could you fill in and return the form attached to this letter, using the enclosed stamped addressed envelope. If you are willing to be interviewed as part of the study I will telephone you to arrange a time to meet, once I receive your reply. If you indicate you do not wish to take part or if I do not hear from you, you will not be contacted again.

Thank you very much for reading this.

Yours sincerely,

Ewan Kelly
(Researcher)

APPENDIX 10.

Baby Loss Information Form

Baby's Name:	
Parents' Names: Mother: Father:	Chaplaincy Involvement: Blessing Baptism Naming (Non religious) Funeral – Religious Non-religious
D.O.B. Gestation:	Date of death: Date of funeral:

Rituals – Co-constructed
          Emergency
          No prior contact	

Addresses: Mother:	Father:
Married/single/separated/divorced	
Telephone number (s)	
Consultant's Name:	
General Practitioner Details: Name: Address:	
Telephone Number:	
Chaplains Name:	
Midwife's Name:	

Ewan Kelly/FB/1.02.02

Appendix 11

Details of mode of recruitment

Through letter of invitation sent by post – 8

Through obstetrician at post-natal review – 6

Through SANDS - 2

Appendix 12

Patient Identification Number for this Study:

CONSENT FORM

Title of Project:
The Role of Baptisms, Blessings or Naming Ceremonies and Funerals in Grieving the Death of a Baby – Listening to the Voice of Bereaved Parents

Name of Researcher: Ewan Kelly

Please initial

1. I confirm that I have read and understand the information sheet dated ....(version.....) for the above study and have had the opportunity to ask questions.

2. I understand that my taking part in this study is entirely voluntary and that I am free to withdraw at any time, during the interview or after, without giving any reason.

3. I understand that this interview is being tape recorded and that what is recorded will be typed out, but that my name will not be on any written material.

4. I agree to take part in the above study.

Name of parent	Date	Signature

Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Lothian Ethics Committee Research Committee Consent Form

Appendix 13

Information Letter to GPs/Consultants

Dear Dr   ,

Research Study
The Significance of Ritual in Grieving the Death of a Baby – Listening to the Voices of Bereaved Parents

I am writing to inform you that   has/have agreed to take part in the above research project. She/he /they has/have been invited to be part of this study because a hospital chaplain worked with them, at their request, to create and perform either a religious or non-religious welcoming (baptism/blessing/naming) and /or funeral ritual for their baby. The study will run from July 2002 till October 2003.

Through interviewing the parents of twenty babies who have died and collating emerging themes from those in-depth interviews, the study aims to -
- understand the lived experience of bereaved parents who have chosen to ask a hospital chaplain to help them mark the life and death of their baby by creating and performing with them a welcoming and/or funeral ritual,
- enable a deeper understanding of ritual and its role in the holistic care of parents around the time of death of their baby, therefore aiding reflection on the current practice of hospital chaplains and informing how they construct and share rituals with bereaved parents in the future.

In 2001 149 babies died (including second trimester losses, stillbirths and neonatal deaths) in the Simpson. During that year the chaplaincy team (three whole time non-denominational chaplains and a half-time Roman Catholic chaplain) performed 63 funerals and 30 welcoming rituals.

The Study Information Sheet given to your patient(s) to enable informed consent emphasises that she/he/they can withdraw from the study at any time before or during the interview and also contains contact numbers for the bereavement counsellor attached to the Simpson and for Edinburgh SANDS. The interview with your patient(s) will take place two to four months following their baby's death, either in their own home or in the chaplaincy in the RIE. Parents will be interviewed, depending on their choice, alone, with their partner or with another supportive person.

The study has been reviewed by the Lothian Research Ethics Sub-Committee on Paediatrics and Reproductive Medicine and is funded by a small project grant form the Chief Scientist's Office. I am a hospital chaplain currently working in the Simpson and am the main researcher involved in this project. Should you wish any more information about this study please contact me at the above telephone number.

Yours sincerely,

Ewan Kelly
(Researcher)

Appendix 14 Resources to aid chaplains and parents co-construct rituals to mark the life and death of a baby who has died *in-utero*

Practical advice for creating informal and formal ritual moments

Allen, M. and Marks, S. 1993 *Miscarriage – Women Sharing from the Heart*. New York: John Wiley.

Davis, D. 1996 *Empty Cradle, Broken Heart – Surviving the Death of Your Baby*. Golden, Colorado: Fulcrum.

Jay, C: 1995 *A celebration of life – the organisation of a service of remembrance for babies and children loved and lost*. High Wycombe: Child Bereavement Trust.

Kohner, N. and Thomas, J. 1995 *Grieving after the death of your baby – a book for parents and families*. Bourne End, Bucks.: Child Bereavement Trust.

SANDS 1995 *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. London: SANDS.

Stewart, A. and Dent, A. 1994 *At a Loss – Bereavement Care when a Baby Dies*, London: Balliere Tindall.

Resources to inform the content of formal ritual moments

Astley, N. 2003 *Do not go gentle – poems for funerals*. Tarset, Northumberland: Bloodaxe Books.

Baby Naming Society *A Naming Ceremony for babies lost during pregnancy or who have died around the time of birth*. Kempsey, Worcester: Baby Naming Society

Church of England 2000 *Common worship: services and prayers for the Church of England*. London: Church House Publishing.

Church of Scotland 1994 *Book of Common Order*. Edinburgh: St Andrew's Press.

Dominica, F. 1997: *Just My Reflection: Helping parents to do things their way when their child dies*. London: DLT.

Galloway, K. 1996 *The pattern of our days – liturgies and resources for worship*. Glasgow: Wild Goose Publications.

Hamilton, D. 1999 When birth and death come together: The right rite? *Scottish Journal of Healthcare Chaplaincy* 2(2):15-18.

Lamb, J. 1989 *Bittersweet... hellogoodbye. A resource in planning farewell rituals when a baby dies*. St. Charles MO.: SHARE.

Methodist Church 1999 *The Methodist Worship Book*. Peterborough: Methodist Publishing House.

McRae-McMahon, D. 2001 *In this hour – liturgies for pausing*. London: SPCK.

Orenstein, D. (ed) 1994 *Lifecycles Vol. 1: Jewish Women on Life Passages and Personal Milestones*. Woodstock, VT: Jewish Lights Publishing

Oswald, R. 1999 *Transforming Rituals*. Washington D.C.:Alban Institute.

Pierce, P. 2003 *Miscarriage and Stillbirth – the changing response*. Dublin: Veritas.

Shawe, M. (Ed) 1992 *Enduring Sharing Loving. For all those affected by the death of a child*. London: DLT (in association with the Alder Centre).

Uniting Church of Australia 1994 *A Service to follow the birth of a stillborn child, or the death of a newly-born child*. Melbourne: Joint Board of Christian Education.

Ward, H. and Wild, J. 1995 *Human rites – worship resources for an age of change*. London: Mowbray.

Withrow, L. 1999 *Occasions of prayer*. London: SPCK.

Marking Life and Death:

Co-constructing Welcoming and Funeral Rituals for Babies Dying In Utero or Shortly After Birth

Ewan Kelly

A
Contact

Pastoral Monograph

Marking Life and Death:

Co-constructing welcoming and funeral rituals for babies dying in utero or shortly after birth

Ewan Kelly

Lecturer in Practical Theology, University of Edinburgh
(Formerly a Hospital Chaplain at the Royal Infirmary of Edinburgh)

Introduction

This monograph seeks to explore some of the theoretical and theological reasoning, as well as the psychological need, behind the creation of ritual to mark the life and death of babies dying in utero or shortly after birth.

In our postmodern society where there is no longer a single shared metanarrative which informs our individual and collective sense of identity and worldview, creating appropriate and relevant rituals to mark the life and death of babies has become increasingly challenging for hospital chaplains and other providers of spiritual care. This monograph lays out some principles, with the aid of two different case studies, which may be helpful tools to aid theological reflection before and after practice, when seeking to co-construct with parents a welcoming (baptism, blessing or non-religious naming) or funeral ritual around the time of the death of their baby. It also argues that whether the ritual performed is religious in nature or not, the theological perspectives which the chaplain involved brings to such pastoral encounters crucially underpins the process of the creation of the ritual, its content, how he or she facilitates the ritual and hence the significance of the ritual, both to the baby's family and the chaplain themself.

1. What is Ritual?

> The meaning of ritual is deep indeed.
> He who tries to enter it with the kind of perception that
>   distinguishes hard and white, same and different, will
>   drown there.
> The meaning of ritual is great indeed.
> He who tries to enter it with the uncouth and inane
>   theories of the system-makers will perish there.
> The meaning of ritual is lofty indeed.
> He who tries to enter with the violent arrogant ways of
>   those who despise common customs and consider
>   themselves to be above other men will meet his
>   downfall there.
>
> Xunzi (third century B.C.E.)[1]

Introduction

Ritual fulfils deep human need for individuals, families and communities in relation to self, others and (for many) God, especially during times of transition and uncertainty. Involvement in ritual potentially touches the whole of our human personhood – there may be physical action, stimulation of our imaginations and feelings, a stirring of our spirit, senses and sexuality as well as intellectual engagement. Thus ritual is of great interest to sociologists, psychologists and anthropologists as well as to practical theologians. Before proceeding to reflect in some depth about the co-constructing of rituals by chaplains and parents around the time of the death of their baby, it is important to make some observations about ritual, in general terms, gleaned from the aforementioned disciplines.

A Definition of Ritual

Rituals are amongst the most basic of human activities and indeed many birds and animals similarly are involved in creating and using patterns of behaviour to communicate without the use of words.[2] Paradoxically, as Xunzi's poem suggests, rituals are also highly complex phenomena which contain and are associated with a myriad of meanings and any succinct definition or understanding of ritual will be

---

[1] C. Bell, *Ritual: Perspectives and Dimensions*. Oxford University Press 1997, before preface.
[2] R.M. Oswald, *Transforming Rituals*. Alban Institute 1999.

4

limited. However I find the following by Anderson and Foley a helpful starting point:

> 'Ritual for us is certainly ordered, patterned and shared behaviour, but, more than that, it is an imaginative and interpretative act through which we express and create meaning in our lives.'[3]

Ritual therefore may be a corporate public act which takes place within the context of the worship of a community of faith but ritual is also inherent to the structure of our daily lives and the way we relate to others, for example, the ritual of a family evening meal around a table where the day's events are discussed. Driver argues that ritual does not evolve out of religion, as often has been traditionally thought, but out of human existence and development.[4] Ritual is a fundamental part of humanity's response to social, political and communal life. Hospitals are places where ritual is part of the daily routine. Strange, for example, examined the ritual of handover in nursing practice (which happens in every ward and unit two or three times a day) in terms of its function and meaning for its participants.[5] Strange concluded that the handover ritual helped to provide a framework for social contact, psychological support and valuing what is integral to nursing knowledge and practice. During a time of handover nurses are able to share their patients' stories and their care of those patients, and their colleagues are involved in interpreting what has been happening on the ward, to individual patients and the atmosphere on the ward as a whole, before they begin their shift. Handovers importantly involve story-telling, verbally and non-verbally, but moreover they are also essential concrete tools which enable the collegial and professional nature of nursing to be developed and sustained.

Ritual-like Activity, Ritualization and Ritual

> 'The most clear cut examples of ritual, those depicting various genres of ritual, tend to be a matter of communal ceremonies closely connected to formally institutionalised religious or clearly invoked divine beings.'[6]

As Catherine Bell, a sociologist, points out there are a certain group of clearly defined patterns of human behaviour which society identifies readily as ritual. These we could think of at one end of a continuum of ritual and ritual-like activity. At the other end might be those

[3] H. Anderson and E. Foley, *Mighty Stories, Dangerous Rituals*. Jossey-Bass 1998, p. 26.

[4] T.F. Driver, The Magic of Ritual – Our Need for Liberating Rites that Transform *Our Lives and Our Communities*. Harper 1991.

[5] F. Strange, 'Handover: an ethnographic study of ritual in nursing practice', *Intensive and Critical care Nursing*, Vol. 12, No. 2, 1996, 106–12.

[6] Bell, *Ritual: Perspectives*, p. 164.

repetitive routine tasks which help to give shape and meaning to our daily existence, for example, my routine of washing and shaving before having breakfast in the morning. The question is when does a ritual-like activity actually become a ritual? For Bell ritualization is '… the simple imperative to do something in such a way that the doing itself gives the acts a special or privileged status.'[7]

The style or manner of doing creates a type of framework around the act that communicates the message – 'this has extra significance'.[8]

Driver emphasises in his writing that ritual is performance and that it is not just what is said and done during ritual that is important but how it is said and done.[9] However, not every performance is ritual – a television actor in a soap opera making a cup of tea is not ritual, but in Japan being made and served tea in a certain manner may be seen and experienced as ritual. Nerburn (cited by Oswald) helpfully suggests '… ritual is routine infused with mindfulness. It is habit made holy.'[10] Ritualization is the creative process by which humans make their repetitive activity into ritual. Driver puts it this way:

> 'Without its ritualising (new-making) component, ritual would be entirely repetitious and static. Without aiming at the condition of ritual, ritualization would lack purpose and avoid form; it would fall back into that realm of informal, non-communicative behaviour from which it arose … Ritualization is a way, an experimental way, of going from the inchoate to the expressive, from the purely pragmatic to the communicative.'[11]

This has great significance for what I term 'the ritual process' following a baby's death which will be explored later in this monograph. Various tasks may be performed by the baby's parents or hospital staff which in other circumstances may not be considered to be rituals but because they are carried out with love and care and are full of meaning and significance in this context they only be thought of as rituals, for example, parents washing and dressing their baby after his or her death.

Role of Ritual

The role of ritual is multi-factorial but some central themes emerge in the reflections of those with an interest in ritual from different academic spheres.

---

[7] Bell, *Ritual: Perspectives*, p. 166.
[8] Bell, *Ritual: Perspectives*, p. 166.
[9] Driver, *The Magic of Ritual*.
[10] Oswald, *Transforming Rituals*, p. 41.
[11] Driver, *The Magic of Ritual*, pp. 30–1.

Anthropologist and theologian Gerald Arbuckle importantly suggests that ritual is necessary where there is '... possible or real tension in social relationships ...'[12] He then goes on to say:

'Not surprisingly, therefore, all cultures have rituals surrounding the dramatic even fear-creating, experiences of birth, marriage and death. On these occasions, not just individuals are involved, but whole social groups are affected, so tension/conflict must be resolved or hidden to avoid disruption of social relationships ... Ritual, therefore, aims to express solidarity or oneness despite tensions in relationships. Hence, in ritual, the aim is to express unity while, at the same time, being aware that the tensions of daily life always threaten that unity.'[13]

Thus, ritual helps to order our lives, including our worship, and especially brings order and familiarity in times of chaos and uncertainty. As Ramshaw, who has an interest in the relationship between ritual and pastoral care, puts it:

'All ritualization ... is about the ordering of experience.'[14]

The solidarity or oneness described by Arbuckle also alludes to the heightening of community bonding. The effect of ritual on community relationships is central to the work of the British anthropologist Victor Turner. He coined the term 'communitas' to describe the deepening of relationships which can occur during involvement in rituals, which Driver explains:

'Rituals are inherently communal, while at the same time being imaginative and playful, even when most serious. They become bearers of communitas, which is a spirit of unity and mutual belonging that is frequently experienced in rituals of high energy ....'[15,16]

Ramshaw in her important book *Ritual and Pastoral Care* argues ritual in a pastoral context has several functions including the facilitation of the expression of ambiguous feelings at times of transition and providing a framework for the possibility of encountering the mystery and otherness in life and death.[17]

Ritual, therefore, is not just about reminding people that there is some structure and order in the world at a time when perhaps there seems to be no meaning or reason in an individual's or family's life

[12] G.A. Arbuckle, *Earthing the Gospel*. Geoffrey Chapman 1990, p. 97.
[13] Arbuckle, *Earthing the Gospel*, p. 97.
[14] E. Ramshaw, *Ritual and Pastoral Care*. Fortress Press 1987, p. 23.
[15] V. Turner, *The Ritual Process – Structure and Anti-Structure*. Aldine de Gruyter 1969.
[16] Driver, *The Magic of Ritual*, p. 164.
[17] Ramshaw, *Ritual and Pastoral Care*.

due to bereavement or trauma. Ritual is also 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. Grainger helpfully compares religious ritual with art:

> 'The nature of art is not to inform but to question … art asks questions about the meaning of life itself … One could say that art asks questions about the relationship between experience and aspiration, the world as everyday reality and ideal truth. This stands out very clearly in religious ritual, in which men and women reach out to a presence beyond themselves, but do it as themselves, in terms of their own humanity, without pretending. The struggle to give form to chaos, whether subjective or objective, a truthful shape to what was meaningless, is a continual one.'[18]

Anderson and Foley describe the paradoxical nature of ritual activity in terms of the mythical and the parabolic elements that are part of every narrative and ritual.[19] Myth is to do with our aspirations for well-being and the reconciliation of opposites or conflicting thoughts and feelings, whereas the parabolic is related to that which contradicts or confronts our values, beliefs or worldview. Our life stories contain both myth and parable and thus for a ritual to be relevant and authentic it must also incorporate both.

Rituals are vitally important in marking major life transitions. William Bridges helpfully differentiates between change and transition.[20] Change is something that happens to us, i.e. is external, and transition describes the internal psychological process which takes place within an individual as he or she tries to deal with change. Traditionally major life transitions have been known as 'rites of passage' – a phrase developed by the French anthropologist Arnold van Gennep.[21] Driver, however, appropriately suggests that:

> 'Rites of passage are performed not simply to *mark* transitions but to *effect* them.'[22]

Hence creating and acting out a ritual is a way of attempting to aid transition during times of significant change, as well as to acknowledge it. This leads Driver to conclude that rituals are potentially transformative.[23] A funeral for a baby may aid the natural grief process

---

[18] R. Grainger, *The Message of the Rite*. Lutterworth Press 1988, pp. 37–8.
[19] Anderson and Foley, *Mighty Stories*.
[20] W. Bridges, *Managing Transitions: Making the Most of Change*. Perseus Books 1991.
[21] A. van Geneep, *The Rites of Passage*. 1908, Translated by M.B. Vzedom and G.L. Caffee, Routledge and Kegan Paul 1960.
[22] Driver, *The Magic of Ritual*, p. 93.
[23] Driver, *The Magic of Ritual*.

(this topic will dealt will at length later in the chapter) but as Speck suggests:

> 'If the funeral is to be effective, as a rite of passage, in facilitating the grief of the bereaved then those present must be actively involved.'[24]

Not only that, they must be involved in all the three phases, which van Gennep proposed, make up a rite of passage. The three phases of such a ritual are as follows. (We will use the example of a baby's death and funeral in order to show what may be involved in each phase.)

Preliminal (separating) phase

In this phase symbolic behaviour occurs signifying detachment from cultural and social norms. In this case declaring the death of the baby and marking the death by, for example, seeing the baby and registering his or her death.　　　＜ challenge to Tourtsk.

Liminal (transition) phase

In this second phase parents are in an ambiguous state. Turner's description of this period sums up their situation – they '… are neither here nor there; they are betwixt and between …'[25] This phase may last for many months after the funeral, marked by confusion and difficulty in living life with any sense of normality. It is a transition period for the deceased baby also – marked by concern where he or she has gone. This phase is symbolised in the Christian tradition by Holy Saturday (a subject explored thoroughly by Lewis).[26]

Post-liminal (reaggregating) phase

In this final phase the rite of passage is now seen to have ended and the bereaved are now able to function appropriately in their different roles in life. As Turner puts it – they are '… expected to behave in accordance with certain customary norms.'[27] Certain activities associated with the funeral may aid 'the re-entry into the community of those who have been branded or stigmatised by death.'[28] For example

[24] P. Speck, 'Bereavement and Belief: an Anglican perspective' in P.C. Jupp and T. Rogers (eds) *Interpreting Death – Christian Theology and Pastoral Practice*. Cassells 1997, p. 106.
[25] Turner, *The Ritual Process*, p. 95.
[26] A.E. Lewis, *Between Cross and Resurrection – A Theology of Holy Saturday*. Eerdmans 2001.
[27] Turner, *The Ritual Process*, p. 95.
[28] Speck, *Bereavement and Belief*, p. 107.

a small gathering of family and friends after the funeral may offer an opportunity to show support and share stories and experiences.

While ritual can do nothing to alter the circumstances which have enforced painful transition to be lived through, a rite of passage can be a 'gateway' to aid transition. As Grainger helpfully states – 'The rite is the entrance to a new kind of life, a transformed kind of person, a new order of being.'[29]

Ritual Leader – Priest or Shaman

Driver in his book *The Magic of Ritual* compares the priestly role of a ritual leader with that of someone taking a shamanistic role.[30] He feels a priest is associated with maintaining order and ensuring predictability in ritual and as someone who acts as an interpreter and mediator. A shaman, however, takes on a more creative and spontaneous role – allowing ambiguity and facilitating the instinctive expression of feelings in ritual. Driver asserts people try to make connections through a priest but a shaman tries to create an atmosphere in which people make connections or glimpse something other. It is arguable, as Driver proposes, that there is a need for a ritual leader to be both priest and shaman in the creation and facilitation of ritual, especially in the co-creation and facilitation of ritual with parents for their dead or dying babies. There needs to be order, someone managing the ritual but also room for creativity, spontaneity, expression of ambivalent feelings and movement.

Much has been written about the role of ritual in pastoral care within the Christian faith community. However in this postmodern era many pastoral carers find themselves faced with creating and facilitating appropriate rituals with and for people who do not share the same metanarrative as he or she does. The rest of this monograph seeks to wrestle with this issue in the context of a maternity unit where chaplains endeavour to provide relevant spiritual care, including the co-creation and performing of rituals with and for bereaved parents who wish chaplaincy support, whatever their faith perspective or worldview. The role of the chaplain in co-creating ritual with bereaved parents and performing ritual tasks, as well as a theological basis for co-construction, will be explored.

[29] Grainger, *The Message*, p. 7.
[30] Driver, *The Magic of Ritual*.

2. Ritual and Baby Death

Introduction

Postmodern Western society is no longer influenced and informed, in the main, by a single grand or metanarrative, i.e. the Christian story, but by what Middleton and Walsh call 'a veritable smorgasbord of religions and worldviews'.[31] Not only are parents' beliefs and worldviews shaped by a plethora of sources but many young mothers and fathers whom chaplains meet may never previously have reflected on issues of faith. God, the Church and religion in general may not just be peripheral to their lives but may in fact never have been part of their personal or family story. For Brown (2001) secularisation is not just the decline in church attendance and adherence, or the reduction in the social and moral influence of the Church but also a lessening of popular religiosity.[32]

Moreover, parents may never have contemplated the reality of human mortality until experiencing the death of their baby. Death in the twenty-first century, like the expression of spirituality, has become privatised. It has become something that is thought to happen only to octogenarians in hospitals and hospices or on a television or cinema screen. Many young parents will never have been bereaved or touched by the death of someone in their local community prior to the death of their baby. Therefore, not only are they then dealing with the alien landscape of intense and bewildering grief, but they are also faced with questions never previously considered. Such disorientation is also shared by those parents who have been bereaved in the past. Experiencing the death of a baby is not what our postmodern society considers the natural order of life.

> 'If there is a God how can God let this happen? But if there is no God, is there no afterlife? Then where will my baby be? Who is looking after my baby? Will I ever see or indeed parent my baby again?'

Such is the myriad of questions. Such are the mysteries which confront parents when birth and death come together.

A major part of the challenge for chaplains supporting bereaved parents is that there is no longer a shared language or common metaphors or symbols which can be utilised to articulate these mysteries

[31] J.R. Middleton and B.J. Walsh, *Truth is Stranger Than it Used to Be*. SPCK 1995, p. 43.
[32] C.G. Brown, *The Death of Christian Britain*. Routledge 2001.

when facilitating or performing rituals to mark the life and death of their baby.

Parents requesting a welcoming ritual or a funeral for their baby, whether they have religious beliefs or not, can be separated into two groups. Firstly, there are those who, due to the acute nature of events, are not able or for their own reasons choose not to enter into any dialogue with a chaplain. Hence the chaplain cannot develop a relationship with them within which their specific needs may be ascertained. When a baby is in the process of rapidly dying in a neonatal unit, for instance, there may be no time for a chaplain to relate to parents before performing a requested baptism. He or she responds using the appropriate resources from their tradition. However a second group of parents are able and indeed often find it therapeutic to enter into a relationship with a chaplain in which an appropriate welcoming or funeral ritual can be co-constructed. This latter group of parents will be represented in the following two case studies. These are people from whom chaplains, and the Church, can learn much.

Case Study 1:
Co construction of ritual with parents who share the same metanarrative as the chaplain

John and Hazel are a couple who regularly attend their local church. They have two young children who were both baptised and go to Sunday School and the church crèche respectively. Hazel was expecting their third child and had been admitted to hospital after learning their baby had died in utero at thirty-six weeks of gestation, to have her labour induced. Hazel and John at this stage asked to see the hospital chaplain as their own minister was on holiday.

John and Hazel were both very distressed when we met. They shared the story of their pregnancy, their shock and utter desolation and their fears about Hazel giving birth to a dead baby. For Hazel it felt so unfair to have come so close to delivering a healthy baby – only the day before she had felt her baby move. She felt cheated and angry. She also felt she had let her baby and her husband down.

In the midst of our conversation Hazel asked me – 'What can we do for our baby? What can you do? Can you christen the baby? Our other children are christened. Is that what you do in this sort of circumstance?'

Together we explored what their needs were – for themselves and for their baby.

What became clear as we talked, was that Hazel and John wanted to affirm in some way the special significance of their baby. How important their baby was – unique and precious to them and to God – and that he or she had made his or her mark on their family and on the world.

Hazel herself put it this way – 'We want to welcome the little one into our family and God's family. That doesn't sound daft does it? Can you do that?'

I replied that is exactly what we would do and began to suggest some sort of order for a short welcoming ritual. Firstly that together we might name their baby if they wanted, as a person's name was integral to their individuality, their uniqueness. Then say a blessing, perhaps the blessing that was said in church when their other two children were baptised. At this point Hazel nodded vigorously and said 'Yes ... the Lord bless you and keep you.' I suggested I could read a short passage from the bible and then say a prayer about how they felt about their baby and their family, about the situation they were struggling to make sense of and ask for strength and help.

I asked how that felt for them. They both agreed with each other that it felt right and Hazel explained that she'd used the word christening because she couldn't find any other way of describing what she intuitively felt she needed for her baby. We then talked a little more about them choosing a biblical passage and what might be said in the prayer. John, who had been quiet through most of our encounter finished the conversation by indicating that in their helplessness and confusion, it was good to know that, as parents, there was something appropriate that they could do for their baby when he or she was born.

John and Hazel also wanted to know what happened to their baby after he or she was delivered and if having a funeral was the right thing to do. I talked briefly about them having as much time and space with their baby as they needed and that, from experience, parents did find it helpful to have a funeral for their stillborn baby, especially in retrospect. I mentioned that there were various options available to them regarding funeral arrangements and that hospital and community healthcare staff, including the chaplaincy and their own minister, would be able to offer support and give them the information they needed to make the right choices for their family. I then suggested that there would be plenty of time to consider these options once the baby was born and reassured them that nobody was going to pressurise or rush them into making decisions.

Next day I got a call from the labour ward. Hazel had delivered her baby – a boy named Callum. When I arrived both parents were very tearful and found it hard to express how they felt. As I sat with them for a while, Hazel talked more of how unfair it was to lose such a wanted baby and asked why God allows such things to happen. She felt cheated and that nothing made sense right now. However she also was keen to 'do what we had talked about yesterday for Callum'. I checked out if they wanted other members of their family present during their welcoming ritual for their baby and if they wanted anything in particular read. They didn't.

Hazel and John sat on the bed holding their baby between them. June, their midwife sat behind them. She had brought a posy of flowers for the family into the room and placed them on the bedside cabinet. June had said to me earlier that she wasn't very religious but asked John and Hazel if she could stay. They were very glad she was there.

I started by saying ...

> 'In your hurt, confusion and grief following the death and birth of your baby, Callum, is a deep need within you to mark his unique presence in your lives, to welcome your little one into your family and into God's family in heaven and on earth.'

Together we named little Callum and I laid hands on his head and blessed him in the name of the Trinity. Then Hazel, John and I said the Aaronic Blesssing together.

I said we were all there at that moment because of love – especially because of their love as parents for Callum, their love for each other and God's love for Callum and his family. I then read from 1Cor. 13 verses 7,8a and 13 which Hazel also spontaneously joined in with. After a short silence, I read:

> 'Listen to our prayer, O God,
> and hear our cry for help.
> When we are in trouble and don't understand,
> Don't turn away from us.'[33]

I then finished the short welcoming ritual with a prayer which acknowledged Hazel and John's feelings (their hurt, confusion, anger, shock and sense of failure), their questions of God and their struggle to make sense of their loss. I also stated they had done their best for their baby and that Callum was safe and at peace in God's care, and gave thanks for the wonder and beauty of Callum. I asked for strength and help for Hazel and John to keep listening and supporting each other and for Sarah and Kerr, their other children, and the rest of the family. The prayer ended by asking that June and her colleagues would also continue to find the resources they needed to do their jobs with the humanity and compassion that they share.

Before I left I gave them a Blessing Certificate with Callum's name on it for them to keep and to serve as a marker for memories in the years to come. Callum was buried a week later in a part of a local cemetery specifically set aside for babies during a short funeral service, conducted by John and Hazel's parish minister.

---

[33] An adapted version of Psalm 102 v1–2 (Good News Bible).

Case Study 2:
Co-construction of ritual with parents who do not share the same metanarrative as the chaplain.

In this case study the baby's parents had chosen not to be present at the crematorium on the day of their baby's cremation, but had approached our chaplaincy team a month later wishing they had marked their baby's life and death in some way.

Janice and Michael are representative of many couples in our post-modern era. Their beliefs and worldviews were not formulated from one particular metanarrative but from an eclectic range of sources. In the course of our discussion they indicated, for example, that neither of them had been brought up in families which had any church connection but through friendship with a Muslim family in their street they expressed admiration for theistic religions where family life was a central component. It was clear that Michael's scientific training had nurtured empirical tendencies within him. Janice loved working in her small garden which made her feel connected to the earth, had a regard for the sacredness and tranquillity of city centre churches and cathedrals in which she sought peace and quiet on occasions, and an active interest in yoga. Janice described herself as agnostic and Michael didn't assign himself any particular label.

Janice miscarried her baby in hospital at eighteen weeks of gestation. Lily was a much wanted first baby. After delivery, Janice and Michael had both seen their baby but had chosen at this stage not to have a funeral. During our initial conversation it became apparent that, like John and Hazel, they had a real need to mark, with someone else present, the significance and reality of their baby in their lives. Over the course of the weeks following Lily's birth it had become apparent to both Janice and Michael that Janice's late miscarriage wasn't, for them, just the end of a pregnancy but was in fact the death of their baby.

Janice and Michael talked not just about their pain and sadness relating to their loss in the here and now but also about the loss of their hopes and dreams for the future. They wrestled with their feelings of injustice and being cheated as well as trying to fathom why this should have happened to them and to Lily. Out of our conversation developed the concept of a short and simple but dignified ceremony to acknowledge Lily's short life and death. 'To underline she really was here, and how much she was loved and still is,' as Michael put it.

We talked together about the possible content of the ritual, not just about what could be said but about the use of symbols or gestures (such as lighting a candle and the involvement of specially chosen flowers), music and silence. We also discussed where the short ritual might take place and who might be present. Both Michael and Janice very clearly stated that though they were not religious and didn't want a religious service, they wanted a chaplain to be there and 'say something'. Michael also wanted to say a few words about his

daughter. During our first encounter I tentatively suggested a short order or framework for the shared ritual and suggested that my contribution would reflect something of what they had shared with me that afternoon. It was agreed they would get back in touch with me in a few days to finalise arrangements.

I met with them again later that week, two days before the funeral for Lily, to bring the different elements of the ritual together. Whilst looking for and accepting guidance, Michael and Janice had obviously talked through themselves what felt right for them and for Lily, since we last met. The hospital chapel was chosen by the couple as a suitable place to hold the funeral.

The service took place with only the three of us present, as follows:

A candle (given to the couple from the hospital chaplaincy to keep) was lit and a vase of lilies, some open and some closed, was placed on the communion table.

I spoke briefly – stating that today was a difficult but important day for them as they were here to mark the life and death of their much loved daughter who was unique, precious and very special to them both. I acknowledged their grief, their questions and searching for a reason, their dashed hopes and dreams and verbalised some of their thoughts and feelings which they had shared with me. I used a phrase of Janice's – their baby was 'like a Lily which had not yet opened – inherently beautiful but she had not had the chance to open up and bloom,' which summed up metaphorically how she felt about Lily. I also talked about the excitement, anticipation and joy that Lily had brought into their lives while they were pregnant as a couple, that though these feelings were not the same as having Lily they could not be taken from them. Lily's life was short but very significant – she would never be forgotten. Michael and Janice had both said that Lily's death had enabled them to talk a lot as a couple, not just about their present grief but about all sorts of issues, and to bring them closer together. I therefore ended by saying that nothing could take their hurt and pain away following Lily's death but that through this experience their love and understanding of each other had deepened. I then read these few lines from Paul's first letter to the church at Corinth (mentioning these were words written in ancient times but seemed applicable for today) –

'There is nothing that love cannot face,
There is no limit to its faith,
its hope, its endurance.
Love will never come to an end.'[34]

[34] 1 Corinthians 13 v7, 8a and 13 (Good News Bible).

Silence

Michael then read a poem which he had written for the occasion. It talked of the paradox that was having then losing Lily – pure, untainted by life, much loved, bringing much joy yet also it was ironic, but apt, that lilies were associated with funerals, death and pain.

Finally a piece of classical music was played – a CD of Janice and Michael's choice.

I left Michael and Janice to listen to the music alone, as arranged, and to cry together. They then took a lily each from the vase on the communion table and went into the hospital grounds where they threw the petals of the two lilies into the wind. The rest of the lilies, at their request, were left on the communion table.

Principles of Co-Constructing Welcoming and Funeral Rituals

Several key issues relating to the co-creation of rituals around the time of the death of a baby are important to reflect on prior to and following practice.

1. Understanding the Role of Welcoming and Funeral Rituals

It is important to consider that welcoming and funeral rituals do not take place in a vacuum. They are part of an ongoing process which confronts the family with the reality of the life and death of a baby which begin with a positive pregnancy test and potentially may be ongoing throughout a bereaved parent's lifetime. This process may include:

- seeing baby for first time on ultrasound scan and having copy of scan photograph
- feeling/seeing baby move in mother's womb
- seeing baby at or after birth
- holding and examining baby
- washing and dressing baby
- naming baby – usually informally by family, sometimes more formally by a chaplain or other spiritual carer during baptism, blessing or naming ritual
- mementos taken – photographs, hand and footprints, lock of baby's hair
- registering stillbirth or baby's birth and death (if more than 24 weeks gestation)
- birth/death announcement in newspaper
- funeral – which has associated ritual-like activities which are part of the 'whole' funeral process or ritual – choosing clothes for the

baby and things to put in baby's coffin, visiting cemetery(s) in order to choose an appropriate resting place, relating to an undertaker and choosing flowers
- marking grave
- entry into book or garden of remembrance (especially if baby cremated)
- visiting the baby's grave
- returning to see obstetrician and/or neonatologist – to get postmortem and/or test results, performed in order to try to establish a cause of death
- memorial services
- family rituals such as lighting candles on significant days or anniversaries

Whilst there is no doubt welcoming and funeral rituals for babies dying before or shortly after birth have different nuances and emphases, there are a number of shared roles inherent to both forms of rite. They both provide a framework, a structure for various important functions. These include:

> The facilitation of the grieving process and opportunities to fulfil certain tasks of grieving described by Worden.[35] Namely beginning to accept the reality of the baby's life and then death and beginning to experience and live with the pain of that loss. Welcoming and funeral rites act as milestones or markers in a time of transition and major adjustment for what Arbuckle calls the 'tripartite ritual process' – 'separation, liminality and reaggregation'.[36] Both Worden and Arbuckle make the same point – unless the reality of death is confronted and separation from what actually was, as well as what was hoped for, is acknowledged in the ritual process then the chaos and confusion of liminality is prolonged and the gradual reintegration of the family into ordinary living again within their wider family, social and work circles is potentially more difficult.

Kuller and Katz highlight the important sociological role of welcoming and funeral rituals in facilitating grief following the death of a baby:

> 'When a pregnancy is lost, grieving ensues. The social acceptance of that grieving through ritual assists in the progression and resolution of the grief.'[37]

[35] J.W. Worden, *Grief Counselling and Grief Therapy.* Tavistock 1983.

[36] Arbuckle, *Earthing the Gospel*, pp. 97–8.

[37] J.A. Kuller and V.L. Katz, 'Miscarriage: a historical perspective', *Birth: Issues in Perinatal Care and Education*, 21(4), 1994, 227–228, p. 227.

Similarly ritual helps to clarify changes in social status for bereaved parents – they have not only become parents, and always will be a parent, but they have also been bereaved. As Ramshaw puts it – 'Society may need rites of passage to realign and clarify the interactions between people in different stages and conditions.'[38]

In order to construct formal ritual moments which aid the above process it is essential for the ritual to be authentic and grounded in the reality of the desperate pain and confusion felt. Such expression of lament, the search for meaning and reason and a parent's wrestling with God or their own belief system is central to creating an appropriate welcoming or funeral ritual. A chaplain verbalising or summing up a family's feelings not only indicates compassion and empathy but gives permission for these feelings to be owned, felt and expressed; and for questions to continue to be asked and expressed. As Hazel put it – 'Why did God allow us to have Callum for only a few months and then take him away?' Both couples in our case studies were searching for a philosophical or theological reason, not just a medical one, to explain the death of their baby. A families' Good Friday desolation has to be recognised and named before the possibility of Easter Monday (during a funeral) can be introduced. We should never assume what peoples' feelings are but when they have told us or shown us then incorporating them personalises the ritual and validates their emotions. Whether at the heart of a family's story is the Christian tradition or not, the tradition to which the chaplain belongs provides a great resource, as well as a precedent, for providing expression of corporate and individual lament. Middleton and Walsh argue that the Christian metanarrative is universal – applicable in all times and places to all people – for several reasons but especially because it embraces pain, recognises it and owns it as part of the human and divine story.[39] The Psalms, for example, provide a rich seam of examples of human wrestling with suffering, loss and God. As I read the first two verses of Psalm 102 with Hazel and John their heads were nodding in agreement. They were in trouble, they didn't understand – where was God? Was God listening? The wrestling of Job with the problem of theodicy parallels many a parent's seeking an answer to the injustice of their suffering and their baby's death when those who mistreat their children or themselves seem to, in the bereaved parents' eyes, give birth to healthy babies. Even when, as in the case of Michael and Janice, where God is not part of the parents' worldview, the Christian story provides examples of human and divine responses to suffering and loss which inform the chaplain as he or she seeks to create an appropriate ritual. Owning and acknowledging pain and hurt, finding no answer to the question 'why?' as well as living with such tensions

[38] Ramshaw, *Ritual and Pastoral Care.*
[39] Middleton and Walsh, *Truth is Stranger Than it Used to Be.*

and longing for reason and purpose in the face of untimely death is part of the chaplain's metanarrative as well the parents' story.

Ritual moments provide a defined and limited amount of time and space in which families can express their feelings which is contained within 'safe' boundaries. It is as if people give themselves permission to release their emotions within the boundaries of these formal rituals and indeed expect such an outward display of feelings of themselves and others. Janice described how she anticipated that her baby's funeral would be an emotional and draining experience but for her, at that point in time, an important one. Green helpfully describes part of the role of such ritual moments – 'We have to discover ways of dealing with the depths of ourselves without destroying ourselves.'[40] Ritual provides 'a container without a lid on it' as David Lyall put it, within which parents can explore and express the myriad of ambivalent feelings they may have about themselves, their baby and God (amongst other things), that they discover in their depths (Ramshaw provides a fuller account of the role of ritual in acknowledging ambivalence during times of transition).[41,42] Both couples in the case studies shared copious tears together during the rituals performed for their babies. For Janice and Michael it was the first time they had done so together since the death of their baby and they later commented that this was significant to them.

Both formal rituals and more informal ones, such as registering the baby's death or making funeral arrangements, can create some sense of order at a time of chaos and confusion.

Welcoming and funeral rituals for dead or dying babies may help to reaffirm what gives meaning and purpose to a family's story and to acknowledge the importance of their core beliefs and values. John and Hazel were shocked, almost overwhelmed at times, by what had happened to them and their baby. They were bursting with questions and anger, yet for them having their baby named, blessed and welcomed into God's family was essential. There was a need as a family to be part of a ritual which acted out the metanarrative to which they and their baby belonged. For both couples, the rituals performed for their babies also were moments when their implicit love and commitment to each other and their babies was made explicit.

Formal ritual moments may therefore help to bond relationships. They are a forum for shared and felt experience and become part of the lived story of those who are involved. This is certainly true for both couples in our case studies. It wasn't just their communicating and sharing after Lily's death that helped strengthen Michael and Janice's relationship but their involvement in the process of co-constructing and presence at her funeral. Rituals involving other members of the

[40] R. Green, *Only Connect*. DLT 1987, p. 125.
[41] From a conversation with David Lyall.
[42] Ramshaw, *Ritual and Pastoral Care*.

family and members of the community also act to bring people together united in their feelings for the baby and his or her parents. Attending the ritual gives family and friends the opportunity by their presence to convey their support and affirm the significance of the baby.

The ritual moment itself may give meaning in the face of the mysteries of life and death. As Grainger puts it – '… it is not a matter of what it signifies but what it is. It signifies itself … the medium really is the message.'[43] Carr suggests families invest rites such as welcoming and funeral rituals with their own meaning.[44] Therefore the ritual becomes their ritual and that of their baby and is incorporated into their family's story with their own interpretation of what took place and what its role and function was.

Welcoming and funeral rituals for babies also provide a framework for encountering transcendence and foci for reflecting on the mystery of life and death and what may be beyond, for bereaved parents. During the process of co-constructing Lily's funeral, Janice described her lengthy reflections on what life was about, what death meant to her, the possibility of a Creator and whether she would meet her baby again and in what form. She felt having to think about the content of a funeral prompted her into trying to verbalise the thoughts and feelings awoken in her following Lily's death.

The rituals described in the case studies took place in very different environments yet both were tangibly sacred. All of us who were present were not just visibly moved and emotionally touched but were part of something more. These ritual moments were moments of grace. Therefore such ritual moments can also be moments of hope – moments when paradoxically something other is glimpsed and moments when hope can be discovered or expressed. Hope that there is more to life and death than the sheer physical and emotional pain of bereavement. Hope for Hazel and John was that Callum was safe and at peace and that he belonged not just to their family but God's family on earth and in heaven. They found hope in the belief of resurrection – that they would be reunited one day with their baby. Janice and Michael found hope in the reaffirmation of their relationship through their mutual need to talk and share their feelings with each other following Lily's death. It was important for them that this was stated at their baby's funeral. Lily in a real way had brought hope and strength for the present and the future and in some way her parents found some reason and purpose for her short life and death.

Thanksgiving for the hope, anticipation, excitement and love that unborn children bring into a family as well as thanksgiving for the beauty and wonder of the baby once he or she is born, can be important elements of ritual in this context. While the former may be suited

[43] Grainger, *The Message*, p. 21.
[44] W. Carr, *Brief Encounters*, SPCK 1985.

primarily to funerals, parents (like John and Hazel) often in the imme diacy of seeing and holding their baby soon after birth do exclaim how beautiful or handsome their baby is (even when the baby is quite malformed). Pride in his son and amazement at Callum's tiny features was written on John's face as well as a deep sadness as he held his son.

The content of and the ritual itself not only express the parents' love for and investment in their baby, but funeral and welcoming rites also affirm the uniqueness and significance of their child in their family circle and in the wider world. Their child's short life and death has not just made his or her mark on their family's story but on the story of humanity itself. The baby's existence and death and the pain of his or her loss matters. The parents' grief is valid. Walters, in this case talking about adult funerals, underlines this point well:

> 'Ultimately the funeral is not just performed for the deceased, who is no longer there to care; nor just for the family, who may all be dead too: nor just for the community, there may be none; nor just for friends, who may not exist. But the death of a human being must be marked. The funeral belongs to humanity.'[45]

The chaplain will also believe, like many parents from a theistic back ground like Hazel and John, that the baby's life and death is highly significant to God too – God has been touched and moved. This belief not only underpins a chaplain's approach to co constructing and performing such rituals, religious or non-religious, but also his or her being and way of being with a bereaved family, their baby and other staff involved. Central to a blessing or baptism or Christian funeral for a baby is that the baby has been loved from the beginning (Psalm 139 v13–16a – being known and formed by God in our mother's womb) and always will be loved and known (Isaiah 49 v15–16 – the baby will never be forgotten) by God.

Formal moments within the process of ritual prior to and after the death of a baby include, as has been discussed, the opportunity to acknowledge the expression of feelings. One feeling, amongst many, which is normal and perhaps inevitable, when experiencing the death of a loved one, especially a baby, is guilt. Guilt for things done or left undone, things real or perceived to be real which are associated with the death of the baby. Acknowledging this feeling as being part of our human response to such trauma within the context of ritual, when it has been shared with the chaplain as he or she supports the family, can be normalising and helpful in and of itself. Within a religious funeral service prayers for forgiveness can be used. Forgiveness and accept ance are not just conveyed by words but also by attitude and a way of being with people. The approach of the chaplain and how he or she relates to the parents is not lost on them, especially if for any reason

---

[45] T. Walter, *Funerals and How to Improve Them.* Hodder and Staughton 1990, p. 123.

they have terminated their pregnancy. Hence the chaplain's theology, which informs his or her personhood and practice, is central to the response in such situations. Guilt, real or neurotic, and feelings of inadequacy and failure however cannot be magically dissipated by acknowledging them in ritual and may require further exploration with the aid of pastor or counsellor.

Part of the role of ritual moments is also to confront parents, staff and ourselves ... 'with a proper sense of our own limitations'.[46] The vast majority of parents have done and are trying to do their very best for their baby in a situation where human ability to control life events is shown to be limited. Recognition that the best parenting possible has been done in the circumstances, including having a welcoming and/or funeral service, within ritual is important. What has happened is outwith the parents' control. It is not their fault (even when a termination for medical reasons has taken place, the decision made has been with best of intentions and the baby's abnormality itself is not the fault of the parents).

Specific points in this process of ritual may enable families to put down cairns or milestones during their and their baby's traumatic journey which may help them to create and maintain memories. These memories may, in time, help parents to acknowledge and accept the reality of their loss. In this way rituals, religious and non-religious, act as foci around which memories are constructed and retained. Mementoes of rituals, such as the candle used at Lily's funeral and Callum's blessing certificate can stimulate memories when kept and referred to, which provide comfort and hope in the future as well as an aid to storytelling.

Specific Role of Welcoming Rituals

The primary role of welcoming rituals following the death of a baby around the time of his or her birth is to formally acknowledge the life and birth of the baby before letting go in a physical sense at a funeral – saying hello before saying goodbye.

Also of significance is that a welcoming ritual in this context is closely associated with the formal naming of a baby and thus with the giving of an identity and recognition of the baby's individuality and uniqueness. In the future mention of the baby's name in the family circle will be a reminder of the reality of the baby and memories of him or her.

A welcoming ritual also literally enables a family to formally welcome their baby into their family and when a blessing or baptism is performed the baby is also incorporated into God's family on earth and in heaven. This is a formal way of saying the baby belongs and has

[46] Green, *Only Connect*, p. 41.

a home. The blessing performed for Callum was very important for Hazel and John. They had a need to have a minister from their own tradition formally acknowledge Callum's place in their family and in the Church, their family's spiritual home. The short ritual that was co-constructed in consultation with Hazel and John attempted to – '... connect the child's short-lived story with the divine narrative.'[47]

Parents may find it hard to articulate their desire to have their baby blessed or baptised around the time of the baby's death, and indeed it will probably be based on gut feeling and parental instinct rather than intellectual reasoning. Their reasons may be about following family tradition, concern about the eternal destiny of their child or the need to do something for their baby in a time of helplessness and loss of control. Underlying their request may be a plethora of spiritual and pastoral needs. In order to meet these needs chaplains have to respond with sensitivity, openness, creativity and above all a listening ear.

In conclusion, the role of welcoming and funeral rituals for babies dying in utero or shortly after birth is both paradoxical and ambiguous. On the one hand they offer the possibility of shape and structure, of hope and ultimate meaning but on the other hand they offer a framework for the authentic expression of lament, questioning and exploring life and faith issues.

2. Process of Co-constructing Ritual

Central to the concept of co-construction of ritual is the premise that ritual evolves out of story. The story of:

- the family and their baby,
- the chaplain,
- and the encounter or dialogue between the chaplain and the family – the meeting and engagement of their stories.

The process of co-construction thus involves the chaplain being aware of his or her own story and what informs it prior to encountering the family, establishing a relationship with the bereaved parents in order to enable them to share their story and for the chaplain to be aware of the internal feelings and the dynamics of the interaction as the chaplain's story meets with that which is being heard and experienced. The chaplain also has to be aware that the family's telling of their story and the process of co-construction will become part of the ritual process and will be remembered, as the chaplain will, as part of the baby's and family's story. It is not just the formal ritual moment which may be helpful and potentially healing for parents but also the process of co-constructing the ritual itself. Thus the approach, theology and ultimately the personhood

---

[47] Anderson and Foley, *Mighty Stories*, p. 133.

of the chaplain is central to the spiritual care provided and the ritual constructed.

A multiplicity of experiences and facets of life shape both a family's and a chaplain's story and thus their response to the death of a baby, their attitude to ritual and how their stories engage. These include:

- Life experience – especially previous losses and bereavements
- Family background and upbringing – family response to death in the past, traditions and family folklore. For example – are babies baptised, are family members cremated or buried and what roles do family members traditionally take on depending on their gender and status when dealing with a death?
- Religious beliefs and worldview – do chaplain and family share the same metanarrative? What stories inform the couple's belief system? What is the chaplain's motivation or raison d'etre for being involved? What do all involved feel about an afterlife? What are the images of heaven individuals hold in their heads, if any, and in whose company do they believe the baby is in? What are their images of God, if any?
- Cultural background

In establishing a relationship in which the chaplain hopes vulnerable parents will share of themselves with him or her, a chaplain has not only to act with sensitivity but with integrity. The chaplain has to be open about what the chaplain considers his or her role to be and what his or her agenda is. Thus a chaplain has to have worked out for themself what he or she feels his or her role is and the boundaries of it prior to meeting with parents. The chaplain has to gently explore what the parent's expectations are (of the chaplain and of any ritual which they may want) but also make clear his or her own expectations (this may not be possible or appropriate in the immediacy and distress of a labour ward or neo-natal unit before a welcoming ritual is performed). A chaplain should make it known from the outset of the relationship with the parents whether he or she is prepared to perform a non-religious ritual.

Families may need gentle encouragement, indeed given permission, to explore for themselves as well as with the chaplain what they might want said and done during ritual. Many families will assume that the chaplain has control of the process not them, and indeed be fearful not only of suggesting that they have a say in what happens but even of meeting the chaplain at all.

Ritual is not something to be done to the parent's baby it is a moment to be shared with them and in order for it to be a true sharing their story must be heard, understood and incorporated into the ritual itself. Bohler suggests there are three ways to listen when engaging with a family's story:

Firstly, to listen to the whole story, pull together the fragments and reflect back the essence of the story to ensure that what has been thought to be heard was correct and understood. When listening to Hazel and John's story prior to the stillbirth of Callum the key need for them seemed to be that of marking his uniqueness and special place in their family and God's family. It was important to check that out and have it affirmed by his mum, before empha-sising it in our planned blessing and naming ritual. Secondly, for the chaplain to tease out the metaphors or images from the story and highlight them. In this way the listener is hearing the story-teller's interpretation or meaning of their own story. A good example of this is Janice's likening of baby Lily to an unopened flower – she had inherent beauty which was not able to open up and bloom. Thirdly, for the listener to interpret the story with suggested images or metaphors which help to uncover the under-lying meaning. These images or metaphors may help parents to unravel or gain new insight into their story in the confusion of their bereavement and may be incorporated into a ritual through the use of words, said or sung, or music, symbol or gesture.[48]

Co-constructing ritual involves not just listening and interpreting but also the sharing of information by the chaplain, in order that parents can make informed choices. Chaplains, therefore, before engaging in creating rituals with parents need to be aware of practical issues including – appropriate physical care of the baby and parents, physical limitations of ritual content in the hospital context (for example, lighting of a candle may be a major fire hazard), what local alternatives there are for making funeral arrangements and what local provision there is for apt disposal of the baby's body. If a chaplain does not know the answer to a parent's question it is important that he or she is aware of resource people around who may. An important part of co-constructing ritual is thus handing back control to parents, if they want it, to enable them to do the best they can for their baby in a manner that is appropriate to their family's story. John was very relieved to hear, even before his dead baby was born that there was something he and his wife could do for their baby, which felt right for them as a couple, in circumstances which rendered them feeling useless and helpless as parents. In order to enable this to happen chaplains have to be sure of their facts and share information in a sensitive and timely fashion. It was not appropriate to go into great detail about alternatives for funeral arrangements with John and Hazel in the immediacy of labour being induced and trying to get their heads round their baby's death as well as how we might ritually welcome their baby. At that stage it was sufficient to say that they could have a funeral if they wished, and that

[48] C.J. Bohler, 'The Use of Storytelling in the Practice of Pastoral Counselling', *Journal of Pastoral Care*, Vol. LX1;1, 1987, pp. 63–71.

from experience, the majority of bereaved parents (whose baby was stillborn) found this important to do so, and support would be available to help them with that.

During the process of co-construction the chaplain is not merely acting as a listener and sharer of information but is also utilising various resources as he or she acts as a guide in such unknown and frightening territory (for a fuller account of guiding as a function of pastoral care see Clebsch and Jaekle).[49] These resources will include – reflections on previous experiences of supporting and co-constructing ritual, conversations with other chaplains and colleagues in the wider healthcare team, written material and research (for example Anderson Wretmark's study on reality confrontation following perinatal death) as well the metanarrative and particular tradition to which he or she belongs.[50] The chaplain may suggest a possible framework for a particular ritual within which to weave the baby's, the family's and other relevant stories as well as making suggestions as to how those narratives are articulated or expressed. Both couples in our case studies found this imperative. Living through a totally alien experience, they had no idea how the ritual which they felt was needed could be structured or held together and were relieved to have guidance regarding content as well as form. To this end, especially while co-constructing funerals with parents, chaplains may suggest or offer certain resources which might provide content for the service or help verbalise parents' thoughts and feelings (chaplains working within the Royal Infirmary of Edinburgh routinely offer parents the opportunity to take home and consider various resources, including an anthology of material containing an eclectic mix of poetry, prose, prayers and hymns from different worldviews collated by Frances Dominica, the director of a children's hospice, with bereaved parents specifically in mind).[51] It is important that guiding and making sensitive suggestions is only done after the parents' story and their needs have been heard – the ritual begins with and evolves from their story.

It is essential in the process of co-constructing ritual that parents, where possible, have time and space to think, feel and reflect in the absence of the chaplain. In a time of confusion and turmoil parents need time by themselves to mull over and absorb what has been shared and discussed. There should be no pressure, again where possible, for parents to make decisions regarding welcoming and funeral rituals in a hurry and reassurances made that it is absolutely normal to find it hard to do so. Indeed parents should be positively encouraged to take their time in thinking through what has been discussed and suggested – for what is done cannot be undone. It is in this time – in their own time and usually at home in a more familiar

[49] W.A. Clebsch and C.R. Jaekle, *Pastoral Care in Historical Perspective*. Harper 1967.

[50] A. Andersson Wretmark, *Perinatal Death as a Pastoral Problem*. Graphic 1993.

[51] F. Dominica, *Just My Reflection*. DLT 1997.

space – that the content of a funeral service can be considered and possible resources read and reflected on. The aim of the process of co-construction is for parents to be able to look back in the future and feel that they were able to do their best for their baby and themselves. They were able to formally say hello and goodbye to their baby in a way that was right for their family. John and Hazel were able to take time over night to affirm for themselves, what was initially felt at a gut level, they wanted and needed for Callum. Janice and Michael took nearly ten days, after an initial phone call of inquiry, and much time, effort and discussion to make final decisions about the short funeral service for Lily.

Theological Basis for Process of Co-constructing Ritual

Every human being has a unique story and has needs which are important to her or to him. Listening to and responding to the needs of individuals was central to Jesus' ministry. He paid attention to individuals and what they sought from him – he listened to their particular story – amongst the stories of many. Jesus responded to the specific needs of individuals, not just to the general needs of people of his time, whom he encountered. For example, the woman who suffered from severe bleeding was singled out by Jesus from a gathered jostling crowd after she touched his cloak and he gave her, and her story, his undivided attention (Mark 5 v24–32). For those who seek to co-construct ritual with grieving parents there is a need to begin where the parents are, not where the chaplain thinks they are, and to hear their unique story and the unique story of their pregnancy and their baby. It is not just the rituals themselves which involve moments of grace. The sharing of stories, the telling and the listening, is also sacred.

All who lose a baby will have needs but we cannot assume their needs are all the same. Therefore each welcoming and funeral ritual, informed by story, will accordingly be different and special in its own way.

Being involved in the co-construction of ritual with parents means taking risks and not always being in control. It means taking seriously what others feel, think and believe and being prepared to let parents set the agenda, if they feel comfortable doing so. Co-construction means entering into a relationship in which the chaplain is unsure of what will happen, what will be created and how he and his story will be touched and changed. The tradition to which the chaplain belongs underpins all of this. Brueggemann puts it this way:

'The biblical tradition is not about control but about vulnerability ...'[52]

[52] W. Brueggemann, *Interpretation and Obedience*, Fortress Press 1991, p. 17.

Co-construction is about getting alongside, travelling with parents and being part of their story for a while. The ritual thus evolves out of a shared journey and the chaplain's understanding and interpretation of it. Following his death and resurrection Jesus joined two of his bereaved friends on the road to Emmaus. They did not recognise him and as a stranger he shared their journey with them, helping his friends to interpret their recent experience in light of their metanarrative. It was only when he sat at a table with them and together they shared the ritual of a meal together that '... their eyes were opened ...' (Luke 24 v 31) to the reality of what had taken place. Often it is during or after a welcoming or funeral ritual that parents begin to realise what has happened to them and their baby. Their interpreting and reinterpreting of events may continue throughout their lifetime.

A welcoming or funeral ritual encapsulates, retells or rather re-interprets, a baby's and his or her family's story in light of a shared grand narrative or, as often in our postmodern world, a number of narratives (including those of the chaplain as well as the parents). Jesus told stories, during his ministry, which helped and still helps people to reinterpret their stories in light of his. Chaplains therefore, as they co-construct and then perform rituals are not just listening to and interpreting stories they are also in the business of re-interpreting and re-framing stories, in a manner that takes into account the worldview of the parents and the chaplain.

3. Content and Form of Welcoming and Funeral Rituals

A basic principle in creating appropriate rituals for babies near to or after death is to personalise the ritual – for the ritual essentially belongs to the baby and his or her family. This can done by using the everyday names of the family involved, especially the baby's, and by weaving details of the baby's and family's story into the ritual. During Lily's funeral, Janice and Michael's hopes and dreams for Lily were mentioned and the feeling her expected arrival evoked in them. Had she been a more mature and well-formed baby I would have talked about her movements in her mother's tummy, her parents' pet names for her, what and who she looked like after birth and how her parents felt about seeing her and holding her (if they had). All of this not only helps to personalise the rite but also grounds it in the reality of the family's story – the baby was and is a real part of their narrative. It would not normally be appropriate to describe these elements of the family's story at length during a welcoming ceremony but certainly commenting on the looks of the baby or the pride of his or her parents may feel right, for example, in the prayer said after Callum's blessing we thanked God for ... 'the wonder and beauty of this handsome wee boy'.

The language used is – '... not the language of the church, but the language of the everyday.'[53] The language, metaphors and images which are incorporated into such rituals have to be relevant, comprehensible and personal. For John and Hazel it was entirely appropriate to use church language and the gestures and images of our shared tradition in the short service of blessing. When working with parents who do not share the same metanarrative as the chaplain, as with Michael and Janice, this is not so. By using the above model of co-construction of ritual it means that the chaplain is open to discovering new ways of describing or imagining God, heaven and the mysteries of life, death and suffering. Some parents will have developed their own metaphors, symbols, images and language which capture something of the depth, tragedy and otherness of their experience, for example, Janice's metaphor of Lily's inherent yet unfulfilled beauty and potential pictured in an unopened flower.

Careful and creative attention to the use of symbols and gestures within welcoming and funeral rituals is something chaplains should give careful prior thought to whilst at the same time being prepared to let them occur, if they intuitively happen on the part of the parents or the chaplain, in the present moment. Symbolic actions and gestures may represent and articulate something far beyond the bounds of language. John and Hazel together holding their baby between them as he was blessed spoke volumes about what he meant to them both, his place in their family as well as their approach to parenting and their feelings for each other. I also felt it was very important for me to touch Callum as I blessed him – symbolising the intimacy of God's touch and care for him. Michael and Janice scattering lily petals taken from the funeral service where there were no physical remains, into the wind represented something of their need to let go of Lily into the mystery which follows death. At the beginning of the ritual a candle was lit – a symbol of stillness and peace and of hope. For other parents carrying their baby's coffin into the crematorium or lowering their baby down into his or her grave can be profoundly symbolic of their need to parent and care for their child to the very last.

The most common way parents, relatives and other people are involved in rituals, especially funerals, is the arranging or bringing of flowers. For parents, like Michael and Janice, the choosing and arranging of flowers is a symbolic act of love and care and in their situation the flowers quite literally represented their daughter. June, by bringing a small posy of flowers into the delivery room where Callum and his parents were, especially for his blessing, was not only an expression of sympathy but a mark of reverence and respect of what was going to happen. June, though not religious, recognised something of importance, something other than usually happened in that

[53] G. Nelson, 'Hospitals' in G. Legood (ed.), *Chaplaincy: the Church's Sector Ministry*. Cassells 1999, 75–82, p. 81.

delivery room, was going to take place and she in some way wanted to mark it.

In the face of what is an indescribable loss, not only are symbols and gestures important to enable the acknowledgement, articulation and ownership of feelings and relationships, but silence is too. Silence as the chaplain hears the parent's story but silence also as part of the ritual moment. Silence as a mark of respect but silence also as a realisation of the limitation of words. Silence which can be filled by the memories and dreams, hopes and fears, guilt and regrets, wrestling and reasoning of those present. Silence in which people can be and express themselves as they are.

Music too can articulate, in a similar way to silence, that which eludes the spoken word during a funeral service. Music chosen specially for the ritual not only personalises the service but grounds it in the family's story and serves as a very powerful reminder of the reality of the funeral and thus the baby. The piece of music chosen by Michael and Janice was not only familiar and liked by them both but had been played a lot in the family home during their pregnancy. They felt it appropriate that this piece became, for them, Lily's music.

The words of songs played at the crematorium or graveside also are of great potential significance to parents, as in a very real way the lyrics articulate for parents how they feel about their baby and his or her death. For many young parents in this postmodern age, pop songs have replaced hymns as a means of communicating their feelings, their questions and their beliefs and worldview.

It is not just in the process of co-construction that parents want to be involved. Many, to a greater or lesser degree, want to be actively involved in the welcoming or funeral ritual itself. This may be planned or purely spontaneous, as happened during Callum's welcoming service when his parents not only named him but joined in the blessing and a biblical reading. As well as being involved in symbolic acts and gestures, some parents or older siblings may wish to write something of their own to be read though few, like Michael, wish to speak during the rite. Staff too, or other members of the family, may read or be involved in various ways – playing music, singing, bringing drawings or stories specially created for their baby brother or sister – or show their love and respect in gestures outlined above (such as bringing flowers or lowering the coffin into the grave). All who are present at such a ritual moment are actively involved – no-one is a passive observer – and are drawn into the story of the baby and his or her family that has evolved and is evolving.

Often parents find the words and insights of others who have known pain and loss to be comforting and helpful. Pieces of prose and poetry already known to parents or offered by the chaplain may often be read during a funeral.

Resources from the chaplain's own metanarrative can help chaplains and parents, though not necessarily sharing that grand narrative, to articulate relevant thoughts and feelings within ritual moments in the face of the mystery of life and death coming together. From personal experience, many parents who would not consider themselves religious in any way before experiencing the death of their baby do however choose readings from the Bible, a prayer or the words of hymns to be read at their baby's funeral when given the opportunity to choose material from a variety of sources in their own time and space (it is given by offering an anthology of resources, described above, with the explanation that it contains religious and non-religious material and that they are free to choose anything that they feel is appropriate for them and their baby).

The significance of biblical lament has already been mentioned as being of considerable help in creating authentic rituals in such situations but the chaplain may feel other areas of Scripture may be helpful to use not just during Christian rituals. This has to be sensitively done but the Bible provides a rich seam of literary material describing the pain and joy of human life and relationships, which have meaning for the believer and non-believer alike. For example, verses about the nature of love, from Paul's first letter to the church at Corinth were read during both Callum's blessing and Lily's funeral.

Liturgies created from within different denominational traditions will also inform the chaplain's story, approach and choice of content of any ritual performed but as Green puts it … 'they (such liturgies) should be used flexibly and imaginatively'.[54] Even when the parents do share the same metanarrative as the chaplain and thus share the same language and understanding of familiar symbols and metaphors, chaplains have to attend to the particularity and peculiarity of the uniqueness of each baby, each family and each ritual moment. No two welcoming or funeral rites are the same in content, context or co-construction.

Whatever the eventual content and form of the welcoming or funeral rite during the process of co-construction, parents need to be given appropriate information and options so they truly can, within the limitations of the particular context of the ritual and guided by the chaplain, make informed choices.

In summing up how chaplains should approach co-constructing the content and form of welcoming and funeral rituals for babies dying near birth, these principles suggested by Anderson and Foley for creating new rituals should be borne in mind –

- 'Let the story of the crisis or loss, change or transition, – the whole story – be heard.

[54] Green, *Only Connect*, p. 49.

- Allow a significant time for non-verbal symbols in this ritualising.
- Resist the compulsion to explain such action.
- Attend to the peculiarity of the moment.
- More is not always better; sometimes less is more.'[55]

Therefore, though a ritual moment has many elements to consider beforehand and to reflect on afterwards, invariably something which is short and simple with few words and includes meaningful gestures which attend to the moment, is most appropriate.

4. Context of the Ritual

The chaplain also has to be very aware of the emotional and physical context within which ritual moments will take place as they seek to co-construct ritual. As has been explored, for the ritual to be relevant and authentic the circumstances in which the ritual takes place have to inform its content.

Where the ritual takes place is also of great importance to the family's story. Welcoming rituals will most commonly occur in the immediacy of a neonatal unit, labour suite or in a room in a post-natal ward. Whilst these venues are by necessity geared primarily for the physical care of babies and their parents, they can and do become sacred spaces during ritual. It is the attitude and approach of those involved and those by necessity (in a neonatal unit) in the nearby vicinity, as well as the ritual moment itself which transforms the functional hospital space. More than this it is also the willingness of those present to be open and attentive to the moment. In the immediacy of the ritual parents and relatives will be distressed and vulnerable, their focus being primarily on their baby. How the chaplain, and other staff, are during the ritual and how the ritual is performed I suspect will influence how the physical context is perceived and remembered by families rather than the surroundings. June's bringing of flowers into the delivery room as well as her respect for and awe of the moment is an example of this. For those few minutes during which Callum was blessed, that ordinary, functional and rather drab delivery room, for parents, chaplain and midwife, became sacred. It was a time and place in which grace was tangibly shared.

Where funeral rituals take place will be greatly informed by family tradition, the beliefs of the couple and their degree of need to have a place to return to associated with their baby and perhaps to continue to parent their baby. Thus the decision whether to cremate or bury their baby, and where, has great importance for the immediate and the long-term future of the family's story. It is important that the place where the funeral is held feels appropriate for the parents precisely

[55] Anderson and Foley, *Mighty Stories*, p. 130.

because they will remember for the rest of their days the context in which this ritual occurs and may or may not choose to visit it in the future. Thus this choice needs to be an informed one and chaplains should encourage parents to think about it carefully and indeed to visit the proposed place for the funeral if they have not already done so. Michael and Janice, though not Christian, wanted to have Lily's funeral service in a place which was other, peaceful and had associations for them with their baby (she was born in the hospital).

Many parents choose to have their baby buried in a cemetery, or rather in a part of a cemetery specifically designated for babies, in order that their baby can be laid to rest in the company of other babies. This may be something they wish specifically mentioned during the funeral. Those attending a burial in such a place cannot help but be moved by the context in which the ritual is taking place. Many parents find immense comfort in having a place to return to which is associated with their baby and some spend a great deal of time and effort tending the grave. Thus, they are still able, in some way, to parent their child.

5. Ritual Integrity

I have explored the importance of the need for welcoming and funeral rituals for babies to have an integrity which enables their content and form to be appropriate and relevant to the context in which they take place and to the family's and chaplain's stories. I have also discussed the need for the chaplain to be open and honest about the metanarrative that informs the chaplain as well as being up front about his or her approach to working with parents whose frame of reference is different from the chaplain's.

However in addition, rituals that are meaningful and have integrity – what Ramshaw calls 'ritual honesty' – Anderson and Foley feel 'the public, private and official meanings (of the ritual) converge.'[56,57] That is the shared meaning of the act as it is carried out, the original meaning of the act (when it was first performed or shared) and the meaning of the ritual for any individual involved are similar. This does not always happen as individuals have different interpretations and perceptions not only of the ritual but of the narrative out of which the need for a rite to take place arose. Moreover, in acute situations, as has been discussed, it is not always possible, nor indeed pastorally appropriate to begin to explore parents' understanding of rituals which they request. However, it is important for the chaplain to have considered the private and official meanings of the particular ritual prior to being involved in situations where co-construction is possible as well as gently exploring the private meanings of the parents and sharing the

[56] Ramshaw, *Ritual and Pastoral Care*, p. 56.
[57] Anderson and Foley, *Mighty Stories*, p. 30.

official meaning of the ritual with them during this process. Further-more, once the ritual has been performed the chaplain may gain much by reflecting on his impression of the shared corporate meaning of the ritual moment, as well as what it meant to individuals involved. This not only informs his future practice but potentially deepens his theo-logical understanding.

6. Ontological significance of Chaplain

To what extent is what is said and done during a ritual moment impor-tant and meaningful to parents or how it is said and done? The sharing of God's love and compassion in traumatic circumstances will to a greater or lesser degree depend not on the ritual itself but how the chaplain is in such circumstances and how the chaplain relates to the baby, his or her parents and the staff he or she is working with. The chaplain's ability to be natural and allow others to be themselves during the process of co-construction and the ritual itself I am sure has a great bearing on how the ritual moment is experienced and perceived.

At the heart of Jesus' pastoral ministry was his ability to be himself and express how he felt. We are reminded of his humanity and vulner-ability as he wept with Mary over the death of her brother Lazarus (John 11 v35).

Chaplains also have to be aware of what they may represent to fami-lies and staff as they seek to offer support around the time of death of a baby and thus why parents ask them to perform welcoming and funeral rituals. Chaplains may potentially represent many things to parents and thus may carry many roles in the process of co-construc-tion and performing rituals. Chaplains are certainly perceived as people who are used to and skilled in, or are simply associated with, handling or wrestling with ... 'the meaning of life itself and its ulti-mate significance'.[58] Carr then helpfully goes on to say:

> 'The minister's role is thus assigned to him, and is one which on the whole he does not determine and which cannot be aligned to other "experts".'[59]

Within the hospital context other healthcare staff who work with bereaved parents also help shape the chaplain's role with their own expectations and experience of clergy. Some of what chaplains may represent to parents and staff may include:

a. Embodying Christ or at least being a representative of the Church or the particular tradition to which the parents belong. This was certainly the case for John and Hazel.

[58] Carr, *Brief Encounters*, p. 14.
[59] Carr, *Brief Encounters*, p. 14.

b. Being a 'Man or Woman of God' with the perceived ability to find the right words at the appropriate moment. This was certainly what Michael and Janice saw me as even though we did not share the same metanarrative. This priestly function of the chaplain is not just about being a wordsmith, it is about feeling with and understanding, as far as it is possible, the parent's situation and needs. It is about holding pain, experiencing it and then and only then, articulating the shared lament and our human and the heavenly response. Furthermore people do associate a chaplain or clergyperson's role with ritual. This is part of our perceived priestly function – not only can we say the right words but we are entrusted with being able to do the right thing the right way. Ramshaw puts it well:

> 'At times when people need a sense of order or meaning, a handle on ambivalence or an approach to mystery, it may be the ritual authority of the pastor that draws them, even if they do not consciously define their need as having any ritual dimension.'[60]

In addition she also makes the point that simply the presence of a chaplain or 'holy person' may '"bless" the event with his symbolic presence.'[61]

c. Chaplains may be one of very few people (especially in the case of intra-uterine death), including the midwife who delivers the dead baby, who meets the baby and hears the baby's and family's story. In this way the chaplain may represent humanity or wider society both during the process of co-construction and during the ritual itself (especially if the parents choose not to have others present). It was highly significant for Michael and Janice that someone else shared in their baby's funeral and had heard and become part of their story. This not only was a release for them to share their fears, anxieties and hurt with someone else and have these feelings heard and validated, but my presence symbolised society acknowledging the reality of their baby and the significance of their loss.

d. A reminder of the possibility of transcendence in the present situation – that there is hope in a time of pain and bereavement and that there may be something more, something else after life rather than just death being the end. Most people whether Christian or not, will have difficulty in verbalising what this might be but a chaplain's presence may represent mystery and otherness in the midst of the harsh reality of death.

[60] Ramshaw, *Ritual and Pastoral Care*, p. 57.
[61] Ramshaw, *Ritual and Pastoral Care*, p. 73.

36

e. On the other hand chaplains working within maternity units are associated paradoxically not just with what may be beyond death but with death itself. Chaplains are not just a reminder to parents of the mortality of their baby but are a reminder to parents and staff alike of the fragility and mortality of human life itself. Therefore chaplains can be professionals who are both needed and wanted, but also avoided and shunned.

f. In our postmodern world the chaplain may be seen to represent an out-dated and irrelevant institution which has no real significance to some bereaved parents. In fact for some parents the term chaplain may be totally meaningless. They will not know what a chaplain is and does – or has it something to do with a moustached man with a funny walk who appeared in silent films?

7. Role of Chaplain

I would like to suggest that the role of the chaplain while co-constructing ritual with parents has different nuances from the role of the chaplain while actually performing ritual.

As has been explored, the role of the chaplain while helping parents to construct a ritual appropriate for their baby and their story involves the chaplain listening, interpreting, sharing information, guiding and helping families to bring together the important elements of a ritual. The chaplain is empowering people who by circumstances have lost control of events in their lives and enabling them, with guidance, to shape and mould a ritual that evolves out of their story and its engagement with the chaplain's. The metanarrative to which the chaplain belongs and the theological outworking of it may or may not be verbalised to any great extent but nevertheless it implicitly informs his or her personhood and practice. It is those who request welcoming and funeral rituals who control (if they feel able) the process and it is the chaplain's role to manage it (see Carr for a fuller account of clergy managing but not controlling the bereaved).[62] However during the ritual itself the chaplain also takes on other roles, mainly of a theatrical nature. Walters makes the following comment about the role of the celebrant during a funeral:

> 'At a time of grief, even if people do not want a priest, they do need someone to orchestrate proceedings, to act as master or mistress of ceremonies who can enable those present to regress safely into their emotions and safely out again.'[63]

During the ritual the chaplain has a dual role. He or she takes responsibility for stage-managing the practicalities of the welcoming or funeral rite – ensuring the different parts of the ritual come together as one

[62] Carr, *Brief Encounters.*
[63] Walter, *Funerals and How to Improve Them*, p. 225.

and the different players involved (staff or undertakers and family members) are sure of their roles, their lines (where applicable) and their timing. Michael and Janice very much looked to me to ensure Lily's funeral flowed and Michael took his cue from me when to speak. However as well as holding the ritual together and directing its content, most commonly the chaplain is also the main performer – acting and articulating on a formalised stage where the divine and the family's story, explicitly or implicitly, meet.

8. Significance of Co-constructing Ritual for Chaplaincy and the Church

Jacobs sums up the importance of listening for the chaplain whilst co-constructing ritual with bereaved parents:

> '... listening is the precursor to understanding, to interpreting, and to help the teller interpret (albeit in the simplest terms) the significance of the story now, in this place, at this time, and with this listener. There may be times when listening to the narrative in this way will go beyond pastoral care, to the making of a personal theology.'[64]

Such involvement in the co-construction of ritual with bereaved parents therefore grants chaplains opportunities for our stories to be touched and challenged by such engagement if we are open to the stories of the parents we engage with. By working closely with those who are experiencing life and death coming together to co-create appropriate rituals for them and their baby and by then reflecting on such encounters, chaplains are not only learning how to improve our care for such families. We are learning more about ourselves as human beings. As Wilson puts it in his aptly named book *The Hospital – A Place of Truth*:

> 'The hospital is a place where we have to face ourselves as we are: it is therefore a place of potentially liberating insights.'[65]

This is as true for members of staff as it is for patients and their loved ones. If our experience of co-construction has transformed our personal story then this alters the way we engage with the grand narrative to which we belong.

Not only do chaplains have the opportunity to wrestle with theology and theodicy by involvement in co-construction but also to learn a new language and new metaphors which convey something of

---

[64] M. Jacobs, 'The Use of Story in Pastoral Care (Part One: Hearing Stories)', *Contact* 95, 1988, 14–21, p. 21.
[65] M. Wilson, *The Hospital – A Place of Truth*. University of Birmingham 1971, p. 145.

the mysteries of life, death and suffering as well images of God and an afterlife. In our postmodern era, church language and ancient biblical images no longer are part of the majority of peoples' everyday lives. Parents struggling to make sense of the death of their baby use a variety of sources which are part of their own everyday experience to articulate their ideas and beliefs. In hearing, using and taking seriously such insights and word-pictures chaplains have the opportunity not just to utilise these as resources for individual rituals, but as resources for our own personal spiritual development and the deepening of the Church's understanding of postmodern life as well as how people in this era relate to suffering, death and God.

This model of co-constructing ritual also enables chaplains to develop their own theological and psychological understanding of what ritual itself is about, especially welcoming and funeral rituals for babies. In engaging with parents and reflecting on what parents bring to and invest in ritual moments, chaplains can benefit not just by becoming more sensitive to and aware of relevant issues, but also by reflecting on and gaining insight from what it is that chaplain, families and staff are actually sharing together during ritual. This is an ongoing process, as each ritual moment is unique.

The Church therefore, in the form of the chaplain, has the opportunity to grow and learn, to hear and understand, to experience and to interpret through working with those who seek ritual marking of what is a time of major trauma and transition in their family's story.

Availability of back numbers of *Contact*

Past issues of the Journal are available post free at £4.00 each. Those marked with an asterisk are available in photocopied form at £4.00 (post free). Orders should be sent with money to the Business Manager Mr John Norman, 'Newhaven', Junction Road, Lightwater, Surrey GU18 5TQ. Cheques payable to *Contact Pastoral Trust*.

Contact Pastoral Monographs

Contact Pastoral Monographs are published annually in association with *Contact: The Interdisciplinary Journal of Pastoral Studies.*

Contact is sponsored by the Clinical Theology Association, The Association for Pastoral and Spiritual Care and Counselling of the British Association of Counselling, the Westminster Pastoral Foundation, the College of Health Care Chaplains, and the British and Irish Association for Practical Theology.

Details of subscriptions are available from the Business Manager, *Contact*, Mr John Norman, 'Newhaven', Junction Road, Lightwater, Surrey GU18 5TQ, who can also supply further copies of this and previous monographs.

1   **Ethics and new reproductive technologies: on listening to feminism** (1991)

Anthony Dyson

2   **The new age and pastoral theology: towards the resurgence of the sacred** (1992)

Michael S Northcott

3   **Men, masculinity and pastoral care** (1993)

Mark Pryce

4   **A vision of pastoral theology** (1994)

Stephen Pattison with James Woodward

5   **Embracing the paradox: pastoral care with dying and bereaved people** (1995)

Margaret Lloyd

6   **A needle-quivering poise: between prayer and practice in the counselling relationship** (1996)

Jessica Rose

7   **The pastoral counselling relationship: a touching place?** (1997)

Margaret Lyall

8   **Telling tales: the narrative dimension of pastoral care and counselling** (1998)

Gordon Lynch and David Willows

9   **Building a church for strangers** (1999)

John Swinton

Three Dimensions of Spiritual Care in an Acute Hospital Setting

Ewan Kelly

Acute Hospital Context

Acute hospitals at the beginning of the twenty-first century are large, busy, high-tech and stressful places to be admitted into, to visit or to work in. Medical knowledge and technology has developed at a great pace in the past two or three decades – complex investigative and surgical procedures are now commonplace. Life can now be sustained and supported in intensive care and neo-natal units where in the past it would have ended. Expectations of the general public regarding health care provision have increased greatly, only to be matched by the pressure to run a modern, effective and caring service within tight financial constraints. Ethical decisions of great complexity with significant implications for patients, their loved ones and staff are made on a daily basis. Acute hospitals are places of ever increasing movement and change – patients stay for a shorter time and patient turnover is greater than ever before.

Acute hospitals are places where the best and worst of human experience are encountered. They are places of hope and healing, places where new discoveries are made and new beginnings born. However, they are also places of sudden death and bereavement, places where layers of loss are lived through and the limitations of humanity and medicine all too starkly confront us.

Care in such an anxiety-provoking environment seeks to be holistic, involving a whole range of health care professionals working together to respond to the physical, psychological, social, cultural and spiritual needs of a patient.

Three Dimensions of Spiritual Care

I. Spiritual Care as Being Present

'Then they (Job's friends) sat on the ground with him for seven days and seven nights without saying a word, because they saw how much he was suffering.' (*Job* 2:13)

When Job's friends were willing in the face of his great suffering to be with him and say nothing – not offering him advice, their point of view or their worldview, not judging him or quizzing him about his feelings – at this time they truly were his comforters.

'Being There,' the title of Peter Speck's (1988) much read book exploring the spiritual dimension of people in sickness and in health, hints at what much of spiritual care is about – being present with others in times of distress, if they want someone with them. However, simply to equate spiritual care with 'being there' without unpacking what this may mean to patient or carer is to scratch the surface of something potentially very profound.

For the purposes of this discussion I will equate 'presence' with a quality of 'attentiveness to the present moment'.

After some qualitative research into what she terms as the 'Ministry of Presence' by hospital chaplains in Philadelphia, Janet Stokes (1999. 198) wrote:

> 'Ministry of presence is clearly defined by patients more in the sense of accompanying the patient in distress than passing the time of day.'

Being attentive to the present moment with someone who is hurting means having the motivation and desire to get involved, to be exposed to whatever the patient is going through and reflecting on. It is more than making a social call. It is taking a risk. It is taking a step into the unknown and being prepared to deal with that unknown, moment by moment.

To be really attentive to the present moment means to cast aside assumptions about the other person – how an individual may be feeling in, or dealing with, their particular situation. It means to begin with where person is at that particular time on their journey through life. It means being prepared to accept the other as he or she is at that moment – to create a safe place in which patients can truly be themselves and express themselves as they need to. Likewise, it means the carers truly being themselves too, being authentic, moment by moment during the encounter. For the greatest asset we have as carers is ourselves - our humanity and our willingness to be vulnerable.

Henri Nouwen[1] puts it this way –

> 'When we honestly ask ourselves which persons in our lives mean the most to us, we often find it is those who instead of giving advice, solutions or cures, have chosen instead to share our pain. The friend who can be silent with us in an hour of grief, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness is the friend that cures.'

When crisis or trauma makes a huge tear in an individual's tapestry or life story there is nothing a carer can do or say to take away the pain or to fix the tear – all we can do is offer ourselves to be with the individual, for a time, as they experience and live through the pain and confusion of loss or bereavement. Cassidy (1988) uses a series of sketches in her book *Sharing the Darkness* to illustrate how the professional tools of a doctor (her diagnostic instruments and competence to use them), a priest (the sacraments) and finally the counselling skills of a health care professional become useless in certain situations of great pain and suffering. In the final illustration the patient and the health care professional are depicted as both naked – stripped of all their resources. They are both helpless and hurting.

As professional carers and as human beings that is so very hard because our natural inclination is to want to help make things better – to try to fix the situation. It can be very difficult for a carer to stay, to be present,

in such situations if needed. And yet in such moments where a health care worker is present with a patient, sharing for a while their pain and helplessness, in that touching point of one human story with another is affirmation that the patient's pain and feelings are valid and appropriate. There is also the recognition that they as an individual have worth. They are important. They matter. Jean Vanier[2] eloquently .. describes the therapeutic value of spiritual care as being present :

'Through a caring committed presence people will discover
That they are allowed to be themselves:
That they are loved and so are lovable.
That they have gifts, and their lives have meaning
That they can grow and do beautiful things......'.

In the immediacy of the moment, in a time of distress, very few people find meaning in their suffering but in the following months and years people may be able to pick up the threads of their lives again to weave a new pattern in their tapestry. However part of their story now is the loss or bereavement which was lived through and the tear experienced becomes incorporated into the tapestry that was, is and will be their life story.

The relationship which we have described between patient or relative and carer is one of mutuality, of sharing something awful, of both feeling helpless and confused and both, at times, desperately wanting to run away from the situation. In such situations when care and compassion and love are shared as well as distress, paradoxically, moments of transcendence can also be experienced - moments where something greater than the current trauma is experienced in the personhood, in the very being of the other person (patient or carer), which give hope and strength and courage. Lyall (2001. 140) describes such glimpses of transcendence in this way :

'..from the depths of a pastoral relationship which manifests availability without imposition there often emerges a Word which transcends words. There is a sense in which the pastoral

relationship is both parabolic, pointing beyond itself to a deeper grace, and poetic, evoking within the imagination images of transcendence.'

When a Chaplain is the carer present

Spiritual care is a collaborative effort, potentially involving relatives, friends as well as healthcare professionals from a variety of disciplines. In the end it is up to the patient or their loved one, the person who has the spiritual need, to choose whom (if anyone) they want present with them . If it is a chaplain who waits with them in their time of distress as well as hopefully providing a sensitive human presence, such a person being there may be important to the individual in other ways.

a) Chaplain as Representative of the Christian Story

For some patients it may be important to have a chaplain present with them in a time of distress because the chaplain may represent something of the Christian narrative to the individual or perhaps, more accurately, something of the patient's interpretation of the Christian narrative. The chaplain may explicitly represent the love, care, forgiveness, compassion and quite literally the presence of Christ in difficult situations for some people. It is not what the chaplain does or says that matters but by being present Christ's love is incarnate. This is not to say doctors, nurses and other healthcare workers do not embody these characteristics for patients and their families also (whether the healthcare workers believe they do is another matter). However for some patients, the very presence of someone who explicitly, by their job title and their training, may represent key elements of their faith and belief system is comforting and strengthening. In this respect the chaplain may 'exercise all the authority of priesthood' (Autton 1968. 28) not just in the saying of prayers and the sharing of the sacraments but also by being present.

b) Chaplain as Representative of God

For other individuals for whom the Christian story is not part of their own individual narrative, the chaplain may still be seen as someone who represents God, a greater being or a higher power. Consequently, some people in times of stress would choose not to have a chaplain with them as they have no such belief or are wrestling with the issue of why, if there is a God, God could let this happen to them or to their loved one? Feelings about God are often projected on to chaplains at such times and may be a decisive factor regarding the patient's wishes for a chaplain to be present or not. For some people it may be cathartic to express to a chaplain their anger about God and about their helplessness in their current situation, i.e. for the chaplain's presence to enable such expression.

c) Chaplain as representative of 'things spiritual or of another world'

Chaplains may be seen by people with or without a particular system of beliefs as individuals who have reflected on life and death, the meaning of suffering and helplessness. This paradoxically can mean the chaplain is both wanted and shunned as he or she can be seen as someone who represents hope in the face of or after death but also, as Carr (1985. 107) puts it, 'he (the clergyman) may also become the purveyor of death, the death-man.'

Chaplains may be viewed as people who are associated with 'other worldly things' or with prayer and meditation. Indeed, for some patients it may be important that they perceive chaplains to have had a theological, philosophical and spiritual training. Thus some individuals may more readily explore such issues in the presence of a chaplain rather than another healthcare professional. Willis (2000. 393) puts it this way –

'They (patients) want someone willing to explore with them ultimate issues. They expect us to be in awe of and conversant about the *numinous,* about what Rudolph Otto termed *mysterium tremendum et*

fascinans, "the tremendous and fascinating mystery". They assume we believe that what is seen is not all there is.'

d) Chaplain as a 'neutral' presence

Patients may choose a chaplain to be with them simply because they perceive a chaplain to be neutral – someone who has nothing to do with their medical or nursing care or the decision-making about the care of their loved one. Chaplains are not part of their family or circle of friends and the chances are that the patient concerned will never see the chaplain again in their life. This may enable the patient to talk to someone about issues which otherwise would remain unspoken.

e) Chaplain as 'trusted' presence

For many individuals chaplains represent someone who can be trusted, someone who will hold confidences about sensitive issues - as one patient put it, 'like talking to a priest in a confession box.'

f) Chaplain as 'unhurried' presence

Many patients feel very guilty about taking up the time of nurses, doctors, physiotherapists and other healthcare workers whose jobs involve physical and other aspects of care, as well as spiritual support. Chaplains are generally perceived to have more time to offer to individuals as they are not offering physical care. Chaplains pop in and out of wards and units. They are not seen moving between patients, doing many practical things, responding to numerous requests – often at the same time – as nurses can be. Chaplains are not perceived, on the whole by most patients, to be as busy as other healthcare professionals. Having someone present with you who, you feel, does not need always to be moving on, doing other things or attending to someone's physical needs can be important. Individual nurses and doctors may not project this message by their persona or approach but their uniform or perceived role may be associated with the immediate physical needs of patients, being busy and overstretched.

II. Spiritual Care as Listening

Since ancient times there has been evidence that those who were '... troubled and distressed have yearned for an interested and concerned listener' (Jackson 1992. 1624). Jackson goes on to give examples from the Psalms of the Old Testament which '...make it clear that listening has been viewed by many as having the potential to ease a person's distress and suffering'.
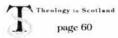
For example:

> 'Listen to my prayer, O Lord, and hear my cry for help!
> When I am in trouble, don't turn away from me!
> Listen to me....' (Psalm 102 :1&2)

Such listening is not passive but again requires a quality of attention to the present moment. It is active and reflective and involves '..entering into their (the client's) frame of reference, their view of the world and developing an empathetic relationship with them.' Burnard (1987. 379)

Such profound listening requires much concentration and energy. As Jackson (1992. 1628) indicates, '(T)he healer truly hearkens to the sufferer – that is to say, the effort is to hear and to know or understand.'

Spiritual care thus allows patients or their significant others to tell their story and means for carers that we have to respond in such a way as to show that, moment by moment, we not only are hearing what is said but we are reflecting back to the individual the very essence of that story and the feelings associated with it. This not only indicates to the teller that we understand what is being said and felt, but it also allows patients to hear their story again for themselves.

'Oor Wullie' is a well-known comic-strip character who appears in a Scottish Sunday newspaper every week. At the end of each adventure, at the end of each day, Wullie is to be found sitting on his bucket looking back at the day, reflecting on what has happened – the

highlights, the sad and happy events, the mistakes he has made, the trouble he has got into and how he got through it, the experiences that have left him puzzled and so on. In short Wullie is someone who takes stock of his life at regular intervals, while sitting on his bucket.

Much of what spiritual care is about is listening - enabling people to sit on their buckets and take stock; enabling them to tell their story and thus hear their story, perhaps for the first time; enabling them to remind themselves of the different facets of their life story; allowing them to talk about their regrets, to express their questions of themselves, of others and of God and to put themselves in touch with the ways they dealt with difficulty and distress in the past - what helped and what didn't. In this way individuals may discover or perhaps rediscover inner resources or coping mechanisms which may help them through their present circumstances.

Perhaps too, in the telling of their story and in their questioning and wrestling, they may find some sense of meaning in life and find hope for the future. However, as Burnard (1987. 381) describes it, one of the main challenges facing the healthcare professional (in this case Burnard is referring to nurses) in providing spiritual care is

> '….to listen, to accept, to explore and finally to offer no ready answers. This is clearly a difficult task but a rewarding one. In the end, persons who discover their own meaning and their own reason for believing in what they do will usually be the most satisfied. The nurse's (or any other healthcare worker offering spiritual care) task is not to get in the way of that process taking place. But equally and almost paradoxically, it is the nurse's task to get involved with the dispirited person. The balance between standing back and being immersed is a difficult one to achieve. It is also, a very human and important one.'

Burnard reinforces again the importance of the need for quality of attention to the present moment when offering spiritual care – listening to oneself, as a carer, as well as listening to the patient – enabling the carer to walk the fine line between 'standing back and being immersed'.

Enabling individuals to tell their stories in times of stress or confusion may be an opportunity for them to re-frame or re-interpret their story in a manner which may help them to deal with their situation. Birch and Miller (2000. 193) suggest :

'The invitation to re-tell past experiences can (then) become an opportunity for (re)constructing narratives in different ways, evolving different perspectives on the past, leading to different understandings of the present, with implications for the future.'

Attentive listening also involves honesty and integrity on the part of the carer: honesty to say that we don't understand or don't follow the patient's story and honesty to say that we don't know the answers to questions when we don't. This may involve questions about God's existence or theodicy or why certain things have happened the way they have. In most cases when patients are verbalising such questions they are not looking for answers but the opportunity to explore them and to vent their thoughts and feelings.

III. Spiritual Care as Being Absent

In an acute hospital, many encounters which a chaplain has with distressed patients, relatives or staff involve a single meeting or a small number of fleeting visits. After being present, leaving is not just an obvious necessity but it often occurs more quickly than either patient or carer anticipates. For example, X-rays and pre-meds have to be taken and surgery has to be performed. Hospitals are busy, bustling places and patients become weary during visits. Patients go home, are transferred or die. Learning to leave and to let go is as much part of spiritual care in hospitals and as being present.

Being present with another can be important - it can bring comfort and encouragement, affirmation and hope - but there is always a time when we, as carers, have to leave because of the patient's needs and, at times, because of our needs. Leaving individuals, letting go, can be difficult – especially if they are distressed, or someone we have got to

know well or someone whose company we enjoy. If as chaplains, we believe that we embody the love and care of Christ, perhaps Jesus' words to his friends – 'If I do not go, the helper will not come to you.' (John 16:7) – may help us to let go or hand over the individual into God's care.

For when we leave, the helper, as Nouwen (1977) suggests, fills the space which we have left. We do not leave those we have been with alone – when we withdraw, the Holy Spirit is present.

None of us is the Almighty. Our presence with others may be a reminder of God and his love and concern for individuals and families but we are not the ever constant presence of the God of Jacob (Psalm 46). For various reasons, patients and their significant others may want time on their own when they are in hospital. Indeed they may need time on their own or with their loved ones - time in which to think, to reflect, to take stock and to rest and recuperate. However, when we withdraw, we can be assured there is another who is always there, always present.

R S Thomas (1993. 457), the Church of Wales priest in a rural parish on the Atlantic coast, captures beautifully in his poem 'The Other', the constant wakeful presence of God, day and night. He describes lying in bed at night listening to the waves breaking on the shore

'…..And the thought comes
Of that other being who is awake too,
Letting our prayers break on him
Not like this for a few hours,
But for days, years, for eternity.'

When leaving, we can let those we care for go into the care, into the presence of that other being who is always awake and always attentive.

Leaving, letting go is also essential for chaplains so that we can come back – to the same or the next person, refreshed and restored, ready to

be present again in the next moment with the whole of our being. So there needs to be a balance for all who care for others between being present and being absent— a balance of being with and being away from.

There is a story told about Antony, one of the desert fathers, a wise and insightful monk who lived between two and three hundred years after the death of Christ.

'One day Antony was relaxing with some friends outside his hut when a hunter came by. The hunter was surprised to see Antony relaxing, and rebuffed him for taking it easy. It was not his idea of what a holy man should be doing. Antony replied "Bend your bow and shoot an arrow", and the hunter did so. "Bend it again and shoot another arrow", said Antony. The hunter did so, again and again. The hunter finally said, "Father Antony, if I keep my bow always stretched, it will break." "So it is with the monk," replied Antony, "if we push ourselves beyond measure, we will break. It is right from time to time to relax our efforts." (Au and Cannon 1995. 111).'

In conclusion, spiritual care in an acute hospital involves a willingness to be attentive to oneself and the other in the present moment. In that moment and in the relationship which is established are potentially glimpses of something more which transcends any situation and may offer hope to patient, chaplain or both. However, being present, listening actively and sharing pain and helplessness is costly. Letting go and leaving those we seek to support in the company '(O)f that other being who is awake too' is also an important (though often understated) part of spiritual care, and essential for the well-being of patient and chaplain.

Bibliography

Autton, N., *Pastoral Care in Hospitals*, London: SPCK, 1968.

Au, W. and Cannon, N., *Urgings of the Heart*, New York: Paulist Press, 1995.

Birch, M. and Miller, T., "Inviting Intimacy: the interview as therapeutic encounter" in *International Journal of Social Research Methodology*, 2000, Vol. 3, No. 3, 189-202.

Burnard, P., "Spiritual Distress and the nursing response" in *Journal of Advanced Nursing*, 1987, 12, 377-82.

Carr, W., *Brief Encounters*, London: SPCK, 1985.

Cassidy, S., *Sharing the Darkness*, London: Darton, Longman & Todd, 1988.

Jackson, S.W., "The listening Healer in the History of Psychology" in *American Journal of Psychiatry*, 1992, Vol 149, No.12. 1623-1631.

Lyall, D., *Integrity of Pastoral Care*, London: SPCK, 2001.

Nouwen, H., *Out of Solitude*, London: Harper Collins, 1975 cited by Salt, S. in "Towards a definition of Suffering" in *European Journal of Palliative Care*, 1997, Vol 4, No.2. 58-60.

Nouwen, H., *The Living Reminder*, New York: Seabury Press, 1977.

Speck, P., *Being There*, London: SPCK, 1988.

Stokes, J., "Ministry of Presence and Presence of the Spirit in Pastoral Visitation," in *Journal of Pastoral Care*, 1999, Vol 53, No2, 191-99.

Stoter, D.J., *Spiritual Aspects of Healthcare*, London: Mosby, 1995.

Thomas, R.S., *Collected Poems 1945-1990*, London: Phoenix, 1993.

Willis, R.W., "To What Shall We Liken the Hospital Chaplain" in *Journal of Pastoral Care*, 1999, Vol 53, No.4. 391-94.

[1] Cited by Salt (1997. 60)

[2] Cited by Stoter (1995. 23)

PREPARATION FOR PROVIDING SPIRITUAL CARE

Ewan Kelly

Abstract: Spiritual care has become recognised as part of the holistic care offered collaboratively by health care professionals (HCPs), family and friends in hospitals and in the community to patients and their significant others. This article seeks to explore, from the perspective of a hospital chaplain working in an acute hospital setting, several issues which need to be considered by HCPs prior to offering spiritual care to others. These include HCPs having a degree of insight into their own personal story as well as questions about what they understand the nature of spirituality, spiritual need and the assessment of spiritual need to be. This article is based on the premise that in offering spiritual care to others we have to develop an ongoing awareness of who we are and what our needs are, as well as the needs of the other.

Key words : awareness, moment, story, spirituality, spiritual need, assessment

The Spiritual Carer's Story

Those who offer spiritual care, be they a chaplain, nurse, physiotherapist or doctor, potentially will enter into relationships where highly personal information and feelings may be shared. There is potential for much good and much harm to come to both patient and carer. In order that during an encounter with a patient we as carers can separate out what are our own feelings or issues from those of the other, we have to be very aware of our own personal story. Issues arising for the carer, if noted and owned, can be shelved during the encounter and dealt with at another time. Unless we are aware that our own feelings and worldview may be touched or challenged by involvement in spiritual care then an encounter may well end up being more about our issues than the patients.

What are the significant elements - experiences, prejudices, wounds, losses, bereavements, skills obtained through training and individual needs – in the carer's story? What are the wider narratives which have touched us and have helped to shape our beliefs, values and worldview – our family, circle of friends and our religious and cultural background? What is it the healthcare professional (HCP) brings to an encounter at any particular moment? How aware are we of our own spirituality? What gives our lives meaning and purpose? What is our theological stance and /or philosophical outlook on life, death, suffering, the existence of God and the possi-

bility of life after death? What are buttons in our lives, at the present time, that when pressed may lead to distress and an inability to function as a carer?

How as a HCP am I feeling right at the moment of being with a patient or family? Up all night with a young child at home and desperately needing sleep tonight, had a bad day with administrative work and now developed a throbbing headache – is it appropriate that this chaplain goes to be with a family on the neonatal unit whose baby is critically ill? Can someone else go?

Spiritual care in the acute hospital setting is about responding to needs in the present moment - the patient's needs and us as carers, acknowledging our needs too. It is often also about disengaging from one moment with one patient , letting go of that moment and then preparing ourselves for the next moment with the next patient. Importantly, it is also about us as HCPs revisiting particular moments later, at a suitable time, to reflect by ourselves, with colleagues, a supervisor to unpack what that moment was about for the patient, for me as a human being (not just as a HCP) and how I felt we related to each other .

What is Spirituality?

The word spirit has its roots in the Latin word 'spiritus' and is associated with a force that gives animation or breathe to life. Heyse-Moore (1996, p300) considers the spirit to be the 'essence of life'. As well as something very deep within the human makeup, traditionally the word spiritual has also been associated with the transcendent, the sacred or the 'otherness' in life – different faith groups and cultures having varied perspectives and understandings of its complex nature. However in more recent times it has come to have a much broader meaning – life experience out with that which is considered religious is now thought to have the possibility of being spiritual. Grasping the meaning and concept of things spiritual in our modern pluralistic world is not easy and Bellamy (1998, p185) makes an important point when she says –

'The term spiritual, however, needs to remain elusive if it is not to betray its very identity; inherent to it is the concept of searching rather than finding.'

To be spiritual is to be human i.e. every human being has a spiritual dimension to his or her life (though individuals may not name it as such). In this post-modern world the majority of people are not affiliated to any particular religious tradition or faith group Equating things spiritual with things religious is to narrow and constrain the former.

The spiritual element in our lives is something, which can be described, in relational terms –
'..a capacity for self-transcendence that is expressed by expanding personal boundaries intrapersonally, interpersonally and transpersonally – inward, outward and upward. Transcendence can be found within or beyond self, depending upon one's religious or philosophical beliefs.' Reed (1998, p43)

Throughout our lives there is an ongoing deep-seated desire to understand ourselves, the world and those around us more fully, as well as what may be beyond the physical makeup of our environment. This driving force may become more immediate at certain times in our lives.

For example, in an acute hospital setting, many individuals become concerned with deep questions about their lives, suffering, death and the possibility of the existence of a greater being.

'Crisis situations, whether they be loss, illness or hospitalisation, bring one face to face with the ultimate issues of life – the limitations of one's humanness, the loss of personal and environmental control, and the meaning of pain and suffering in the overall purpose of life. The questions of why and when events occur raise the issue of a God who does or does not exist and is or is not involved with one's life.'
Stoll (1979, p1575)

However our spirituality is not just something, which comes into play as we seek to find meaning and purpose at significant or special times in our lives – good or bad.

'...if one reflects upon daily living it is often the mundane rituals such as going to work, doing the washing or walking the dog that bring meaning and purpose to everyday life.' McSherry (2000, p28).

Each of us weaves for ourselves a tapestry in life - made up of many different threads. These threads are the different aspects of our lives, which give meaning, shape and purpose to our existence - everything from enjoying a bath to watching rugby, special relationships we have, our beliefs and values to our membership of the church or a miner's welfare club. Each thread has its place and may seem insignificant or taken for granted in daily life but on admission to an acute hospital and being faced with issues which Stoll describes above may create a tear – large or small - in the person's tapestry, and the patient or relative has to begin to deal with threads that have been severed and may never be able to be repaired again.

A desire to make sense of life and significant events in life is a universal, shared experience and yet our own spirituality, whatever we understand it to be and its role in our lives, is a highly subjective thing. Simon Bailey (1996, p61), an Anglican priest, put it this way -

'What is spirituality? It is something to do with attempting to explore...taking the risk, setting out. Something to do with the capacity in us to make that beginning – the need the desire, the unrefusable urge....In the words of RS Thomas:

Enough we have been given wings

and a needle in the mind
to respond to his bleak north.

There are times even at the Pole
When he, too, pauses in his withdrawal
So that it is light there all night long."

This need, this desire, this *"needle in the mind"* is right at the very heart of us, deep at my mysterious centre and yet it's a very common, shared thing too.'

It is a risk to consider wrestling with spiritual issues , to be open to the *"needle in the mind"* and yet in acute hospitals many patients, relatives and staff are forced to do so by circumstance and their involvement with people they are caring for.
Woodward (1997), in his definition of the spiritual underlines the importance of this element in our human makeup. It is -

'..the essentially human, personal and interpersonal dimension which integrates and transcends the cultural, religious, psychological, social and emotional aspects of the person.'

The spiritual dimension in all of us holds together and is greater than all the other components of our makeup, including our sexuality (which Woodward omits). It is that element in us and beyond us that makes each one of us truly unique and gives us, at times, the ability to see beyond what is happening in the present moment.

What are Spiritual Needs?

Several chaplains – Speck (1988), Stoter (1995), Woodward (1997) and Cobb (1998), as well as writers from the nursing profession including – Stoll (1979), Highfield and Cason (1983), Bunard (1987), Narayanasamy (1991), Ross (1997) and McSherry (2000) have described various aspects of spiritual need and distress.

Most succinctly Bunard (1987, p377) describes spiritual distress as …

'..the result of total inability to invest life with meaning. It can be demotivating, painful and cause anguish to the sufferer.'

Narayanasamy (1991, p7-8) on the other hand gives a more comprehensive list of spiritual needs -

the need for meaning and purpose
the need for love and harmonious relationships
the need for forgiveness
the need for a source of hope and strength
the need for trust
the need for expression of personal beliefs and values
the need for spiritual practices, expressions of concept of God or Deity
the need for creativity

Central to all descriptions of spiritual need is a search to find meaning, reason and purpose in the individual's current circumstances. In the immediacy of acute hospitals – in the accident and emergency department, in intensive care, labour ward or in any acute ward, circumstances can change in a moment. As a working definition for use when considering the spiritual needs of a patient or their significant others I would propose the following –

Spiritual need is that aspect of an individual's personhood which seeks to make sense of and find meaning in, the present moment. Any such exploration is done in light of an individual's previous life experience and aspirations for the future and involves, potentially, consideration of any significant element of their unique life story.

Thus spiritual need is something dynamic – it can change from moment to moment as external circumstances and internal perceptions, thoughts and feelings, change – and is ongoing, especially during or after a crisis. As well as being multi-faceted, involving an individual reflecting on potentially any part of their own story, spiritual need is also multi-layered – the depth of the patient's need and their ability or motivation to explore such need can change very quickly in an acute hospital context. At what level individuals want to explore any spiritual need, at any moment in time, will depend on various factors –

- how they interpret their present circumstances
- the privacy of their surroundings
- how they relate to the HCP present with them at that moment i.e. how they interpret the HCP's story as revealed by their profession, their appearance, their manner, their spirituality etc.
- their physical and psychological state

- their personality and ability to articulate thoughts and feelings

Therefore in responding to these needs HCPs need to be sensitive to the cues that they are given by the individual, at that moment, in order to let that person begin their exploration at a depth they feel safe and comfortable with. The level of the patient's self disclosure may alter during the encounter or at a later time. For example, prior to visiting time a patient may mention to a HCP that they are getting a visit from a member of their family and talk about where the person lives and what they do for a living. However following the visit the same individual may want to explore some very personal issues relating to family relationships, prompted by the time spent with their visitor.

Spiritual need involves questioning and searching. Hence often it is difficult for a person to articulate precisely their spiritual needs to another in the present moment of a traumatic event. Their values and beliefs may be called into question or may provide a source of comfort and strength. In a moment of particular spiritual need an individual may well be reflecting on the past or contemplating the future in light of what is happening to them or their loved one in the present.

Assessment of Spiritual Need

Traditionally a patient's spiritual, or rather religious, needs were assessed on admission to hospital – the patient was asked their religious affiliation, if they wished their minister, priest or religious leader to be notified and if they wished the hospital chaplain to visit them – and by doing so assumed to be responded to adequately.

However as has been discussed, an individual's spiritual needs can change very quickly in an acute hospital environment, for example as a patient gains more information about their condition or the bad news they have been given begins to sink in. Therefore assessment of those needs has to be ongoing. For patients, articulating spiritual needs and asking for support can be difficult as this may mean discussing very intimate issues in an often far from private environment. Also, patients may be wrestling for the first time, in stressful circumstances, with issues which are hard, for anyone, to articulate.

Therefore Cobb's point (1998, p110) that spiritual needs are most effectively assessed in *'a relationship of trust, respect and usually out of their (the client's) life story,'* is paramount.

Some hospitals and hospices have devised tools to aid assessment of spiritual needs. Whilst this ensures that this aspect of care is not forgotten and may aid some patients to verbalise their needs, there is a danger that a 'tick the box and move on' approach to spiritual needs and care develops. In an already dehumanising environment it is important that assessment of an individual's spiritual needs is done sensitively and at a pace which enables the individual concerned to feel safe enough to share with the HCP involved at least part of their life story.

Assessment may or may not involve the use of an assessment tool but will certainly require good observational and communication skills as the cues given by patients regarding their spiritual needs are both verbal and nonverbal.

As with photography, where the quality, depth and feeling of a photograph depends on the skill and experience of a photographer as well as the quality of the camera, so assessing spiritual need depends on the professional and personal attributes of the HCP as well as the assessment tool used. Assessing an individual's spiritual needs at one moment may give great insight into their needs at that time but it is only a snapshot relevant at that moment and set of circumstances. When assessing spiritual needs we as HCPs need to be aware of the colour of lens we are looking through as we take the snapshot, as we assess the patient's spiritual needs. Spiritual assessment, as with spiritual care, begins with self-awareness. Our own story – our own worldview, beliefs, values and life experience influence greatly the way we view the world and other people and thus any assessment of the spiritual needs of others.

Spiritual needs may be recognised by HCPs but not always by patients and their families themselves. Sensitive exploration of issues elicited may enable help to be offered and 'hidden' needs to be met. However some people may refuse such support and HCPs have to respect the privacy and individuality of all we seek to care for. As Ross (1997, p38) puts it –

'We should not assume, therefore, that all patients will have spiritual needs which require constant attention. Some may choose to deal with them in their own way and in their own time. We should respect a patient's right to refuse spiritual care'.

Conclusion

Spiritual care does not begin with the patient nor does it begin with assessment of his or her spiritual needs. It begins with the HCP who seeks to offer such care.

At the heart of spiritual care is the personhood and the spirituality of the care-giver. It is essential that we as caregivers have begun to look at our own individual stories (where we have come from, where we are now and where we would like to be heading) and our own mortality, as well as realising we don't have all the answers about ourselves (and never will). Being aware of personal and professional limitations is important, as is the ability to seek help for ourselves and to refer patients and their loved ones to other HCPs when appropriate. Developing our active listening or counselling skills by attending appropriate training courses would also be of benefit and aid our self-awareness.

Offering spiritual care also involves taking risks. There is a need for an awareness of our own story, including any greater narratives that may shape our story, and the story of the context in which we are working. However more than that, there is also a need for open-ness to the possibility that during any encounter our story may be challenged, and indeed significantly changed, by what takes place. This may not just affect how we approach our work as HCPs and how we relate to our hospital context, but it may also profoundly alter our interpretation of own personal story, as well as our interpretation of the wider narratives that inform it.

In responding to the ever changing spiritual needs of others in the present moment there is the challenge for us as spiritual care-givers to attend to our own dynamic spiritual journey and spiritual needs which also, as we are as much human as those we care for, change through our experience and sharing of life with others.

References

BAILEY S. 1996 *The Well Within: Parables for living and dying* DLT, London

BELLAMY J. 1998 *Spiritual Values in a Secular Age* In COBB M., ROBSHAW V.(eds) The Spiritual Challenge of Healthcare Churchill Livingstone, Edinburgh

BUNARD P. 1987 *Spiritual Distress and the nursing response*, Journal of Advanced Nursing 12, p377-82.

COBB M. 1998 *Assessing Spiritual need: an examination of practice* In COBB, M. ROBSHAW, V. (eds) The Spiritual Challenge of Healthcare Churchill Livingstone, Edinburgh.

HEYSE-MOORE L. H. 1996 *On Spiritual Pain in the dying* Mortality Vol. 1 No. 3, p297-315.

HIGHFIELD M., CASON C. 1983 *Spiritual Needs of Patients: are they recognised?* Cancer Nursing 6(3): p187-92.

MCSHERRY W. 2000 *Making Sense of Spirituality in Nursing Practice* Churchill Livingstone, Edinburgh

NARAYASAMMY B. 1991 *Spiritual Care; a resource guide* Quay, Lancaster

REED P. 1998 *The re-enchantment of health care: a paradigm of spirituality.* In COBB M. ROBSHAW V. (eds) The Spiritual Challenge of Healthcare Churchill Livingstone, Edinburgh

ROSS L. 1997 *The nurse's role in assessing and responding to patients' spiritual needs* International Journal of Palliative Care Vol. 3, No. 1. p37-42.

SPECK P. 1988 *Being There* SPCK, London

STOLL R. 1979 *Guidelines for Spiritual Assessment* American Journal of Nursing Sept., p1574 – 1577.

STOTER D. 1995 *Spiritual Aspects of Healthcare* Mosby, London

WOODWARD J. 1997 *Some Straw for the Bricks? – Developing Standards for Spiritual, Religious and Cultural Care*, Middleton, Warwickshire (unpublished)

Ewan Kelly is chaplain at the Edinburgh Royal Infirmary, Edinburgh.